
Opportunities and barriers of using the Patient Activation Measurement to improve the care process

*A case-study about the experiences and
perceptions of caregivers and patients in
primary care*



Title page

Title: ***Opportunities and barriers of using the Patient Activation Measurement to improve the care process – a case-study about the experiences and perceptions of caregivers and patients in primary care***

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Preface

When I was preparing to start the final phase of my master Health and Society, my master thesis, I knew I wanted to step out of my comfort zone when it came to choosing a subject. During my education over the past five years, I have developed an interest in youth and education and therefore have done a lot of projects around this topic. Because this thesis is my final project of these five years of education, I wanted to take the opportunity to broaden and push myself to study another interesting subject. With this in mind I went to my supervisor who suggested a subject around Patient Activation, which also relates closely to current issues in Dutch society. This subject was new to me, but after getting myself familiar with the concepts I became very enthusiastic. Especially because my supervisor offered the opportunity to combine theory with practice, since there were connections with a General Practitioner (GP) who was looking for other ways to deal with new care demands in the current society.

During this thesis I did not only learn a lot about doing research and what research processes entail, but I also learned a lot about myself. I learned how to put things in perspective and became more confident about my own capabilities. Looking back at this, I view both these personal and educational processes as positive, because I believe this led me to a better thesis. There are a few people in specific I want to thank, who made these important processes possible.

Firstly, I like to thank all the respondents who contributed to this research for their honest stories. Also in this context I want to thank the caregivers for making time in their busy schedules and the doctor's assistants for always helping me with the organizational side of this study. In particular I want to thank Dr. Pieter Jansen, who gave me the opportunity to do research in this GP practice and who always assisted me with issues surrounding content as well as organization.

Secondly, I like to thank my supervisor, Lenneke Vaandrager. Not only did she always provide me with useful feedback on the content of this thesis, but she also let me tell my personal ups experiences during this research. This provided me with the context I needed, that certain issues are a normal part of the process in which I am not alone. After our meetings, I always came back with renewed energy and input to make a next step.

Thirdly, I like to thank all the people who provided my with the mental support I needed to finish this study. In particular, my parents and my sister who had to listen to steps I made in my head and needed to verbalize in order to put it in writing. The same goes for my friends, most of which also were or are going to the process of writing their thesis and therefore could relate to some struggles I went through. I can even say that I made new friends during the last phase of the writing process, who provided me with the structure and confidence I needed to finish this thesis and I am proud of the end result that is in front of you. I hope you enjoy reading this thesis.

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Summary

Introduction – Self-management is important in the treatment of chronic diseases such as diabetes. Self-management can help patients regain autonomy and improve quality of life. It can also prevent further complications of the disease, which can relieve pressure on caregivers in primary care. Self-management means that patients need to take an active role in the care process and that caregivers need to assist patients in taking this active role. However, self-management can have a different meaning for the patient and the caregiver. A patient is mainly concerned with a subjective burden of the disease, and a caregiver is mainly concerned with treatment adherence. A recently developed measure, the Patient Activation Measure (PAM), measures the care needs a patient has and how much responsibility a patient is able and willing to take. Patients are divided in four levels: level 1 indicates a lowly activated patient and level 4 indicates a highly activated patient. This measure can assist in bringing caregivers and patients together. Based on the outcome of the PAM a caregiver can suit care to the level of activation of a patient. To assist caregivers in suiting care to this level and therefore improving the care process, general guidelines were previously developed that provide strategic goals and action plans for each activation level. The aim of this study is to explore opportunities and barriers experienced by caregivers and patients of using the PAM to improve the care process by putting the patient in a central position in order to suit care to the individual situation. The PAM is used during consultations with diabetes patients in a General Practitioners (GP) practice in Ede (the Netherlands).

Method – This study developed an intervention: diabetes type 2 patients in the GP practice were asked to fill out the PAM in advance of a check-up consultation. Caregivers were informed about the PAM results of their patients before this consultation. The caregivers then incorporated PAM results in the consultations. This intervention was tested in a pilot (8 caregivers did 12 PAM consultations). After the pilot, the intervention took place with 11 caregivers who did 35 PAM consultations. After these consultations, semi-structured interviews took place with caregivers and patients about their experiences and perceptions of using this measure to improve care. Inductive coding was used to analyze these interviews.

Results – Caregivers reported that the PAM triggered a conversation, raised awareness both for themselves and the patient, ensured preparation and gave confirmation of how activated caregivers thought their patients are. On the other hand caregivers also reported that these experiences were different with patients with a low activation score. Caregivers felt limited assistance for practical applications from the measure on how to approach these patients differently than they already did in previous consultations. As a result, they reported to focus on other aspects of care, such as discussing blood pressure, instead of initiating a conversation about responsibility. Also some caregivers were more experienced in using conversation methods that put the patient central in the care process and therefore they did not see any additional value of using the PAM. Opportunities for practical implications of using the PAM are in embedding the measure into the GP practice. This embedding should ensure an overarching standard about the PAM as a measure, while at the same time make it possible for each caregiver to decide how and when the PAM can improve the care process. Barriers for practical implications of using the PAM are in the reservations caregivers have about the measure.

Patients reported that the PAM triggered a discussion with their caregivers about different topics and it raised awareness about a subject patients normally do not think about. In addition the PAM could emphasize their views and needs with the caregiver periodically, which can improve the care process. For patients who felt their care was already well adapted to their personal needs, the PAM was not perceived to improve the care process. Opportunities for practical implications of the PAM are in the notion that the PAM ensures collaboration within the GP practice, since it shows that caregivers want to work with the patients. A barriers for practical implications of the PAM is the perceived difficulty of interpreting specific statements in the PAM. Some statements were perceived to be clear and easy to answer, but some statements were perceived difficult to interpret and difficult to answer.

Conclusion – The PAM offers possibilities to improve the care process and put the patient in a central role, since it makes the caregiver more able to suit care to the individual situation of the patient. Especially for caregivers who want more assistance in helping their patients with self-management and who want to put the patient in a central and active role the PAM can be of additional value, because it ensures preparation and raises awareness. In this case it is important that the caregiver and the patient can together find a suitable method and a suitable moment in time to use the PAM. A suitable method relates to either filling out the measure before the consultation or asking selected statements from the measure in an informal way. A suitable moment in time relates to when time is available to discuss a different topic, such as taking responsibility for self-management, than normally is discussed during a consultation.

For patients who score low on the level of activation, it is questionable whether this measure is appropriate. Firstly, because especially these patients can have difficulty interpreting the statements which can result in unreliable answers. Secondly, because caregivers feel less able to adjust the care process to suit the needs of these patients or initiate a conversation about responsibility with these patients. To further assist caregivers in using the PAM, the measure needs to be improved to fit the purpose of using it to suit care to the individual patient and caregivers need to be trained to use the PAM with patients with all activation levels.

1. Introduction

In the Netherlands, 25% of the people have at least one chronic disease (Van der Lucht & Polder, 2010). With the current rise in life-expectancy the amount of people with a chronic disease will only become higher (Blokstra et al., 2007). As a result of this rise in prevalence of chronic disease, different needs in the care process become apparent. Since the care process in chronic diseases is a continuous process, one important need can be self-management by patients. For the patient self-management can be important, because it can help in regaining autonomy over their (quality of) life (Petek, Rotar-Pavlič, Kersnik, & Švab, 2010; Van den Arend, Stolk, Krans, Grobbee, & Schrijvers, 2000). For caregivers self-management of patients can be important as a secondary or tertiary preventive tool (Hendriks, Plass, Heijmans, & Rademakers, 2013). Secondary strategies aim to '*limit the course of a disease or to reduce the risk of recurrence*' and tertiary strategies aim to '*prevent existing health problems becoming worse, and to reduce disability due to health problems*' (Koelen & van den Ban, 2004, p. 38). In order for patients with a chronic disease to effectively self-manage this disease, they are expected to take on an active role in their care process (Clark, 2003; Holman & Lorig, 2004; Kilo & Wasson, 2010). Patient Activation is a relatively new concept that looks at the level of activation and responsibility a patient is willing and able to take in a care process (Hibbard & Gilbert, 2014). Hibbard, Stockard, Mahoney, and Tusler (2004) developed a Patient Activation Measurement (PAM) tool, which measures self-assessed knowledge, skills and confidence of a patient about managing their disease and the likelihood they will put this into action.

Diabetes is an example of a chronic disease which can need self-management of the patient in order to keep their disease in control, regain autonomy and improve quality of life (Petek et al., 2010; Van den Arend et al., 2000). However, effective self-management can have a different meaning for the patient and the caregiver, such as a subjective burden of disease for the patient and medical adherence for the caregiver (Denig, Dun, Schuling, Haaijer-Ruskamp, & Voorham, 2012; Gorter, Tuytel, de Leeuw, Bensing, & Rutten, 2011; Hajos, Polonsky, Twisk, Dain, & Snoek, 2011; Heijmans et al., 2001; Holman & Lorig, 2004; Van den Arend et al., 2000). In order to assist patients with a chronic disease in their care process and self-management, the caregiver and the patient need to work together where they both know each other's position. This can require a responsibility from the patient as well as an assisting or complementing role from the caregiver in contrast to just telling patients what to do (Hajos et al., 2011; Heijmans et al., 2001; Holman & Lorig, 2004). Knowing the level of activation can contribute to working together, because it gives caregivers a better

understanding about the patients' individual context (Hibbard & Gilbert, 2014; Hibbard, Mahoney, Stock, & Tusler, 2007).

The current study is an explorative case study in a GP practice in the Netherlands on the possibilities of using the measurement of Patient Activation (the PAM) to improve the care process by assisting caregivers to put the patient in a central position and suit care to the individual situation. Patients in this study are diagnosed diabetes type 2 patients. Putting the patient central and suiting care to the individual situation of the patient to improve the care process means that if the caregiver knows the Patient Activation level of the patient (measured by the PAM), he or she can adjust their approach towards the patient. Patients with a lower level of activation can have different needs and views about their care process. These patients have less knowledge, skills or confidence to self-manage and their care can be suited to this level and the situation a patient is in (Hibbard & Gilbert, 2014; Hibbard et al., 2004). Research shows that providing care that is suited to the Activation level of a patient can be more effective in raising the activation level and engaging the patients in healthy behaviors (Hibbard, Greene, & Tusler, 2009). This suggests that when a caregiver is more aware of the activation level of the patient, he/she is able to take on an assisting and complementing role towards the patient in certain parts of the care process. In this case the caregiver and the patient collaborate. At the same time it can be important to stimulate higher levels of Patient Activation, because if a patient has this higher level he or she can better communicate to the caregiver what he/she wants self-management and assistance with self-management to entail.

Chronic disease and self-management

While a patient with a chronic disease does not always feel sick, treatment (preventive or otherwise) will impose on the patients' regular life. There are certain consequences of being diagnosed with a chronic disease that the patient needs to deal with, such as persisting symptoms and no cure, continuous medication use, behavior change (diet, exercise etc.), changed social and work circumstances, emotional distress and a responsibility to participate in decision-making about the care-process (Holman & Lorig, 2004).

The main difference between a curative disease and a chronic disease is that there is simply no cure for a chronic disease. This especially makes self-management an important part of the treatment, because patients need to engage continuously in health practices (Holman & Lorig, 2004). Self-management can have positive effects on patients autonomy (Mars, Proot, Janssen, Van Eijk, & Kempen, 2007; Moser, van der Bruggen, Widdershoven, & Spreeuwenberg, 2008) and quality of life (Klis, Vingerhoets, De Wit, Zandbelt, & Snoek, 2008; Petek et al., 2010), but it is not always easy for a

patient. Dealing with a chronic disease requires a lot from the patient and is more than just medical coping (Petek et al., 2010). Furthermore, changes in lifestyle and other self-management techniques to prevent further complications only pay off on the long-term, which makes it difficult for patients to find a rationale for self-management (Weijman et al., 2005).

Even though taking on an active role in self-management can be difficult for patients, it remains an important dimension of this concept (Hendriks et al., 2013). Therefore self-management can be defined as: "*the care taken by individuals towards their own health and well-being: it comprises the actions they take to lead a healthy lifestyle; to meet their social, emotional and psychological needs; to care for their long-term condition; and to prevent further illness or accidents*" (Koetsenruijter et al., 2014, p. 2).

Differences between patients and caregivers

Research suggests that the meaning of self-management and who is responsible for care, can differ between caregivers and patients (Gorter et al., 2011; Hajos et al., 2011; Heijmans et al., 2001). Self-management according to caregivers is usually based on a medical perspective, which means that caregivers expect patients to adhere to treatments and medication the caregiver prescribes (Adhien et al., 2013; Borgsteede et al., 2011; Voorham, Haaijer-Ruskamp, Wolffentbuttel, Stolk, & Denig, 2011). Patients do not only look at their disease from a medical perspective, but they especially take a subjective disease experience into account (Heijmans et al., 2001). For example, Hajos et al. (2011) studied disease experience in diabetes patients and concluded that patients see their disease as serious which causes moderate levels of emotional distress, while caregivers underestimated the perceived seriousness of this disease and the levels of emotional distress. A reason why patients and caregivers differ in their opinions about self-management and responsibility, is that only the patient knows the impact of living with the consequences of their disease and the treatment (Holman & Lorig, 2004). While a caregiver can just tell a patient to make healthy lifestyle changes, it is up to the patient to incorporate this in their everyday life, which is sometimes easier said than done. This can be different for each individual, because it is so interwoven in someone's unique life situation (Moser et al., 2008).

As a result of this gap between the caregivers understanding and the patients' experiences, patients often reported a loss of autonomy and less self-efficacy (Hajos et al., 2011). At the same time caregivers reported feeling a lack of ability to properly address psychological skills a patient requires to deal with their chronic disease and a lack of resources to do this. The solution to this gap can lie in working together and complementing each other's knowledge (Holman & Lorig, 2004): the caregiver

has necessary medical knowledge and access to technical quality care (Arah, Roset, Delnoij, Klazinga, & Stronks, 2013) and the patient has knowledge on how care can effectively be interwoven in their individual life (Moser et al., 2008). As stated before, effective self-management might require an active patient, but a patient will need time to adjust to this role and to practice with this role (Petek et al., 2010); and he/she will need assistance to become one (Holman & Lorig, 2004).

According to the Dutch ministry of public health, welfare and sports, patients in general should be central to and take an active role in a care process (where possible) to contribute to good health and quality of life (Ministerie van Volksgezondheid, 2010). However in practice it is not always possible for a patient to take on this active role, because he/she does not have the right knowledge, skills or confidence (Rademakers, Nijman, Brabers, de Jong, & Hendriks, 2014). Furthermore, caregivers need to be prepared to take on a role that is more assisting and complementing than telling people exactly what to do (Ursum, Rijken, Heijmans, Cardol, & Schellevis, 2011). Methods are needed that assist the caregiver in getting insight in the individual situation of the chronic patient (Hendriks et al., 2013). One possible method can be the Patient Activation Measurement, since it emphasizes how active and responsible a patient can and wants to be.

2. Theoretical framework

The level of activation of a specific patient can be measured by the Patient Activation Measurement (PAM) (Hibbard et al., 2004). It measures self-assessed knowledge, skills and confidence of patients about managing their disease and the likelihood they will put this into action. The higher the level of Patient Activation, the better the patient will understand their possible responsibility in the care process and feel able to fulfill this role. Patients are asked to give their opinion about 13 statements (PAM-13, see table 1). Statements are about beliefs and confidence around taking responsibility, being active and about self-assessed knowledge. Patients can give the following answers on each statement: (1) totally disagree, (2) disagree, (3) agree, (4) totally agree, or (5) not applicable. A score between 0-100 will result from the completion of the PAM, and four main groups are divided based on levels of activation. These levels range from high to low activation levels. Figure 1 gives an overview of these four levels. Levels of Patient Activation are not static, but can change over time.

Knowing the level of activation of a patient can enable the caregiver to approach the patient as is suitable in the specific situation of the patient (Hibbard & Gilbert, 2014). The Patient Activation level also gives the caregiver insight in how vocal the patient can and wants to be. An active patient might be better in expressing how they want the care process to be shaped than an inactive patient, while at the same time a more directive approach can possibly be more suitable for inactive patients. If a caregiver can assist in increasing the Patient Activation level, the communication between the patient and the caregiver can improve because the patient will be able (and wants to) take more responsibility in the care process and express their views about their needs and wants.

Since chronic diseases require an elongated relationship between the caregiver and the patient, caregivers might already know a bit about how the patient views their responsibility. Whether and how the PAM can add to this existing relationship and improve the care process, needs to be researched. Currently, several studies showed the PAM to be a scientifically valid and reliable measure and it can measure changes in Patient Activation accurately and consistently over time (Hibbard & Gilbert, 2014). The PAM is also validated across different ethnic groups, different languages, different cultures and different health conditions (Brenk-Franz et al., 2013; Ellins & Coulter, 2005; Fujita et al., 2010; Hibbard, Mahoney, Stockard, & Tusler, 2005; Hibbard et al., 2004; Maindal, Sokolowski, & Vedsted, 2009; Rademakers, Nijman, van der Hoek, Heijmans, & Rijken, 2012; Steinsbekk, 2008). The PAM is a measure in which the caregiver is provided with a simple overview about the patients' context of reasoning. The results the PAM provides can be a starting point for a

conversation between the patient and the caregiver on how the care process can suit the individual patient.

Table 1. Thirteen-Item Patient Activation Measurement (PAM-13) (Hibbard et al., 2005)

- | | |
|----|---|
| 1 | When all is said and done, I am the person who is responsible for managing my health condition |
| 2 | Taking an active role in my own health care is the most important factor in determining my health and ability to function |
| 3 | I am confident that I can take actions that will help prevent or minimize some symptoms or problems associated with my health condition |
| 4 | I know what each of my prescribed medications do |
| 5 | I am confident that I can tell when I need to go get medical care and when I can handle a health problem myself |
| 6 | I am confident I can tell my health care provider concerns I have even when he or she does not ask |
| 7 | I am confident that I can follow through on medical treatments I need to do at home |
| 8 | I understand the nature and causes of my health condition(s) |
| 9 | I know the different medical treatment options available for my health condition |
| 10 | I have been able to maintain the lifestyle changes for my health that I have made |
| 11 | I know how to prevent further problems with my health condition |
| 12 | I am confident I can figure out solutions when new situations or problems arise with my health condition |
| 13 | I am confident that I can maintain lifestyle changes like diet and exercise even during times of stress |



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Figure 1: The four levels of Patient Activation

Patient Activation levels in relation to other self-management concepts

Patient activation has similarities with other concepts used in self-management research, such as readiness for change, self-efficacy and health literacy. This can raise the question why particularly Patient Activation is a useful concept in this study. One main advantage is that PAM scores are comparable over time, which means a caregiver can monitor patients. Especially in chronic diseases it is possible that the activation level decreases over time, because health deteriorates (Rijken, Heijmans, Jansen, & Rademakers, 2014). For caregivers it can be important to be aware of this decrease in order to adjust their care approach.

Another advantage of using Patient Activation is that it captures elements of concepts as readiness to change and self-efficacy. The levels of Patient Activation show similarities with the trans-theoretical model. This model states that taking action depends on which stage of change someone is in (Norcross, Krebs, & Prochaska, 2011; Palmer & Whybrow, 2014). In each stage (pre-contemplation, contemplation, preparation, action and maintenance) a patient is differently motivated for changing a certain behavior. Similarly, in each activation level a patient has different views, needs and capabilities for taking action in their care process. The advantage of using the level of activation is that it is a more general concept, which means that it is not linked to a specific behavior while at the same time it incorporates aspects of readiness to change (likelihood of putting behaviors into practice). Studies around the trans-theoretical model have suggested that suiting care to the stage of change a patient is in, can improve their readiness to change a certain behavior (Beckie, Beckstead, Schocken, Evans, & Fletcher, 2011; Jimmy & Martin, 2005; Johnson et al., 2008). However, other studies did not observe a change in behavior when care was suited to the stage of change in comparison with regular care (Chan et al., 2012; Mastellos, Gunn, Felix, Car, & Majeed, 2014; Tuah et al., 2011). In order to improve the care process, care can be suited to the level of activation, similarly to suiting care to the stage of change of a patient. Research is needed on how care can be suited to the Patient Activation level in practice. Hibbard et al. (2009) did develop guidelines on how caregivers can approach patients based on the different activation levels (Table 2). One practical technique of conducting a conversation that can help the caregiver to put the patient in a central position, is Motivational Interviewing (MI) (Noordman, de Vet, van der Weijden, & van Dulmen, 2013; Palmer & Whybrow, 2014). Studies have suggested that MI is effective in suiting care based on Patient Activation levels (Hibbard et al., 2009; Linden, Butterworth, & Prochaska, 2010).

The guidelines in Table 2 show that elements of readiness to change are incorporated, because in level 1 the focus is on creating awareness where the focus in level 4 is on creating skills on maintenance of behaviors. These guidelines also show that Patient Activation levels take self-efficacy

into account, because the different levels focus on building confidence and skills of the patient. These guidelines also illustrate that Patient Activation levels a has a linkage with the concept health literacy, since in higher levels patients are expected to understand their disease and have skills to appropriately use information about their disease and medication. Especially strategies in the lower levels are focused on gaining knowledge and information, which relates to health literacy. The advantage of using the PAM over measurements of health literacy is that it is easier and more reliable to measure. Much debate exists about one definition of health literacy. Nutbeam (2000) identifies different levels of health literacy: functional health literacy (focused on skills), interactive health literacy (social skills which allow active participation in the care process) and critical health literacy (capable and confident in skills and using information in such a way that greater control can be exercised over situations). In the Netherlands only validated measurements for functional health literacy are available (Fransen, Van Schaik, Twickler, & Essink-Bot, 2011), where the PAM also takes dimensions of critical health literacy into account such as having skills and using information. In the concept of Patient Activation, these skills and information are necessary to take on an active role, which is similar to exercising control over a situation.

Table 2 – Guidelines on characterizing patients at each level of PAM (Insignia Health, 2014a)

Level	Likely Patient Characteristics	Strategic Goal	Action Planning
1	Does not feel in charge of their own health and care. Managing health is overwhelming for them with all of life's other challenges. Lacks confidence in their ability to manage health. Has few problem solving skills and poor coping skills. They may not be very aware of own behaviors	Understand they hold the key to their future health and functioning. Understand through their own actions they can have a positive impact on their health. Create awareness between cause and effect. Work on problem solving and coping, using the small steps approach. To build ownership and motivation, focus on the issues the patient wants to focus on	Monitor choices and outcomes: when you do X how do you feel? This could note how they feel when they do the behavior. Consider learning more about your condition, finding one simple thing you could do to take a role (bring 3 questions to your next doctor visit). Patients need encouragement, they can be involved, they can make a difference, they can do this! They need to begin to build confidence
2	May lack basic knowledge about their condition, treatment options,	Gain an adequate knowledge base for making good choices. Build confidence by achieving	Continue to increase awareness and build knowledge. Start taking small steps toward best-practice evidenced based behavior.

	<p>and/or self-care. Have little experience or successes with behavior change. Look to their doctor to be the one in charge. Low confidence in their ability to manage health</p>	<p>successes in very small behavioral modification steps. Start to build stress management and problem solving skills.</p>	<p>Consider small steps like replacing a cookie for snack with a banana. Don't change the whole routine, just one small aspect where they can have success. Do they understand the reasons for their medications and what they are doing for them? Do they understand how to deal with side-effects and what they should be watching for? Have them make a list of things they do and do not understand about treatment options and medications</p>
3	<p>Have the basic facts of their conditions and treatments. Some experience and success in making behavioral changes. Some confidence in handling limited aspects of their health</p>	<p>Start to build on their past experience and successes to increase their confidence and ability in handling all aspects of their condition. Extend and maintain behavior change. Achieve best-practice self-care, still one step at a time, over time. Work on problem solving and stress management.</p>	<p>Start building a sense of efficacy for specific behaviors – taking small steps that relate to their quality of life goals and clinical indicators. Continue to build the knowledge base as it relates to the widening issues that emerge with the new behavioral goals. Throughout level 3 develop best-practice self-care according to evidenced based guidelines.</p>
4	<p>Have made most of the necessary behavior changes, but may have difficulty maintaining behaviors over times or during times of stress</p>	<p>Focus on increasing their confidence and skills for maintaining behaviors and coping with stress. Develop skills in coping and problem solving</p>	<p>The focus is on maintaining behaviors. Start with building a sense of efficacy for coping with problem situations that throw them off track. Identify situation where they still fall short. Develop skills to prevent these: planning ahead for known situations, stress management skills, etc. Continue to build the knowledge base as it relates to the widening issues that emerge with the maintaining behavioral goals. Reach toward new goals to continue to improve health to optimal health. Focus on any 'lagging behaviors'</p>

3. Research gap and current study

The PAM is not yet widely used. Most applications come from the United States and the United Kingdom, where the PAM is mainly used as an outcome measure to predict health behaviors (such as engaging in a healthy lifestyle, taking preventive care, searching and using information about health and care, and more active attitude in conversations with caregivers) (Fowles et al., 2009; Greene & Hibbard, 2012; Hibbard et al., 2007; Mosen et al., 2007; Remmers et al., 2009). There are also Danish (Maindal et al., 2009), German (Brenk-Franz et al., 2013) and Norwegian (Steinsbekk, 2008) translations of the PAM.

Based on positive experiences with the American and the Danish version of the PAM, researchers in the Netherlands also translated the PAM in Dutch (Rademakers et al., 2012) (See Appendix 1). Rademakers et al. (2012) translated the English version in Dutch based on the systematic approach conform instructions of the WHO, which entails a forward translation, expert panel meeting (language experts and health experts), backward translation, pre-testing/cognitive interviewing and consensus about the final version (WHO, 2010). Based on this final version, two studies were conducted (Rademakers et al., 2012). The first study was conducted among chronically ill patients and showed that the Dutch PAM-13 is a reliable measure. The second study was conducted among a specific group of chronically ill patients who also participated in the first study. The aim of this study was to test the test-retest reliability, which was moderate.

Besides this validation study little is known about the practical use of the PAM, for example in primary care settings as a GP practice. The PAM is now getting more attention as a measure to improve the care process and to help to put the patient in a central role. Examples are studies from het NIVEL on the topic of Patient Activation and care use (Hendriks et al., 2013), and longitudinal research about PAM levels in the Dutch population (Rijken et al., 2014). These studies have for example showed that chronically ill patients with a low PAM have different needs of support with self-management than patients with a high PAM level as is evident from Table 2. For example, a diabetic patient with a low activation level is supposed to make a lot of changes in their lifestyle from a caregivers point of view, but based on the activation level the caregiver can decide to only start with small and easy changes and start a conversation with the patient about how they see these changes. Encouragement of the caregiver and small changes will build confidence with the patient. This confidence can also improve the feeling of autonomy and quality of life of the patient. On the other hand, a patient with a high activation level could benefit more from specific care or aid on how to

maintain self-management over their disease in a stressful period. The caregiver who can use the PAM in a suitable way for him/her as well as the patient, will move away from a one-size-fits all approach and give patient-centered care, care that is suited to the individual situation of the patient.

Research questions

The aim of this research is to explore perceived opportunities and barriers by caregivers and patients of using the PAM to improve the care process by putting the patient in a central position in order to suit care to the individual situation. The study will explore how the PAM can be used as a measure to suit care to the individual situation during check-up consultations with diabetes patients in a GP practice in Ede (the Netherlands). The main question central in this study is:

What are opportunities and barriers of using the PAM as a measure to improve care by putting the patient in a central position in order to suit care to the individual situation?

Sub-questions that are answered to get insight in barriers and opportunities are:

- *What are caregivers' experiences and perceptions when the PAM is used during a check-up consultation?*
- *What are patients' experiences and perceptions when the PAM is used during a check-up consultation?*

4. Method

A small intervention took place in the GP practice in Ede, the Netherlands. This intervention entailed diabetes type 2 patients filling out a questionnaire based on the PAM. For using the PAM, a license was obtained through www.insigniahealth.com. The questionnaires were sent back to the practice, where the researcher made an overview of the results. This overview plus the original questionnaire was given to the caregiver in advance of the consultation. The caregiver was asked to incorporate these results in their diabetes consultations with the aim to improve the care process and put the patient in a central position. Caregivers were informed about the PAM and how to use the measure in advance of the study, based on information provided in Table 2. After this intervention, interviews were held with patients and caregivers about their experiences and perceptions of using the PAM to improve the care process.

4.1 Research population

The research population for the intervention consisted of people diagnosed with type 2 diabetes who are guided by the GP practice in the municipality Veldhuizen, Ede, and the caregivers who provide care to these diabetes patients. Several inclusion criteria were defined for diabetes patients to participate in this study.

Patients who were registered in Portavita (the computer system) as diabetes patient and had a check-up consultation planned between the 1st of June and the 28th of August, were included in the study population. The registration in Portavita ensured that during all consultations the same protocol was followed. The consultation planned in the timeframe ensured it was possible to use the questionnaire during the consultations. In the GP practice a person is diagnosed with diabetes if their glucose levels are above 6.9 (on a sober stomach) or 11.0 (non-sober) (Gezondheidscentrum Veldhuizen, 2012). When a person is first diagnosed with type 2 diabetes, he or she will need to establish a routine in his/her self-management. In this time, the new patient will visit their GP more often than when a patient just comes in for check-up consultations. These check-up consultations take place four times a year: one consultation with the GP and three consultations with the practitioners nurse (POH). This study was aimed at patients who have established routines and only come for check-up consultations. In these consultations it was more likely the caregiver had time to discuss the PAM results in contrast with patients who had not established routines. In this last case

mandatory topics about routines in self-management need to be discussed by the caregiver. During a regular check-up consultation several topics are discussed, such as results of important medical aspects of diabetes (e.g. glucose levels, weight and blood pressure), general quality of life, physical complaints, health behaviors (physical activity, diet, smoking, and alcohol), medical adherence and checking the need for foot-care. Results of conversations about these subjects are registered in Portavita. Recruiting was done with help of an intern of the GP practice and one GP. These people had access to a database with all diabetes patients in this practice. Patients were given the choice in advance of the consultation to participate in this study. During recruiting, emphasis was made on the advantages of the PAM, namely that it is an opportunity for the patient to say what they think and that it is an opportunity to put them in the center of the care process.

For caregivers to be included, they had to work in the GP practice Veldhuizen and have diabetes check-up consultations in the timeframe. The caregivers in this research were the General Practitioners (GP) ($n=8$) and the POH ($n=3$). This overall GP practice consists of five GP practices. Out of the eight GPs, two GPs have their own practice and six GPs work in duos in three practices. Patients belong to one of these five practices. Patients who have a consultation with the POH usually go to the same POH, but the POH sees patients of all five practices.

All patients who filled out the questionnaire and all caregivers who conducted consultations in which PAM results were used, were invited for an interview. Patients who did not return the questionnaire in time to ensure that results could be given back to the caregiver before the consultation were excluded, since it was not possible for patients to have experiences or perceptions about using the PAM.

4.2 Research plan

4.2.1 The intervention

Selected diabetes patients were sent an explanatory letter, a written consent form and the questionnaire. In the letter the aim of the research and the added value for the patient was explained, as well as the request to fill out the questionnaire and send this back to the GP practice or deliver the questionnaire at the reception (Appendix 2). To stimulate a higher response rate, a stamped return to sender envelope was provided to the participants. This meant that the participant had the option to deliver the questionnaire personally to the GP practice, which is conveniently located in a shopping center, or the participant could send the questionnaire back without costs. Participants were asked to return the questionnaire one week in advance of their consultation. When

the questionnaire was not returned, the researcher approached the participant on whether they had received the questionnaire and if so, asked if the person was willing to fill out and return this (called: 52 out of 77, answered: 45 out of 77). This included patients who indicated that they had already posted the questionnaire and patients who opted out because they did not speak Dutch or who turned out to be not diabetic.

Once returned, the researcher made an overview of the questionnaire results, which included (1) the PAM score and level, (2) which answers stood out from the PAM, (3) guidelines to approach the patient based on the PAM level (Table 2), (4) answers on the questions about experienced health and the degree of difficulty of the PAM, and (5) other possible remarks that stood out, which were personal and due to ethical consideration will not be shared (Appendix 3). This form and the questionnaire went back to the caregiver before the consultation. The caregiver was asked to prepare these results and incorporate it in their consultations. The use of the PAM results needed to happen in the time given for a consultation (20 minutes) in which also other topics need to be discussed. Caregivers were asked to use the PAM score to get a better understanding in the patients' situation by asking questions in a patient-centered way. To assist the caregiver with this, information about two patient-centered methods were provided by the researcher: Motivational Interviewing (MI) or solution-focused questioning (Appendix 4).

Phase 1 – Small pilot

A small pilot was carried out to test the questionnaire (patients: n=17, caregivers: n=8; all GPs). During this pilot the caregiver was given a chance to test out how the questionnaire works and how they can use the PAM in the consultation. Furthermore, the pilot study gave an indication about the questions besides the previously validated PAM statements. During the pilot the questionnaire consisted of (1) general information of the patient (such as age, gender, length of diagnoses and perceived health), (2) the Dutch PAM-13, (3) rated degree of difficulty of PAM statement (score of 1-10), and (4) an open question related to the patients' experience about the GP practice and their current consultations (Appendix 2). This last question asked one positive point and one point for improvement for the consultation of the GP as well as the POH.

Phase 2 – Evaluation

Thirteen participants sent the questionnaire back and in twelve consultations the results were used. One participant had sent the questionnaire back after the consultation (see Figure 2). Three GPs provided the researcher with feedback on the pilot. The other GPs (n=5) were also invited to give

feedback, but did not respond. All caregivers were given the option of a personal conversation if certain aspects were unclear. Two caregivers who responded with feedback via an electronic feedback form, had a small question that could be answered via email. One caregiver was closely involved in setting up the research project from the beginning. With this caregiver, there was a conversation about what could be changed to improve the reliability of results gathered during the intervention. It was also possible for other caregivers (both who responded to the request for feedback and who did not) to get further information from this latter caregiver, as he served as the link between them and the researcher.

Based on the experiences of the researcher and the feedback of three GPs, some small adjustments were made to the questionnaire and the intervention. In the questionnaire, the question of age was changed in the date of birth. The question since when participants were diagnosed with diabetes was removed, because most participants were unsure about this. The question about positive and negative experiences of the consultation with the GP and the POH was also removed. This question gave the participants the feeling that they were filling in a quality review of the practice and therefore missed the aim of the PAM. The final version of the questionnaire can be found in appendix 5.

Aspects of the process did not change, but some extra aspects were added. Firstly, it was agreed upon that the POH consultations ($n=3$) would also be included in the data collection. Secondly, agreements were made with the doctor's assistants to ensure the caregivers got the results in time. When the overview was completed, a folder with the overview and the filled-out questionnaire went to one of the assistants. This assistant scanned the overview (not the questionnaire) and added this scan to the electronic dossier of the patient. Then the folder went to the mailbox of the GP or the POH who did the consultation. This ensured that the caregiver had the full version of the questionnaire as well as a digital version of the overview. Thirdly, the researcher and the caregiver who was most involved agreed to send letters to participants approximately two weeks in advance of their consultation. In practice, this meant that on Monday all letters of possible participants who had an appointment during the week that was two weeks later from that Monday. During the pilot it was observed that participants who received their letters in the beginning of June, just like everyone else, but only had the consultations at the end of June, often forgot to respond to the request to fill out the questionnaire. Sending the questionnaire at this time ensured that every participant had the letter in time to read through, but at the same time had to respond quickly enough that the letter could not be forgotten.

Because nothing has changed about the PAM part of the questionnaire and the way the consultations were done, the PAM scores and the experiences of caregivers in de pilot were included in the results.

Phase 3 – The intervention

The questionnaire and the letter were send out to possible participants (n=60), who were identified to have a consultation between 6th of July and the 28th of August. This list was communicated to the caregivers and three people were removed because caregivers did not want them to participate. No further information was provided due to patient confidentiality. 57 participants received the letter and the questionnaire. 39 questionnaires were returned and 35 consultations were held where the results were used (Figure 2). In total with the pilot and the research combined, 52 questionnaires were returned and 47 consultations were held where the results were used.

4.2.2 Data collection through interviews

After the consultation, patients were invited for an interview to talk about their experiences and perceptions about using the PAM in the consultation. Caregivers were also invited for an interview after they concluded their scheduled consultations during data collection.

A semi-structured interview was carried out in which the main aim was to explore if the PAM could improve the care process and suit care to the individual patient. Open questions were formulated beforehand about what both the patient and the caregiver thought, if and how the PAM contributed to improving the care process as well as their opinion about the measure; and what they hope using this measure can achieve (Appendix 6 and 7). The interview was done by the researcher in person at a location chosen by the participant (the patient or the caregiver). For patients this was in their own home and for caregivers it varied between their own home and their office in the GP practice.

Patients were requested to participate in the study by telephone. Interviews were scheduled between 1 day and 1.5 weeks after their consultation, to minimize recall-bias. In total, 9 interviews were done between the 27th of July and the 26th of August. Length of the interview varied between 30 minutes and 50 minutes. At least one patient was interviewed of each GP practice (except one practice) or POH. For one practice and one POH, two patients were interviewed, because time allowed the researcher to gather more data.

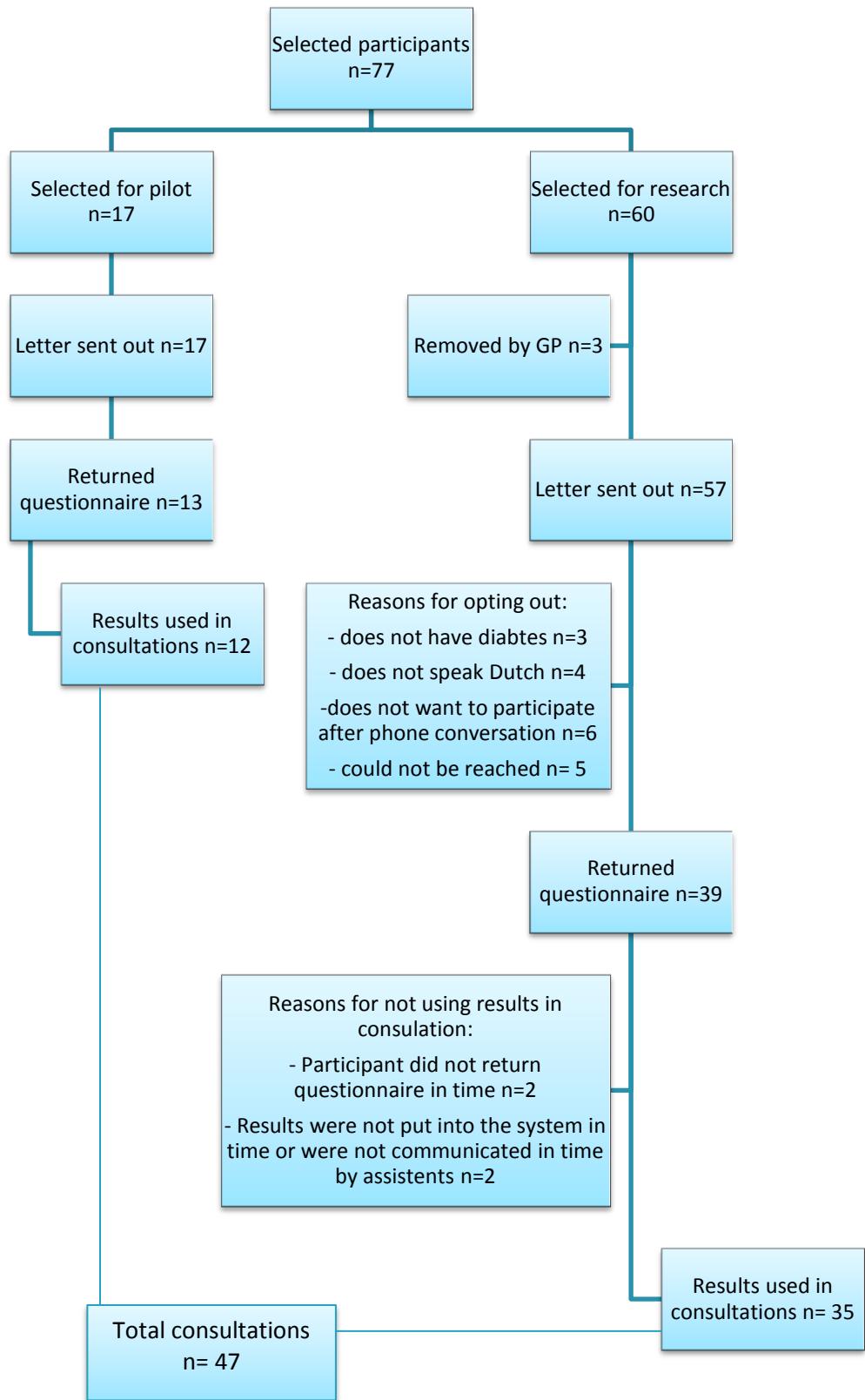


Figure 2 – Overview of respondents

Interviews with the caregivers took place between the 24th of August and the 4th of September after they had completed all their scheduled consultations. The time between the final consultation and the interview was kept short so that caregivers could still recall their experiences. Caregivers were firstly approached via email. If they did not respond, a reminder was sent out after two weeks. After this reminder, some caregivers still did not respond. A final reminder was sent out, with an emphasis on the urgency when the last moment was possible for an interview. Additionally, one GP gave these remaining caregivers a personal reminder. In total 8 of the 11 caregivers were interviewed. Length of the interview varied between 20 minutes and 50 minutes. Two caregivers could not be interviewed as a result of personal reasons (and were a part of the same practice) and with one caregiver contact could not be established.

4.3 Ethics

Informed consent was obtained (explanation of the aim of the study, expectations of the patient, anonymity etc.) and the participant was informed about ethical considerations (e.g. option to refrain from an answer, confidential person if issues or questions arise during or after the questionnaire or interviewer) with a separate form of the letter (Appendix 2). The patient was also informed that he or she could stop with the study at any time. All participants were asked to sign this form and send it back with the questionnaire. To further guaranty the privacy of the patients, no data was sent via email. Overview forms (Appendix 3) were printed on an internal computer of the GP practice and scanned to put into the confidential system of Portavita with the help of the doctor's assistants. To ensure anonymity, patients received a ID number related to their caregiver and the order in which questionnaires were returned. This means that patient 101 had a consultation with the caregiver who was given number 100 and was the first patient to return the questionnaire. Patient numbers could vary between the number 101-109, 201-206, 301-308, 401-404, 501-509, 601-605, 701-707, and 801-804.

The informed consent patients gave earlier also applied to the interview. During the interview anonymity and confidentiality was explicitly repeated, especially towards the remarks patients made regarding the practice of the GP/POH. The caregivers who participated in the study did not sign a consent form, but there had been transparency about research aims throughout the research. At the start of the interview, anonymity and confidentiality was verbally explained. Caregivers were asked if they understood and agreed with this verbal explanation, which all of them did. Each participant (patient as well as caregivers) was asked for permission to record the interview. Recording was done

for personal use of the researcher in order to transcribe interviews at a later point in time. All participants accepted.

4.4 Data analysis

Mean scores of gender, age, self-rated health, PAM score and level and the difficulty were calculated with Excel, as well as the average score on each individual statement of the PAM. These calculations were also made for patients with a low activation level (1-2) and a high activation level (3-4)

The interviews were fully transcribed and analyzed by a qualitative analysis program (Atlas.ti). Inductive coding was used. After discussion with another researcher, it was decided that two coding trees were going to be developed. These coding trees were in accordance with the sub-questions central in this research: the experiences and perceptions of caregivers and patients. Comments were divided into a theme content and a theme process. Within these themes, a division was made between comments of caregivers and patients. The theme content explores what the PAM did during the consultations or what kind of effect the PAM had on the consultations. The theme process explores practical experiences and perceptions of using the PAM as a measure. Figure 3 and 4 show the categories and sub-categories under each theme.

After coding in these (sub)categories with Atlas.ti, further coding was done by hand, because this provided the researcher with an image on how points within sub-categories related to themselves and how sub-categories related to each other. The most important points are also found in Figure 3 and 4. The most illustrative quotes were added to illustrate the findings. To ensure anonymity all quotes were provided with an ID number. Because caregivers knew the ID numbers patients got during the intervention new ID numbers were created. For caregivers this ranged from 1-8 and for patient this ranged from 1-9. Since all interviews were done in Dutch, quotes were translated into English. Each quote was also numbered with a number between 1 and 40 before the ID number of the participant ⁽ⁿ⁾. In Appendix 8 all original Dutch quotes can be found.

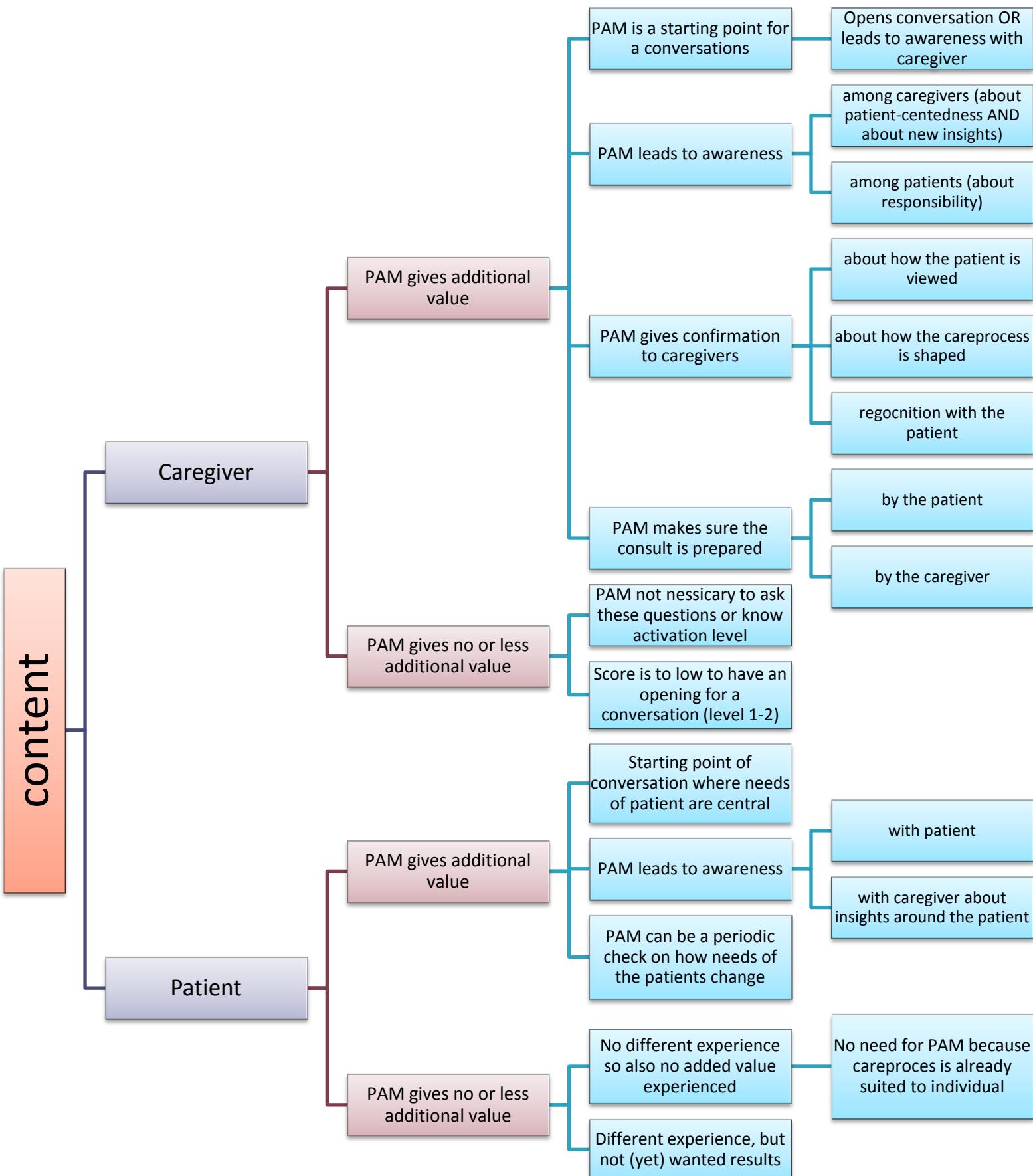


Figure 3 – Coding tree of the theme content

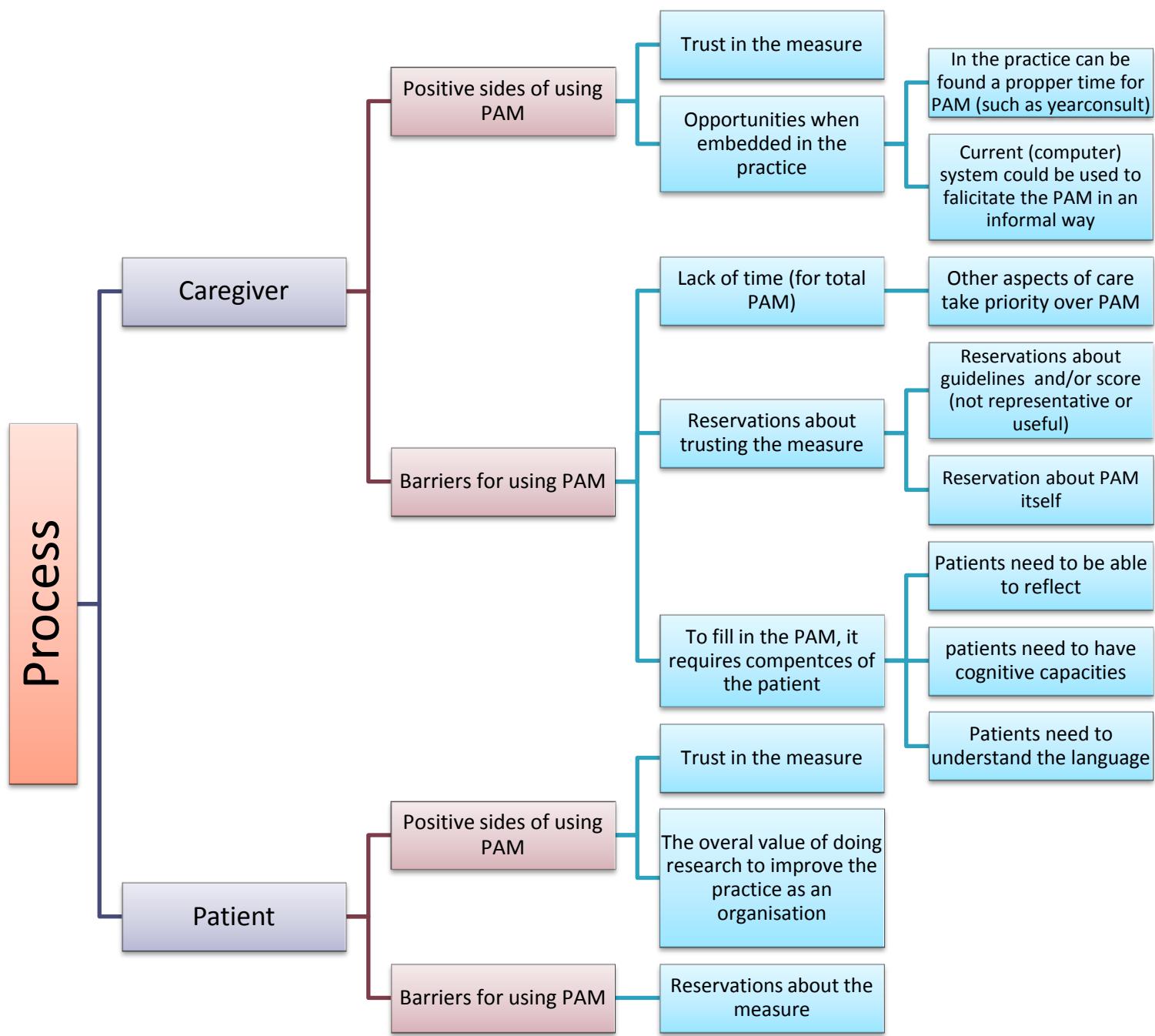


Figure 4 – Coding tree of the theme process

5. Results

In total 52 questionnaires were returned (pilot and research). Of these participants 33 were male and 19 were female. The average age was 70,5 years old. The youngest participant was 48 years of age and the oldest participant was 95 years of age. On average patients rated their health at a 7,3 on a scale from 0 to 10. The average PAM score was 56,3 and the average Patient Activation level is 2,4. Participants gave a 7,1 on average on a 1 to 10 scale when asked about the perceived difficulty of PAM statements. Table 3 shows these results with additionally showing how many participants filled in the question. Table 3 also shows these results after patients are divided in two groups: lower activation levels (levels 1 and 2) and higher activation levels (levels 3 and 4). This division demonstrates that the age is evenly distributed among the activation levels. However, patients with a higher level did rate their health higher (7,6 vs 7,0) as well as they perceived the statements to be easier (7,5 vs 6,7).

Table 3 – General results of the intervention

	SD		Minimum		Maximum	
	Level 1-2	Level 3-4	Level1-2	Level3-4	Level1-2	Level3-4
Age	70,5 (n=52)		48		95	
	70,0 (n=23)	71,0 (n=28)	48	49	86	95
Self-rated health	7,3 (n=50)		3		10	
	7,0(n=22)	7,6(n=27)	3	10	6	10
Pam score*	56,3 (n=51**) (level 3)		39,4 (level 1***)		84,8 (level 4***)	
	47,8 (n=23) (level 1)	63,3(n=28) (level 3)	39,4 (level 1)	55,6 (level 3)	53,2 (level 2)	84,8 (level 4)
Perceived difficulty of PAM statements****	7,1 (n=50)		3		10	
	6,7(n=23)	7,5 (n=26)	4	3	10	10

* To get a valid score, 10 out of 13 statements need to be answered

** Since 1 patient has an invalid score, the number of patients divided into different levels does not add up to the total number of patients who filled in the question of age, self-rated health and perceived difficulty

*** See Figure 1 (page 5) about the explanation of the four PAM levels

**** Scored by patients on a scale of 1 to 10. 1 is very difficult and 10 is very easy

Table 4 shows the average results of each statement in the PAM, as well as the average result of the statements when the population is divided in patients with lower activation levels (levels 1 and 2) and higher activation levels (levels 3 and 4) (full statements can be found in Table 1, page 5). Statement 1 and 2 stand out in the average of the total population. These statements are about

responsibility and taking on an active role and are scored the highest (e.g. between agree and totally agree). The statement which is scored the lowest is 12, which is a statement about how confident a patients feels to find solutions when new problems arise with their health. This statement is scored between disagree and agree. Other lower scoring statements are 10 and 13, which relate to being able to maintain lifestyle changes (10) even during times of stress (13). Patients with lower activation levels score the highest on statement 1 and 2, where their average answer is close to agree. These patients score lower on statement 12, where their average answer is close to disagree. All other average answers are in between agree and disagree. These averages indicate that patients with a lower activation level do want to take responsibility, but can lack either knowledge, confidence or skill. Patients with higher activation levels also score high on statements 1 and 2 and score lower on statement 12.

Table 4 – Average result* of each statement in the PAM

	Average of total population	Average of level 1 -2	Average of level 3-4
1	3,31	3,09	3,50
2	3,31	3,09	3,50
3	3,12	2,91	3,29
4	3,04	2,78	3,26
5	2,98	2,65	3,25
6	3,19	2,91	3,43
7	3,24	3,00	3,43
8	3,02	2,72	3,25
9	2,90	2,60	3,11
10	2,88	2,52	2,18
11	2,98	2,64	3,25
12	2,52	2,09	2,89
13	2,86	2,48	3,19

* Results can vary between 1 and 5, where 1=totally disagree, 2=disagree, 3=agree, 4=totally agree and 5=not applicable

5.1 Caregivers' experiences and perceptions

The first sub-question was: '*What are caregivers' experiences and perceptions when the PAM is used during a check-up consultation?*'. This section describes these experiences and perceptions that became evident from the interviews with caregivers.

5.1.1 The PAM improves the care process

Overall caregivers reported several positive experiences with using the PAM during their consultations. In these situations the PAM had the opportunity to improve the care process. Firstly, the discussion of the PAM results opened a conversation, which means it functioned as a trigger to discuss a subject that normally is not discussed. Secondly, filling out the PAM and discussing the results led to awareness about the importance to put the patient central and about new understandings of the patient. Caregivers also reported the PAM led to awareness with patients about topics patients normally do not think about. Thirdly, using the results and having a conversation with the patient about PAM related subjects gave the caregiver a sense of confirmation about how they previously viewed and approached the patient. Finally, the PAM ensured preparation of the consultation.

Trigger for conversation

Many caregivers made the remark that as a result of the request to discuss PAM results, it opened a conversation about subjects that are not standardly discussed in a regular check-up consultation.

*"Positive is that by using the questionnaire.. you can start a conversation about it: where are they [the patient] and what do they find important in the assistance they get around care. It is easier for me, because you have that list and you say: I see you filled out this answer, can you tell me more about that, or maybe we have to do something about this, or I suggest meeting again shortly. So in that way you can use it."*¹ (Caregiver 1)

Some caregivers mention that they see potential in the measure to specifically start a conversation with patients who do not show up for their consultation. Then patients can see that the caregiver wants to work together and listen to their individual needs.

*"There is indeed a group of people who think: I'm listening to the same story again [during the regular check-up consultations]. For those people it could be useful, because then they will see that their needs are also important and taken into account"*² (Caregiver 2)

Awareness with caregiver and patient

Awareness is related to different issues. Firstly, knowing about the PAM raised awareness with caregivers about the importance that the patient needs to be in a central position in order to stimulate self-management.

*"At a certain time I heard of the PAM. I read it and understood it immediately. But before this I never really thought about that subject and I also did not see that you could do something with it. I knew there were differences between patients, but I did not realize that we [caregivers] are really used to telling patients a standard story that is the same for everyone and that you can also do it differently if you know who the person in front of you is. Then you can tell a different story. So what has improved for me is that I have a better understanding about this, and also can do more with it."*⁶ (Caregiver 5)

This experience was also evident during the consultations when caregivers used the PAM.

*"Then we had a whole different conversation. This patient usually came here with the attitude of: you want to know all this and I'm trying hard, and you always nag that I'm not doing well. An attitude with a lot of resistance: I only come, otherwise I will get even more nagging. And now, I thought with this patient... I was surprised that this patient filled it out and if you then also apply the technique of MI, it does complement each other. You really put the patient central in that case."*³ (Caregiver 3)

Moreover, caregivers became more aware about new understandings around their patients. Discussing PAM statements showed caregivers how patients think about activation and responsibility for self-management. Because these views and beliefs can influence a patients' behavior, the caregiver now had a better understanding on how they can assist a specific patient during their care process.

*"That [a certain answer on the PAM] is really something substantial. Then you think: maybe I have to tell a bit more about this. It is really clear... and this also [pointing to a PAM statement], understanding what causes are, what the disease is and entails. Answers on that provide you with information, if you see that a patient doesn't agree."*⁴ (Caregiver 4)

*"Because sometimes you assume that people know things, but you cannot always assume that off course. Most of the time you will come back to that, but not in that specific conversation. So in this conversation you could do that, what the patient was missing."*⁵ (Caregiver 2)

Many caregivers also acknowledge that the patient starts to think about responsibility and experiences during their care process. Caregivers mentioned that most patients do not really think about these things and that the fact these statements were asked led to the awareness about their role in the care process and thinking about how they want this role to be.

*"It is good that statements are asked outside of the normal questions I usually ask, because they are going to think about their disease and responsibility... The fact that statements are asked, make people think. The answer isn't even that important."*⁷ (Caregiver 6)

Confirmation for the caregiver

Caregivers reported to feel confirmed about views they had about activation levels of their patients and about how they previously approached their patients during the care process. Firstly, the PAM result itself could be a confirmation for the caregiver about how they view the patient. For example, if a patient had a low score (level 1) or a high score (level 4), this confirmed how the caregiver viewed the patient previously.

*"Well, with patients who score very low, I think it is about right. That's also how I see the person. With the very high scoring people, I had one, that person is also highly educated and is pretty self-sufficient in managing the diabetes. So for me that was more of a confirmation."*⁸ (Caregiver 6)

During the conversation between the caregiver and the patient, the caregiver could also get the confirmation from the patient that the care process is indeed suited to the needs of the patient.

*"Actually that's how I usually do it, but now I can see from the patient if it's really the case. You don't always know this off course. You can make an educated guess on how much patients are involved with their disease. On how they are in front of you during a consultation, you can guess how they see their disease and how much assistance they want, so than I usually respond to this demand."*⁹ (Caregiver 2)

Prepared consultations

Caregivers reported that the consultation was more prepared, by both the patient and themselves, than regular consultations as a result of the PAM. The patient was asked to fill out the questionnaire in advance, which entailed that they needed to think about the subject responsibility and their needs in the care process. The caregivers experienced this as positive.

*"I like that people already looked at the statements at home and that they prepared the subject [the PAM statements]. When they come to the consultation that some preparation has been done. Which makes a huge difference for me."*¹⁰ (Caregiver 5)

The caregivers also commented that they could prepare themselves, as they could see the results of the PAM in advance. They perceived this as positive, because this way they could adjust their consultation where needed according to the specific situation of the patient.

*"You know in advance where people see issues and you can arrange your consultation in such a way to address this, and prepare for this. That's what I found positive"*¹¹ (Caregiver 2)

As a result of this preparation from the caregiver, some of them decided not to discuss all the statements of the PAM, but focus on certain issues they thought were relevant to discuss.

*"You are not going to discuss the entire questionnaire, but you pick out some things which you think might be interesting to talk about. You can also ask the person if they want to talk about something specific in relation to the questionnaire. So than you do not talk about every statement, but separate what is interesting or not in advance."*¹² (Caregiver 4)

5.1.2 The PAM does not improve the care process

Caregivers also mentioned situations when the PAM did not improve the care process. Firstly, some caregivers responded they could not support patients who score very low (level 1). They also suggest that these patients were unable to answer the statements or to have a conversation about these statements. This makes working together more difficult for the caregiver.

*"To understand and to talk about this subject at all... Even if you simplify the statements more than they already are, it has a high abstraction level for people. Because people are stuck in the idea of: I'm sick and opposite me is a doctor, I have a complaint and the doctor will solve it. For those people it is difficult to take a step to the idea that they also have a role. As a result the conversations with people with a lower score are more difficult, because I think it is a difficult subject [taking responsibility] for these people."*¹³ (Caregiver 5)

One caregiver specifically noted that she thought it was unfortunate the measure did not assist with these patients. In her opinion lower scoring patients (level 1 and 2) can make the most progress and as a result have better self-management.

Secondly, some caregivers question whether they need the PAM specifically to ask questions about responsibility and say they already know the activation level of the patient.

*"I actually don't know if I would send out a list [the PAM]. If I think that there is a chronic condition present in which it is important that people experience their own health and can influence this... You could just ask this directly."*¹⁴ (Caregiver 7)

Caregivers acknowledged the fact that it is important to know about their patients' needs and wants in the care process, but mention that they know the patient well enough to estimate patients' views.

*"I do the yearly check-up consultation with these patients for a number of years now. And I also see them for other health-related problems. In time you get a certain image of someone and this is a lot more time than one questionnaire off course. At a certain moment you know how people deal with these things and how to approach them."*¹⁵ (Caregiver 6)

Especially caregivers, who were already used to talk about self-care and self-management with their patients, reported that the PAM did not add anything to improve their consultations.

*"From what I can tell that's already how I do my consultations: I respond to the needs of the patient."*¹⁶ (Caregiver 2)

One caregiver (ID=8) specifically mentioned that the experience with the PAM did not improve the care process and did not help suit the care process to the individual situation, but only proved to be a distraction. This caregiver decided not to continue with the PAM in the consultations during the research period.

5.1.3 Opportunities for practical applications of the PAM

Caregivers reported several opportunities for how to use the PAM in the GP practice. The caregivers acknowledge that the PAM itself has opportunities to use in the GP practice in respect to the validity of the measure. Not all statements, but most (shorter) statements are seen as clear. Also it is mentioned that the PAM is relatively short in comparison to other questionnaires.

*"These are good statements, people thought long and hard on how to formulate these statements. So I think it works well and that it is measures what it needs to measure. I think that's positive."*¹⁹ (Caregiver 5)

The main opportunity the caregivers mentioned are the possibilities the measure offers to be embedded into the GP practice in order to improve the care process. Caregivers state that the PAM statements could be incorporated in the computer system that the GP practice currently uses. The PAM can be added to the list of items the caregiver can discuss with the patient, which currently exists of lifestyle factors, experienced health etc.

"Technically speaking, we could add the statements to our computer system. For example, when we check patients' feet, we also have to check several aspects which are different questions just like the PAM. If you put it into the system, then you don't have to do every statement every time. You could also personally, with the GP or POH, ask one specific statement or the whole questionnaire every once in a while. And then you have time to work together with the patient."

¹⁷ (Caregiver 5)

As the caregiver above mentioned, and more caregivers mentioned, is that this system could also facilitate the focus on specific statements the caregivers tried out in the current research and appreciated (as a result of a prepared consultation). Another way to embed the PAM into the GP practice and which also facilitates the informal use of focusing on specific statements can be: to let each caregiver make a decision on when there is a suitable, but already existing, moment in time to start a conversation. Some caregivers see the value in doing this at the beginning of a care process with a patient with a chronic disease and others see the value in doing this when the patient and caregiver are already working together. One suitable moment that specifically stood out, was the yearly consultation with the GP.

"The yearly check-up could be a suitable moment for this [PAM statements], especially in the way the current consultations are organized: we don't discuss that much. Mostly, we sort out all information of the patient [such as blood pressure, weight etc.], and if those things are going well, than you have time to do this, so therefore it could be a suitable moment. Then you can pick out what you like, because of the extra time." ¹⁸ (Caregiver 4)

5.1.4 Barriers for practical applications of the PAM

Caregivers also reported several barriers if the PAM is used in the GP practice. Caregivers foresee issues with (1) PAM as a measure, (2) suitability for a broader population, and (3) time management.

Reservations about the measure

Reservations caregivers have about the measure relate to two aspects. Firstly, they mention reservation about the PAM itself, which means the statements and/or answering categories. Regarding the statements, caregivers question if patients understand all the statements and how they interpret the statements. If the patient does not understand or interprets statements correctly, than they question the reliability of the PAM.

"A few patients said that they did not understand all statements. What stand out the most, is the statement when new problems arise with their health, that patients don't know and have little confidence how to deal with this. [Patients interpret this statement differently]"²⁰ (Caregiver 1)

Regarding answering options, the caregivers questioned if answering these general statements with agree or disagree was too difficult, since it is hard to choose either agree or disagree on complex statements.

Other reservations of caregivers about the measure related to the PAM level (level 1 – 4) and the general guidelines about care strategies based on activation levels that was accompanied with the overview (see Table 2, page 8). Relating to the score, caregivers said that the score the patient received did not fit their own personal knowledge about the patient. Since this personal knowledge is the result of years of experience, they trusted this knowledge more than information from the PAM. The guidelines that accompanied the overview were seen as too general with little assistance on how to proceed.

"It [the guideline] is so standard, it can apply to anyone, for everyone that is the case. So it doesn't add anything. It's not specific enough for me."²⁰ (Caregiver 8)

PAM requires competences

As a result of their experiences during the study, caregivers concluded that the PAM is not suitable for every patient in the GP practice. Caregivers mention some specific competences that a patient needs to have to get reliable and valid results. Firstly, patients need to have cognitive capacities. For

example, patients who have memory problems due to dementia or older age have difficulty filling out the statements.

*"Some people are less able cognitively speaking, for example for people with dementia this is not achievable. People can also genetically be cognitively less: when they have a mental disability they cannot do this. People can also get worse in cognitive functioning with age and also when diagnosed with diabetes."*²² (Caregiver 5)

Patients also need to be able to reflect on themselves, according to caregivers.

*"And you have to be able to reflect. So this focuses more on the average group."*²³ (Caregiver 3)

Finally patients need to understand the language in which the statements are written, in this case Dutch. Patients with language problems are a difficult group, according to caregivers. In specific caregivers mentioned immigrants, who often speak limited Dutch but is a substantial group in the current GP practice.

Lack of time

Time issues the caregivers commented on mainly relate to lack of time to complete the PAM with the patient personally during a consultation. Although some caregivers acknowledge that this approach would give a lot of useful information on how the patient thinks and what their individual situation is, the time it takes to get this information weighs more heavily.

*"I think that will cost us too much time that we do not have. It might get us more information, but I think it will be too much because most people do not leave it with that. In that case it can be difficult to cut things short. I think it will be too much time."*²⁴ (Caregiver 2)

In addition, caregivers mention that they do not always have time for additional question(s) or discussion, like the PAM statements. Caregivers are medical professionals. Sometimes there are more urgent matters or problems that have priority, for example:

*"Then it turned out that this patient had a somatic problem, which required immediate attention. As a result the questionnaire was put aside."*²⁵ (Caregiver 4)

5.1.5 Conclusion caregivers

Interviews with caregivers have shown that most of them see usefulness in certain aspects of using the PAM to improve the care process. The PAM served as a trigger for a conversation. This conversation or just filling out/working with the PAM led to awareness with both the patient and the caregiver. For the caregiver these conversations could prove as a reminder to put the patient in a central position. Furthermore caregivers gained new understandings about the patient's views and needs. Since the PAM ensured a prepared consultation by both caregivers and patients, they were able to work together and improve communication. The PAM could improve the care process less when (1) the Patient Activation level was low in which case caregivers felt unable to support patients with taking on an active role, and (2) when the caregiver stated that they already put the needs of the patient in a central position and know the activation level in which case the PAM did not further improve the care process. In this last case the PAM could serve as a confirmation to the caregiver that both the caregiver and the patients are satisfied in the approach of the care process.

This led most caregivers to the conclusion that the PAM has possibilities to use in the GP practice. However, if the PAM wants to improve the care process some aspects need to be taken into account. Firstly, the PAM should add something to improve the consultation of the caregiver. No caregiver should be forced to use a measure they do not find valuable to use or they question the validity of. Secondly, the PAM should be embedded into the GP practice to ensure an overarching standard on how caregivers use the PAM and to ensure the PAM is easy to use. Within this overarching standard each caregiver can have a preference for a suitable moment and a method on how to use the PAM (focusing on specific statements during consultation or fill out in advance to ensure preparation). The caregiver also needs to make an assessment (1) if there is enough time to talk about PAM related subjects, and (2) whether the patient has the competences the PAM requires of them (e.g. cognitive capacities, reflective skills and understanding of the language).

5.2 Patients' experiences and perceptions

The second sub-question in this research was: '*What are patients' experiences and perceptions when the PAM is used during a check-up consultation?*'. This section describes these experiences and perceptions that became evident from the interviews with patients.

5.2.1 The PAM improves the care process

Overall patients reported several positive experiences when the PAM was used during their check-up consultation. Firstly, the discussion caregivers initiated with the patients opened a conversation about topics that are normally not discussed. Secondly, the patients acknowledged that the PAM statements as well as the conversation led to awareness with themselves, because it made them reflect on their thoughts and behaviors. According to patients, the conversation about PAM results also raised awareness with the caregiver since those caregivers gained a better understanding into their patients. Thirdly, patients mentioned that the measure can emphasize their views and needs, which should be checked periodically.

Different topics than normally discussed

Patients reported that in this check-up consultation the caregiver sometimes asked a different question than in the regular check-up consultation. These questions related for example to responsibility. As a result of these questions the patient and the caregiver could have a conversation about a topic that normally would not have been discussed.

*"Last time the doctor asked the question: who is responsible for my health? I said: I am. And then we had a good conversation about that."*²⁶ (Patient 1)

These different questions appear to be especially beneficial for patients who experienced some friction between the caregiver and themselves in previous consultations. Some patients reported that the caregiver was more friendly and understanding than before. This positive experience did not only relate to discussing different topics, but also to the consultation in general.

*"Well, last time the caregiver was very, very friendly. It was unbelievable. The caregiver even gave me a choice: are you coming next time, because it is up to you? It's not mandatory. I thought: what is happening! The caregiver also didn't ask that much, but simply did what they have to do."*²⁷ (Patient 2)

Awareness with patient and caregiver

The patient also acknowledged that the PAM raised awareness for themselves, because it made them reflect. The PAM made patients think about issues around their care process and self-management they normally do not consider.

*"Of course it contributes something, because it makes you think.. If you, in a preventive stage, make people look in the mirror periodically, I think that is good.. That's the story, it is an eye-opener, a good look in the mirror."*²⁸ (Patient 3)

Patients also mentioned that the measure and the conversation raises awareness of the caregiver about how the patient thinks and what the patient needs, which is seen as beneficial for the care process. As such, patients can be put in a central position and care can be more suited to their individual needs.

*"That's the meaning of such a questionnaire, to find out how we, as patients, think about things and how we experience it... The caregiver understands me a little better now. If something happens and the caregiver has to take action if something is not right with me. Then he knows now how I think about certain things... It is good that he knows that, in my opinion. We know each other's point of view."*²⁹ (Patient 4)

Emphasizing patients' needs periodically

Patients mention that it would be a possibility to fill out the PAM more often. They experienced it can be used to express their needs and views about the care process and self-management. They see additional value in filling out this measure periodically to make caregivers aware about changes in the patients views and needs.

*"For me it doesn't have additional value, but in general it is good that periodically something like this happens again, like every two years. That you can say, there are new developments. Maybe there are new ideas and that you can anticipate on that. You might approach people again."*³⁰ (Patient 3)

However, patients also emphasize that the usefulness of the PAM is dependent on the seriousness of the condition, because answers relate to the personal situation.

*"It is very dependent of the situation, but if nothing changes in my situation, this won't change... A drastic change needs to take place to answer differently."*³¹ (Patient 5)

This notion is made by patients, as they also mention the downside of filling out statements like it was done in this study. For example according to a patient: if these statements are asked too often it can become a routine of how it was filled out the last time, in which case the PAM cannot improve the care process since answers do not give a fair overview.

5.2.2 The PAM does not improve the care process

Patients also mention situations when the PAM did not improve the care process. Firstly, some patients did not experience anything different from regular consultations. Therefore, it was not possible to experience an improvement. When asked more specifically what happened during the consultation and how they perceived this, it became evident that most caregivers did ask some different questions which related to the PAM. The caregiver did incorporate this in the consultations, only in such a way that the patient did not experience a change. Patients did not perceive this as negative, because when asked about the care process the patient often said that the caregiver already puts their needs in a central position. Therefore, a number of patients feel that the care is already suited to their individual situation and they feel less need to talk about this with their caregiver.

“I think my caregiver knows me well enough to have an idea about how I think about that. I’m in this GP practice for a while now.”³² (Patient 5)

“It was a similar conversation and I’m happy about how it goes. That is evident from the answers I gave. I’m satisfied, have no complaints, none at all.. It goes how it goes and that is good. I’m very satisfied and it’s just perfect.”³³ (Patient 3)

Secondly, there were two patients who did have a different experience in this consultation in comparison to a regular consultation. These patients experienced some type of friction in the care process. Although they experienced that the caregiver listened more to their needs, they were a bit skeptical whether this measure would solve friction. The current different experience was often not yet what they wanted the care process to be which meant that in their opinion the caregiver could still improve the care process by putting their needs in a central position.

“It was a different conversation as before, but not that.... Not with a different result. I’m also not consulted, they don’t ask me : what do you do [that makes the patients self-management so effective in the patient’s opinion], let’s see, write it down.”³⁴ (Patient 6)

However, they acknowledged that this change might take more time than one consultation and that friction could be solved in the future if changes continue in the direction like it was the case in the previous consultation.

"(R)Do you have the feeling this goal is reached a little bit or is it still far away?

Not after this one time.

(R) What about in the long run?

Maybe

(R)Does it have to continue like the last time?

*The last time, if they do that then yes."*³⁵ (Patient 2)

Thirdly, it was noted by some patients that they do not need a questionnaire like the PAM to discuss subjects as their needs and responsibility with their caregiver.

*"But maybe I would say it before that. I don't need a questionnaire to do that, not just with the GP but also other care institutes. If I don't like something, I just say it. I also have good contacts [with GP practice], I can talk about this very well. I know why this and that, and then they also know what's happening on their side."*³⁶ (Patient 7)

5.2.3 Opportunities and barriers for practical applications of the PAM

The fact that the GP practice does research to enhance care for their patients, such as the current study, is valued positive by the patients. This way they can see that the practice wants to improve and that teamwork is evident in the practice.

*"I see a collaboration and that is useful. There are more requests for research and usually I throw it away, but here I see a collaboration and teamwork. Maybe the pharmacy should be involved too."*³⁷ (Patient 8)

Furthermore, some patients mention that the statements from the measure were understandable which made filling out the statements easier. This can be seen as trust that patients have in the measure.

"Like it was written down, I could read it well. It was just written down in Dutch.

(R)What about the formulation?

*That can be done in many different ways, but this was very clear."*³⁸ (Patient 2)

However, at the same time some patients mentioned reservations they had about the measure. Patients mentioned two aspects of the PAM they specifically perceived as barriers. Firstly, they found certain statements difficult to interpret, which made giving an answer more difficult.

*"There were some statements where I was really doubting my answer: what do I do with this, do I agree or disagree. In those cases the formulation of the statements was a bit unclear."*³⁹ (Patient 4)

Secondly, some patients also made a comment that statements and the scope of these statements were too general.

*"Of course every statement is quite general and on a few statements you cannot specifically say yes or no."*⁴⁰ (Patient 5)

5.3.4 Conclusion patients

Most patients mentioned they noticed a difference in the consultation in comparison with a regular consultation. They noticed that the caregiver asked some questions that related to PAM subjects. In some cases this triggered a conversation about topics which are normally not discussed, such as responsibility and their own needs in the care process. Patients also acknowledged that filling out the PAM raised awareness in themselves about subjects they usually do not think about. They could also imagine that the caregiver was now more aware about their needs and views about responsibility and the care they receive. As a result patients concluded that the PAM could improve the care process, because it can emphasize their views and needs periodically. However, it was remarked that it should not be done too often because if filling out PAM statements becomes a routine it has the opposite effect.

Some patients did not notice a difference. Most of these patients were already satisfied with the care they received and felt it already suited their individual situation. There were also some patients, who noticed a difference, but they did not feel that the care suited their individual situation more than before. These patients experienced friction in their current care process. While they commented that the caregiver was more friendly and positive, the current change is too short to see if something has changed around this friction. Possibilities for practical applications of the PAM are in the notion that the PAM ensures collaboration within the GP practice, since it shows that caregivers want to work with the patients. A barrier for practical applications of the PAM is the perceived difficulty of interpreting specific statements. Some statements were perceived to be clear and easy to answer, but some of them were perceived difficult to interpret and difficult to answer.

6. Discussion

The current case-study identified barriers and opportunities of using the Patient Activation Measurement to improve care and put the patient in a central position by suiting care to the individual situation. Interviews with caregivers and patients showed that the measure provided a trigger for discussing a topic which normally is not spoken about. Filling out the PAM and having a discussion about this with the caregiver created awareness of the patient about topics that patients do not usually think about, such as responsibility. Using the measure in the consultations also raised awareness of the caregiver about the importance of putting the patient in a central position and gaining better understanding about the individual patient. Furthermore, caregivers appreciated that the measure ensured preparation for them in advance of the consultation as well as a prepared patient during the consultation. Patients appreciated that the measure emphasized their needs and views on the care process and responsibility, which could be checked periodically. Caregivers and patients also gave indications on when the measure did not improve the care process. For caregivers this was mainly when Patient Activation scores were low (level 1), in which case they felt that the patient did not understand them or caregivers did not know how to assist these patients. Another instance when the measure did not improve the care process for caregivers, was when they already used an approach which put the patients' needs in a central position. Therefore the PAM could not help them further, even though in this situation the measure could serve as a confirmation about the current satisfaction in the care process. For patients, the PAM mainly did not improve the care process when they felt their needs were already taken into account and therefore did not need a specific measure to voice their needs and views.

These results can support the claim Hibbard and Gilbert (2014) make that being aware of someone's Patient Activation level can assist the caregiver in providing care suited to the individual situation of the patient and therefore improve the care process. In this sense, during the consultations the caregiver and patient worked together to complement each other's knowledge and improved the patient-caregiver communication (Gazmararian, Ziemer, & Barnes, 2009), which can be seen as a solution to the gap between a caregivers understanding of a disease and a patients experience of a disease (Holman & Lorig, 2004). On the other hand do the findings indicate that caregivers did not particularly look at the activation level, but more at answers of specific statements. Using the measure triggered a conversation and created awareness, but caregivers did not specifically suit care to the individual by applying the guidelines that characterize patients at each level of the PAM (Table

2, page 8). Therefore, certain barriers and opportunities need to be taken into account if this measure is used to assist caregivers in improving the care process and self-management of chronic patients.

Experienced barriers

The main barrier identified by both caregivers and the patients, are the reservations about the validity of the PAM, even though the measure is officially validated (Rademakers et al., 2012). If the caregiver or the patient has reservations about the PAM, he or she also will not be inclined to use it or fill it out. For caregivers these reservations mainly relate to the fact that the measure did not assist them with self-management in lower scoring patient and to the fact that the assistance the measure did offer (Table 2, page 8) was too general. For patients these reservations mainly relate to the fact that they had difficulty interpreting certain statements. These reservations can be supported by the average answers on certain statements. For example, statement 1 and 2 have the same average, which can indicate that patients interpreted the statements very similar to each other while their intent is to measure different aspects of responsibility. Both caregivers and patients also indicated in interviews that especially statement 12 was difficult to interpret, particularly for patients with low activation levels (level 1-2). This difficulty is a possible reason why this statement was scored low on average. This observation is similar to an observation made by Packer et al. (2015) who aimed to validate the PAM in a population with neurological conditions. They stated that '*scaling problems may yield measurement error and biases for those with low levels of activation*' (Packer et al., 2015, p. 1587). This distrust caregivers and patients have, can be solved in several ways.

Firstly, the PAM could still be improved on clarity of interpretations despite its established validity. Already in the validation study of Rademakers et al. (2012), some statements (particularly statement 2) were said to be difficult to interpret for patients. However, these statements were never adjusted. Similar to patient experiences of difficulty to interpret statements, caregivers in the current study also implied that certain capacities are needed to fill out the PAM, especially cognitive abilities. This is supported by the finding that patients with lower activation levels (level 1-2, on average a 6,7) perceived the statements are more difficult than patients with higher activation levels (level 3-4, on average a 7,5). Understanding statements is important for communication with the caregiver which is acknowledged by the PAM since it takes dimensions of health literacy into account. The PAM incorporates critical health literacy by answering statements about capabilities and confidence in skills and using information to exert better control over one's life (Nutbeam, 2000). The reason that some statements are difficult to interpret can be that no validated Dutch measurements exists to

measure critical health literacy, which makes it also difficult for the PAM to capture elements of health literacy (Fransen et al., 2011). These elements are especially difficult to understand for patients with lower activation levels. That the validity of the PAM could still be improved on this issue, is also supported by Packer et al. (2015) who state that using the PAM would be more beneficial if it recognized some unique attributes and management challenges, such as ability to adhere with treatment, in certain chronic diseases. A counter argument for this improvement of the measure on clarity, can be that the caregiver and patient should fill out the PAM together so that the caregiver can give clarity where needed. This could be beneficial, because caregivers would not only get answers but also the process on how a patient gets to an answer, since the patient can tell thoughts about PAM statements directly to the caregiver. However, current interviews show that this is not possible in practice, since there is simply not enough time to go through this process.

Secondly, the PAM can be improved on the validity around the current purpose of the PAM, which is using it as a measure in itself instead of a way to get an outcome measure. More and more research is being done on the effect of Patient Activation and how it can influence health behaviors (Fowles et al., 2009; Greene & Hibbard, 2012; Hibbard & Gilbert, 2014; Remmers et al., 2009), while it does not look at how the PAM itself can assist in suiting care. This makes this study innovative, but it is also possible that the score and the guidelines needs further validation for the current purpose of using the PAM. The general guidelines used in this study (Table 2, page 8 and Appendix 4), are mainly derived from previous research around tailored coaching and how this can positively affect Patient Activation scores (Hibbard et al., 2009). However, in the current research caregivers experienced that the guidelines around characteristics of a patient with a certain activation level did not match the patient they already know for years. Therefore, they did not particularly use these guidelines to approach the patient based on the activation level. The PAM measures different aspects such as views about responsibility, and dimensions of health literacy, readiness to change and self-efficacy (Hibbard et al., 2005; Hibbard et al., 2004). All these aspects add up to one score that does not take into account that a patient can score high on one aspect and low on another aspect. For example, findings of this study suggest that most patients score high on taking on responsibility. Even patients with level 1 or 2 state on average that they agree with statement 1 and 2 (Table 4, page 20). As a result of getting a level 1 or 2 indication, the guidelines state that awareness needs to be created about responsibility. However, the statements show that the person already acknowledges this, but issues are on different aspects such as confidence to find solutions for new health problems (statement 12). The guidelines could be more useful to caregivers if it was more specifically aimed at this aspect, which would increase the ability to assist patients with self-management and improve the care process. Adjusting for different aspects you measure in statements, is already done in other

instruments, such as the Four-Dimensional Symptom Questionnaire (4DSQ) (Terluin et al., 2006) and proven to be useful for caregivers in practice (Terluin, Rijmen, Van Marwijk, & Stalman, 2007). More research is needed if the PAM can also be validated for practical applications in a real-life care setting such as the current GP practice.

Thirdly, the trust in the PAM can be improved if caregivers get better knowledge about the measure, and skills and confidence on how to use it. Due to time constraints in the current research, it was not possible to train all caregivers about the PAM in detail. Some caregivers also said that they did not have time to read all the information provided in advance of the study, which could be the reason why caregivers did not particularly suit care to a patients' activation level. In particular, not reading the provided information could have led to confusion about how to use the general guidelines (Table 2). The main critique on these guidelines was that it was too general while it is meant to be general (Hibbard & Gilbert, 2014). One practical solution for this knowledge gap can be education and skills-based training on the PAM. Dures et al. (2014) showed that caregivers who provided routine rheumatological care had the need for skills-based training specific for the care these patient's needs. Since the current consultations are also routine care, caregivers could have similar needs, especially since most caregivers report that they see some value in using the PAM to improve care.

Experienced opportunities

The main opportunities identified in this research are related to the comment of the caregivers that there are possibilities to embed the PAM into the GP practice. Since both caregivers and patients are positive about using this measure, it could be embedded in the existing structure of the GP practice as an organization. However, how the measure can be embedded in an effective way to ensure a practical application of the PAM which improves the care process, varies between individual caregivers and patients depending on various other factors in the setting. This finding is in line with the study of Kadu and Stolee (2015) who found that a one-size-fits-all approach was difficult to implement into practice. According to Aarons, Hurlburt, and Horwitz (2011), an intervention should be fit to each level of the health care organization, in this case the patient, the individual caregiver and the overarching GP practice as an organization. Kadu and Stolee (2015) also found that incorporating change in the system can be a facilitator for effective use of the change. So while the way the PAM is used can vary between the individual patient or caregiver, there should be a general standard in the system. How the PAM can be suitable on the level of the patient, caregiver and the organization, can vary.

Firstly, for the patient it can be useful when the measure is used periodically to trigger a conversation about their experiences and views about the care process and responsibility, but the measure does not necessarily need to advocate increasing the Patient Activation level. The literature states that views about this care process and responsibility around self-management can differ between the patient and caregiver (Adhien et al., 2013; Heijmans et al., 2001; Voorham et al., 2011). However, current findings also indicate that in some cases these views do not differ that much, because patients experienced that the caregiver already takes their needs into account. Patients themselves can have different views on self-management and how the caregiver can assist them with this in the care process. Similar results were found by Dixon, Hibbard, and Tusler (2009), who compared views on self-management with Patient Activation levels: patients with lower PAM scores tended to see effective self-management as adherence with advice provided by their caregivers, while patients with higher PAM scores tended to see effective self-management as being in control. Current findings suggest that both the patient and the caregiver are satisfied with the care process, even when activation levels are lower, as long as the patient and the caregiver agree on their definition of self-management. These different views on self-management between patients could also be incorporated into the provided guidelines about patient characteristics on each activation level. The guidelines state strategic goals and action planning for each level (Insignia Health, 2014b), but the goal partly depends on how the patients views self-management. The concept of Patient Activation assumes that higher levels are more desirable for both the patient and the patient since these guidelines are meant to assist caregivers in increasing the activation level (Hibbard & Gilbert, 2014; Hibbard et al., 2009), but with practically applying the PAM on an individual level this improvement in Patient Activation is not always desirable. Especially if the patient is already satisfied with their care process. This satisfaction is supported by the finding that despite a difference in self-rated health between patients with low levels (7,0 for levels 1-2) and high levels of activation (7,6 for levels 3-4), they both give their health a good score on average.

Secondly, for the caregiver the PAM can assist in better understanding the individual patient, but it can vary how and when he or she finds it a useful measure for improving the care process. This study identified two methods on how caregivers can use this measure in the current GP practice, but more research is needed which method is more effective or desirable in a certain setting. The first method is similar to how the PAM was used in the current research, which was letting the patient fill out the entire PAM in advance and do this periodically. The second method was more informal: asking specific statements of the PAM during the consultation when time allows. Furthermore, caregivers were in agreement that there are certain time constraints connected to the measure, because they

have to take all aspects of care into account. In practice this can mean that sometimes other aspects of care take priority.

Thirdly, although the current research did not specifically look at the practice as an organization, results also suggest that the PAM can be fitted to suit the organization. One specific example caregivers gave, was implementing the PAM into the current computer system of the GP practice. This was especially suitable when an informal method was used, because all PAM statements can be put into this system and be monitored which statements were asked at which time. In this case it would be possible to achieve a small change, because the measure is adopted in a way that considers the individual and the team of caregivers, the setting (the GP practice) and the system in which the measure would be embedded (Ferlie & Shortell, 2001). Even some patients acknowledge that this measure can be used to improve teamwork within the organization, but future research is needed to see what potential the PAM has for this. In this future research also the broader context of the setting should be taken into account. For the GP practice, this could mean on how the other parties in the system, such as doctors assistants, are taken into account. The current study shows that at least one person who has main responsibility is needed, because many patients needed a reminder to return the PAM. Practically this means that as long as patients are not used to filling out the PAM, the GP practice needs to have the resources to set up a system that gets PAM results.

Another opportunity for the PAM lies in the fact that the preparation it provided the patient and the caregiver was valued highly by caregivers. The patient was prepared because he or she had thought about subjects around the PAM before the consultation. The caregiver was prepared because he/she could get an indication about the views and needs of the patient around responsibility and the care process in advance. As a result, the time the caregiver had to discuss PAM subjects could be done more efficiently, since the caregiver could pick out the most interesting aspects for the current consultation. Communication could be improved as a result of this preparation, which made working together easier. Therefore, preparation can also assist in closing the gap between the patient and the caregiver (Holman & Lorig, 2004). The fact that caregivers value this preparation highly is positive, but leaves interpretation on how valuable the PAM specifically is. Another measure or homework assignment for the patient can also cause preparation and as a result raise awareness with the patient and caregiver about their respective roles in the care process. This can also be supported by the notion caregivers make that it is also possible to 'just ask' patients about responsibility and needs in the care process without using the PAM.

Preparation in particular could also lead to awareness about subjects discussed in the PAM, according to caregivers. Caregivers did not particularly relate this to a certain level of Patient

Activation, but found it beneficial for all patients (both patients who take responsibility and who do not). Both caregivers and patients then experienced the PAM to be a trigger for a conversation, which was valued positive. The current research did not identify whether this positively experienced conversation was the result of specifically suiting care to the level of activation or using a method for a conversation where the patient is central, such as Motivational Interviewing (Linden et al., 2010; Noordman et al., 2013). Since Patient Activation is a new concept, more research is needed on what specifically can cause a positive effect when caregivers adjust their care to the level of activation. Although suiting care to stages of change is different from adjusting care to Patient Activation levels, Patient Activation does take aspects of readiness to change into account and more research has been done about this subject. Findings in this field suggest that intensive guidance, such as MI approaches, are more likely to cause positive effects during engagement in the care process than suiting care to a specific stage of change (Aveyard, Massey, Parsons, Manaseki, & Griffin, 2009; Blissmer & McAuley, 2002; Naylor, Simmonds, Riddoch, Velleman, & Turton, 1999). Similarly in the current study, the positive experience of patients during the consultations can also be caused because the measure invites the caregiver to put the patient in a central position in which the patient (no matter the level of activation) feels heard. Especially since caregivers used answers on specific statements more than guidelines to adjust care to the level of activation.

Strengths and limitations

There are several strengths and limitations about this research that need to be taken into account when interpreting the results of this study. Limitations in this research relate to time-constraints and the generalizability of the results. As a result of a limited time span for both caregivers and the researcher, several aspects need to be taken into account. Firstly, the current study acknowledges the importance of the concept Patient Activation, but does not specifically use it as an outcome measure. PAM scores were measured, but only used to communicate back to the caregivers. In relation to how caregivers experienced these results, they mainly state that they experienced a difference in usability between patients with lower levels and higher levels. Future research, which can have a larger time-span, should also look at how using a measure like the PAM affects Patient Activation scores and self-management behaviors. This can be done by implementing a more elaborate intervention around the PAM including training on how to use it and measuring Patient Activation scores before and after the intervention to see if suiting care to the specific activation level has a positive effect in practice, as is suggested by Hibbard et al. (2009). The current study also measured self-rated health. This was mainly measured to provide the caregiver with a better understanding about the current situation of the patient. No conclusions can be drawn from these

averages around self-rated health, but findings did show some variation between self-rated health in patients with low levels of activation and high levels of activation. Future research should see if there is a relation between self-rated health and the level of activation, because self-rated health is an important factor in subjective disease experience and therefore self-management (Holman & Lorig, 2004).

Secondly, in the current study it was not possible to let caregivers assist patients in filling out the PAM, which could have resulted in loss of information regarding insight in thought processes and interpretation. During check-up consultations regular items need to be discussed and checked, such as blood pressure. These items are mandatory and take up most of the time during the consultation, which left it impossible for caregivers to also fill out the PAM with the patient and discuss results. When a caregiver fills out the PAM with the patient, he or she can also get insight in the process how the patient gets to an answer. This will provide the caregiver with more information about the individual situation of the patient. In addition, a caregiver can see if a patient interprets the statement correctly, which will result in more reliable answers. In the current study these processes and interpretations were not visible for the caregiver, because the results were provided to the caregiver in an overview before the consultation.

Thirdly, there was limited time between setting up the intervention and implementing the intervention. In combination with busy schedules of caregivers, it was therefore not possible to educate caregivers in detail about Patient Activation and the measurement. To adjust for this limitation a pilot was developed. However, due to limited response from the caregivers on this pilot, it did not influence the education of the caregivers. More reliable results can be gathered if future research provides caregivers with training about a possible way of using the PAM. This way it can also be ensured that every caregiver starts out with the same basic knowledge. In the current research it was possible that certain caregivers had more knowledge about how to use the PAM than others, which could explain certain differences in uses of the measure.

As a result of the set-up of the current study as a case-study, another limitation is related to the generalizability. Even though this research showed promising results for other GP practices, these practices will have to see what opportunities and barriers are in their setting. Findings can also not be generalized to the entire GP practice, because this case-study only used consultations with diabetes type 2 patients. Caregivers and patients can experience and perceive different opportunities and barriers with another chronic disease. However, the validity of the PAM across different populations shows promise that it also can be a useful measure for different diseases (Packer et al., 2015; Rademakers et al., 2012). Finally, findings can also not be generalized to completely different

settings, such as pharmacies, consultation bureaus, physio's or policy institutions, because every setting has its unique characteristics. Findings show that for a measure like the PAM to be useful for a caregiver (provider) and patient (consumer) it needs to be integrated in the organizational structure and be comfortable to use for all parties involved.

An issue that can both be perceived as a strength and a weakness, is that the research is relatively innovative. Not a lot of research has been done on how the PAM in itself can be used in a practical setting. This makes it difficult to underpin current findings with previous research. However, a strength of this study is that it also shows a need for this type of research and the possibilities the PAM can offer instead of mainly being used as an outcome measure. Future research should aim to generalize certain opportunities and barriers the PAM has and give practical assistance on how this measure can be used. A measure like this should aim to assist caregivers as well as patients to improve communication and make care suitable for each individual patient. With this research a first step has been made in that direction, but in order to see if future change in activation levels and improved care is the result more research in different settings is needed.

Another strength of this study is that due to the set-up of the study as a result of time-constraints unique results were discovered, for example the value that is placed of preparation. At the same time the findings can result in better recommendations for the current GP practice, because the intervention took the practical constraints of the setting into account. Even though these constraints do not allow the caregivers to fill out the PAM with their patients, one recommendation is that in certain cases, especially where the routine aspects of a disease cannot be checked as a result of friction, it could be beneficial to take extra time to fill out the PAM. During the current study, the PAM statements were asked via the telephone in some cases because no other way was possible to get the results. This led to the observation that patients indeed tell about the process on how to come to an answer or ask for clarification about interpretation, similar to implications of Hibbard and Gilbert (2014). If the set-up of the study was different, this observation would not have taken place and therefore this recommendation could not have been made.

Finally, a strength of this research was that a pilot took place before the intervention. Even though this pilot provided little assistance with educating the caregivers, it did provide assistance in improving the organizational side of the study. Clearer agreements were made as a result of this pilot about communication of PAM results to the caregiver. Therefore, the pilot enhanced the validity, because information about PAM results was able to get to the right caregiver in time for them to prepare the consultation.

7. Conclusion

According to both caregivers and patients, the PAM was a trigger for a conversation about how the patient views responsibility, what motivates the patient and how this affects their needs in the care process. The PAM raised awareness about the importance of self-management and what it can entail. The measure assisted the caregiver in improving the care process by putting the patient in a central position. Opportunities for embedding the measure into the GP practice are in finding a suitable way and a suitable moment in time to use the PAM for both the caregiver and the patient. A suitable method relates to either filling out the measure before the consultation or asking selected statements from the measure in, while at the same time there is a general standard on how the PAM is applied in the GP practice. A suitable moment in time relates to when time is available to discuss a different topic, such as taking responsibility for self-management, than normally is discussed during a consultation. This also fits with the opportunity the patients see, that the PAM could serve as a check to periodically discuss changes in views and needs about how the care process should be shaped. The main barrier identified in this research, is the distrust caregivers and patients can have about the validity of the measure itself and the usefulness of the provided guidelines. These reservations can be dealt with by improving the validity of the PAM to the current purpose of using it to improve the care process and by educating caregiver about Patient Activation and how to use the PAM.

8. Practical recommendations

Since this research was a case-study in a specific GP practice, there are recommendations that can be made for this practice in Ede, the Netherlands. Other settings can also use some general recommendations if the PAM will be tried out in these settings. A general recommendation of this research, is that findings suggest the PAM has potential to be used to suit care to the individual situation. However, there are some barriers and opportunities to take into account.

- The PAM should fit the individual caregiver. This means that if a caregiver finds the PAM a useful measure, he or she should be assisted by the setting to use this measure in an appropriate way for that caregiver and patient. At the same time, if a caregiver does not find the PAM a useful measure, the caregiver should not be forced to use it. However, before caregivers can make a decision whether they can find a way use the PAM, they should be informed correctly. One specific recommendation for this is:
 - Provide all caregivers (and possibly doctors-assistance) with information on how to use the PAM to give suited care and provide skill-based training on this subject. Especially training in how the PAM can assist when Patient Activation levels are low is useful, since caregivers said that these groups were the most difficult. If this is done, than caregivers can optimally experience further barriers and opportunities and make an informed decision.
- The patient must feel comfortable to fill out the PAM. This means that the patient must not feel burned by filling out these statements. One way to ensure this, is by not letting the patient fill out the statements too often. Instead it should be used as a periodic check on how views about PAM subjects have changed to see if care needs to be suited to the individual situation differently.
- The PAM should be integrated in the GP practice as a setting to make using the measure as simply as possible for all parties involved (e.g. patients, GPs, POHs and doctors assistance). There are some specific recommendations on how this can be done:
 - Integrating the PAM statements into the current computer system in which caregivers can check of when they discussed which statement. This way not every statement has to be discussed every time, but the caregiver and patient can together find a suitable moment to do this.

- Let patients fill out the (some) statements in advance so that preparation of the subject can be ensured for both the patient and the caregiver.
 - Make sure that an administrative system is set up to ensure good communication between patient – doctor's assistance – caregiver. In the current research, the main researcher was responsible for getting all the information to the right person in time. This experience showed that one person needs to be responsible for gathering PAM scores, putting the PAM questionnaire in the computer system, and ensure the caregiver is aware of this information. For example, this could be one doctors assistant who takes responsibility of the administrative side and communication of information and one caregiver who is an expert on the content of the PAM and can co-ordinate opportunities and barriers which are experienced. One of these two should be responsible for calculating a PAM score and level, which can be easily done with a scorings matrix.
- In the future the PAM has certain possibilities. Three main possibilities are discussed as recommendations:
- The PAM can be useful in re-starting a conversation with people who do not come to consultations. This research showed that this measure can be a trigger to start a conversation about what the patient wants. If the patient feels central, it can be more likely that he or she will come more regularly for a check-up. This can be supported with the experiences of two patients who experienced some friction. These patients were more optimistic that the perceived the caregiver as more friendly and listened better. However, it should be noted that this is a process that will require a longer time-span. Furthermore, it should be noted that the PAM could work better for a certain group of care avoiders than other groups. It will mainly work for a group that does not feel heard and does not feel their own needs are represented enough in the care process. Patients who avoid care because of fear or denial might be more difficult to reach.
 - The PAM can be used on a broader scale, which means more care providers could be involved. The goal of the PAM in this research, was to suit care to the individual situation. Chronic patients or people with other issues have to deal with more than one care organization. Ideally, all these organization (such as pharmacy, consultation bureaus, dietitians, hospitals) should take a patients individual situation into account. Since the PAM is a measure that provides a relatively short and clear overview, it could be used to improve communication between care providers about the individual situation of a patient.

- The PAM can be used as a measurement to monitor Patient Activation over time. Especially in chronic patient, Patient Activation can deteriorate because health will inevitably deteriorate. The PAM is a suitable measurement to identify this in time in order to take appropriate action according to both the caregiver and the patient.

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Appendix 1 – Dutch PAM-13

Hieronder staan enkele uitspraken die mensen soms doen over hun gezondheid. Geef voor elke uitspraak aan, in hoeverre u het ermee eens of oneens bent. Doe dit door het antwoord te omcirkelen dat het meest op uw persoonlijke situatie van toepassing is. *We willen dus weten wat u zelf vindt en niet wat u denkt dat de dokter of onderzoeker wil horen.* Als de uitspraak niet op u van toepassing is, omcirkel dan ‘n.v.t.’

1.	Uiteindelijk ben ik zelf verantwoordelijk voor mijn gezondheid.	Helemaal niet mee eens	Niet mee eens	Mee eens	Helemaal mee eens	n.v.t.
2.	Een actieve rol op me nemen in de zorg voor mijn gezondheid, heeft de meeste invloed op mijn gezondheid.	Helemaal niet mee eens	Niet mee eens	Mee eens	Helemaal mee eens	n.v.t.
3.	Ik heb er vertrouwen in dat ik kan bijdragen aan het voorkomen of verminderen van problemen met mijn gezondheid.	Helemaal niet mee eens	Niet mee eens	Mee eens	Helemaal mee eens	n.v.t.
4.	Ik weet wat elk van mijn voorgeschreven medicijnen doet.	Helemaal niet mee eens	Niet mee eens	Mee eens	Helemaal mee eens	n.v.t.
5.	Ik heb er vertrouwen in dat ik kan beoordelen of ik naar de dokter moet gaan of dat ik een gezondheidsprobleem zelf kan aanpakken.	Helemaal niet mee eens	Niet mee eens	Mee eens	Helemaal mee eens	n.v.t.
6.	Ik heb er vertrouwen in dat ik een dokter mijn zorgen durf te vertellen, zelfs als hij of zij daar niet naar vraagt.	Helemaal niet mee eens	Niet mee eens	Mee eens	Helemaal mee eens	n.v.t.
7.	Ik heb er vertrouwen in dat het mij lukt om medische behandelingen die ik thuis moet doen uit te voeren.	Helemaal niet mee eens	Niet mee eens	Mee eens	Helemaal mee eens	n.v.t.
8.	Ik begrijp mijn gezondheidsproblemen en wat de oorzaken ervan zijn.	Helemaal niet mee eens	Niet mee eens	Mee eens	Helemaal mee eens	n.v.t.
9.	Ik weet welke behandelingen er zijn voor mijn gezondheidsproblemen.	Helemaal niet mee eens	Niet mee eens	Mee eens	Helemaal mee eens	n.v.t.
10.	Ik heb veranderingen in mijn leefstijl (zoals gezond eten of bewegen) kunnen volhouden.	Helemaal niet mee eens	Niet mee eens	Mee eens	Helemaal mee eens	n.v.t.
11.	Ik weet hoe ik gezondheidsproblemen kan voorkomen.	Helemaal niet mee eens	Niet mee eens	Mee eens	Helemaal mee eens	n.v.t.
12.	Ik heb er vertrouwen in dat ik zelf oplossingen kan bedenken voor nieuwe problemen met mijn gezondheid	Helemaal niet mee eens	Niet mee eens	Mee eens	Helemaal mee eens	n.v.t.
13.	Ik heb er vertrouwen in dat ik veranderingen in mijn leefstijl (zoals gezond eten en bewegen) kan volhouden, zelfs in tijden van stress.	Helemaal niet mee eens	Niet mee eens	Mee eens	Helemaal mee eens	n.v.t.

Appendix 2 – Letter, informed consent and questionnaire for pilot



Geachte Meneer/Mevrouw,

Huisartsenpraktijk Veldhuizen doet een onderzoek in samenwerking met de Wageningen Universiteit naar de diabetesspreekuren van de praktijk. Het doel van dit onderzoek is een duidelijker beeld te krijgen van de rol van u als patiënt in de diabeteszorg. Op deze manier kan de zorg beter aangesloten worden bij wat verschillend patiënten nodig hebben. Wij hebben hier uw hulp bij nodig, daarom willen wij u graag uitnodigen deel te nemen aan dit onderzoek.

In deze brief zullen we kort toelichten wat er van u verwacht wordt, als u deelneemt aan het onderzoek. Binnenkort heeft u een afspraak voor een diabetescontrole bij de huisarts of praktijk ondersteuner. Wij vragen u de bijgevoegde enquête in te, voorafgaand aan de afspraak. Deze enquête kunt u terugsturen met de bijgevoegde enveloppe of inleveren bij de assistent van de huisartsen. Graag verzoeken wij u dit minimaal één week vóór uw afspraak te doen. Deze enquête zal anoniem verwerkt worden en al uw gegevens zullen vertrouwelijk behandeld worden.

Tijdens uw diabetes consult kan de huisarts op basis van uw antwoorden zijn of haar consult aanpassen. Eventueel kan de huisarts terug komen op een enkele vraag om bepaalde punten duidelijker te krijgen en uw persoonlijke verhaal beter te leren begrijpen. Behalve het invullen van de enquête hoeft u dus geen extra dingen te doen. Wij zijn na dit consult geïnteresseerd naar uw beleving. Mocht u bereid zijn een kort interview te geven over deze belevingen tijdens het consult, kunt u aan het eind van de enquête uw telefoonnummer invullen.

Mocht u vragen hebben of meer informatie willen over dit onderzoek, kunt u contact opnemen met Bonnie van Dongen op 06-31192662. Op de volgende pagina vindt u een toestemmingsformulier waar uw rechten in vermeld staan als u deelneemt aan dit onderzoek.

Met vriendelijke groet,

Uw huisarts _____ En Bonnie van Dongen (Wageningen University)

Toestemmingsformulier

Dit onderzoek wordt uitgevoerd in samenwerking van huisartsenpraktijk Veldhuizen en Wageningen University als onderdeel van een masterthesis van de opleiding Health en Society. U zult volledig anoniem blijven tijdens dit onderzoek. Dit betekent dat uw antwoorden niet naar u te herleiden zullen zijn wanneer de gegevens verwerkt worden. Uw gegevens zullen vertrouwelijk behandeld worden en niet doorgespeeld worden aan derden. Zowel voor de enquête als voor een eventueel interview geldt dat er geen goede of foute antwoorden zijn. U hebt het recht om op elk moment in dit onderzoek te stoppen met uw deelname.

Mocht u vragen hebben over de gang van zaken van dit onderzoek kunt u contact opnemen met Bonnie van Dongen (06-31192662). Mocht u tijdens of na het onderzoek vertrouwelijke vragen of problemen hebben in relatie tot de inhoud van dit onderzoek, kunt u terecht bij Lenneke Vaandrager (UNI TEL?) of bij huisarts Rekers.

- Ja, ik begrijp mijn rechten en geef met mijn handtekening toestemming tot deelname**

Datum

Naam deelnemer

Handtekening deelnemer

Voeg dit formulier toe als u de enquête inlevert.



ENQUETE

Beste meneer/mevrouw,

Deze enquête zal bestaan uit verschillende onderdelen. Als eerst vragen wij enkele algemene gegevens van u. Daarna worden enkele uitspraken voorgelegd, die mensen kunnen doen over hun gezondheid. Aan u wordt gevraagd in welke mate u het met deze uitspraken eens bent. Tot slot vragen wij u hoe u de huidige diabetes consulten ervaart. Uw gegevens zullen anoniem verwerkt worden en er zijn geen goede of foute antwoorden.

Hartelijk dank voor uw medewerking.

Met vriendelijke groet,

Huisartsenpraktijk Veldhuizen

Deelnemersnummer:

In te vullen door onderzoeker

Algemene gegevens

Naam: _____

Geslacht:

- Man
- Vrouw

Leeftijd: _____ Jaar

Diagnose diabetes sinds : _____ (Maand) - _____ (Jaar)

Naam huisarts of praktijkondersteuner: _____

Hoe ervaart u uw huidige gezondheid?

Omcirkel een cijfer van 0 tot 10, waarbij 0 staat voor een slechte gezondheid en een 10 voor een uitstekende gezondheid

0 1 2 3 4 5 6 7 8 9 10

Uitspraken over gezondheid

Hieronder staan enkele uitspraken die mensen soms doen over hun gezondheid. Geef voor elke uitspraak aan, in hoeverre u het ermee eens of oneens bent. Doe dit door het antwoord te omcirkelen dat het meest op uw persoonlijke situatie van toepassing is. **We willen dus weten wat u zelf vindt en niet wat u denkt dat de dokter of onderzoeker wil horen.**

Als de uitspraak niet op u van toepassing is, omcirkel dan ‘n.v.t.’

1.	Uiteindelijk ben ik zelf verantwoordelijk voor mijn gezondheid.	Helemaal niet mee eens	Niet mee eens	Mee eens	Helemaal mee eens	n.v.t.
2.	Een actieve rol op me nemen in de zorg voor mijn gezondheid, heeft de meeste invloed op mijn gezondheid.	Helemaal niet mee eens	Niet mee eens	Mee eens	Helemaal mee eens	n.v.t.
3.	Ik heb er vertrouwen in dat ik kan bijdragen aan het voorkomen of verminderen van problemen met mijn gezondheid.	Helemaal niet mee eens	Niet mee eens	Mee eens	Helemaal mee eens	n.v.t.
4.	Ik weet wat elk van mijn voorgeschreven medicijnen doet.	Helemaal niet mee eens	Niet mee eens	Mee eens	Helemaal mee eens	n.v.t.
5.	Ik heb er vertrouwen in dat ik kan beoordelen of ik naar de dokter moet gaan of dat ik een gezondheidsprobleem zelf kan aanpakken.	Helemaal niet mee eens	Niet mee eens	Mee eens	Helemaal mee eens	n.v.t.
6.	Ik heb er vertrouwen in dat ik een dokter mijn zorgen durf te vertellen, zelfs als hij of zij daar niet naar vraagt.	Helemaal niet mee eens	Niet mee eens	Mee eens	Helemaal mee eens	n.v.t.
7.	Ik heb er vertrouwen in dat het mij lukt om medische behandelingen die ik thuis moet doen uit te voeren.	Helemaal niet mee eens	Niet mee eens	Mee eens	Helemaal mee eens	n.v.t.
8.	Ik begrijp mijn gezondheidsproblemen en wat de oorzaken ervan zijn.	Helemaal niet mee eens	Niet mee eens	Mee eens	Helemaal mee eens	n.v.t.
9.	Ik weet welke behandelingen er zijn voor mijn gezondheidsproblemen.	Helemaal niet mee eens	Niet mee eens	Mee eens	Helemaal mee eens	n.v.t.
10.	Ik heb veranderingen in mijn leefstijl (zoals gezond eten of bewegen) kunnen volhouden.	Helemaal niet mee eens	Niet mee eens	Mee eens	Helemaal mee eens	n.v.t.
11.	Ik weet hoe ik gezondheidsproblemen kan voorkomen.	Helemaal niet mee eens	Niet mee eens	Mee eens	Helemaal mee eens	n.v.t.
12.	Ik heb er vertrouwen in dat ik zelf oplossingen kan bedenken voor nieuwe problemen met mijn gezondheid	Helemaal niet mee eens	Niet mee eens	Mee eens	Helemaal mee eens	n.v.t.
13.	Ik heb er vertrouwen in dat ik veranderingen in mijn leefstijl (zoals gezond eten en bewegen) kan volhouden, zelfs in tijden van stress.	Helemaal niet mee eens	Niet mee eens	Mee eens	Helemaal mee eens	n.v.t.

Ervaring met de huisartsenpraktijk

U komt verschillende keren per jaar op consult bij óf de praktijkondersteuner óf de huisarts ter controle van uw diabetes. **Hieronder wordt u gevraagd één positief punt en één verbeterpunt van het huidige consult te noemen van zowel de praktijkondersteuner als de huisarts.** Een consult betekent in dit geval vanaf het moment als u de huisartsenpraktijk binnen komt en in de wachtkamer plaats neemt tot aan het moment dat u de huisartsenpraktijk verlaat.

Het jaarlijkse consult bij de huisarts	<u>Positief punt:</u>
	<u>Verbeterpunt:</u>
Het kwartaal consult bij de praktijkondersteuner	<u>Positief punt:</u>
	<u>Verbeterpunt:</u>

Hoe makkelijk of moeilijk vond u deze enquête/stellingen?

Omcirkel een cijfer waarbij 1 staat voor zeer moeilijk en 10 staat voor zeer makkelijk

Zeer moeilijk	1 2 3 4 5 6 7 8 9	Zeer makkelijk
	10	

Heeft u nog opmerkingen naar aanleiding van deze enquête?

Bent u bereidt tot een kort interview over uw ervaringen van het diabetes consult zoals deze komende keer uitgevoerd zal worden, zet dan hier uw telefoonnummer neer:

Hartelijk dank voor het invullen van deze enquête.

U kunt deze enquête opsturen met de bijgeleverde enveloppe óf inleveren bij de receptie van de huisartsenpraktijk in de daarvoor bestemde afgiftekoos. Vergeet niet uw toestemmingsformulier toe te voegen.

Appendix 3 – Overview of questionnaire results for the caregiver

Naam patiënt: _____

Identificatienummer: _____

Naam huisarts: _____

PAM score			
PAM niveau			
	Nummer	Vraag	Antwoord
Opvallende vragen		- - - - -	

Advies bijgeleverd door PAM licentie op basis van PAM niveau:

Overige vragen

Ervaren gezondheid	
Hoe moeilijk/makkelijk vond patiënt de vragenlijst?	

Overige opmerkingen/ verbeterpunten die nu nuttig zijn:

Appendix 4 – Information given to the caregiver

Met het document wat voor u ligt, wil ik u graag wat meer informatie geven over het onderzoek dat ik doe binnen jullie huisartsenpraktijk als onderdeel van mijn Masterthesis voor de opleiding Health and Society. Met dit onderzoek wil ik graag kijken of en hoe de Patient Activation Measurement (PAM) iets voor u kan betekenen. Ik waardeer uw medewerking en tijd zeer. Mocht u dan ook vragen of opmerkingen hebben, kunt u een email sturen op bonnie.vandongen@gmail.com. De PAM is een van de methodes die zorgverleners kunnen helpen meer inzicht te krijgen in hun patiënten, maar is dus niet de enige. Om te kijken of de PAM een nuttig instrument kan zijn, vraag ik slechts van u om deze methode uit te proberen. Mocht deze methode niets voor u zijn nadat u het heeft uitgeprobeerd, is dit geen probleem. Dit kunt u vervolgens aangeven in een persoonlijk interview waar uw mening centraal staat. Dit document bevat allereerst informatie over het begrip Patient Activation en wat het voor u kan betekenen. Daarnaast bevat dit document informatie over twee methoden, die u mogelijk kunnen assisteren de PAM optimaal te gebruiken tijdens het diabetes consult.

Patient Activation en wat het kan betekenen voor u

Patient Activation is relatief nieuw begrip, dat kansen biedt voor u om meer inzicht te krijgen in uw patiënt. Het begrip is lastig te vertalen, omdat in dit geval een gedeelte van de boodschap verloren gaat. Het kingsfund, waarvan u de uitleg over de PAM® heeft ontvangen, definieert Patient Activation als volgt: *'a concept that captures a patient's knowledge, skills and confidence in managing their health and health care and the likelihood that they will put these into action'*. De Patient Activation Measurement (PAM®) is een meetinstrument ontworpen om Patient Activation te meten. Sinds kort is van dit meetinstrument ook een Nederlandse gevalideerde versie beschikbaar (Bijlage 1). Op basis van deze vragenlijst worden mensen in vier niveaus ingedeeld, zoals in Figuur 1 te zien is.

Niveau 1	Niveau 2	Niveau 3	Niveau 4
<ul style="list-style-type: none">• Beginnen met het nemen van een rol• Individuen hebben niet het zelfvertrouwen om een actieve rol te vervullen ten zaanzien van hun gezondheid. Ze zijn geneigd tot het passief ontvangen van zorg	<ul style="list-style-type: none">• Opbouwen van kennis en zelfvertrouwen• Individuen missen zelfvertrouwen over hun gezondheid of over aanbevolen gezonde leefregels	<ul style="list-style-type: none">• Actie ondernemen• Individuen weten de belangrijkste feiten en beginnen actie te ondernemen, maar kunnen een gebrek hebben aan zelfvertrouwen en vaardigheden om hun gedrag vorm te geven	<ul style="list-style-type: none">• Gedrag volhouden• Individuen hebben nieuw gedrage aangenomen, maar zijn mogelijk niet in staat om dat gedrag vol te houden in stressvolle situaties.

Toenemend niveau van Patient Activation

Het idee van deze PAM® score is dat u meer te weten komt over de individuele context van uw patiënt. Op basis van deze score kunt u de patiënt op een bepaalde manier benaderen. Een patiënt met een lage PAM® score, neemt bijvoorbeeld niet veel verantwoordelijkheid op zich in het zorgproces en kan daardoor meer gebaat zijn bij stapsgewijze informatie om aspecten van zijn of haar chronische ziekte te leren begrijpen en kleine successen om zelfvertrouwen op te bouwen. Op de lange termijn kan deze Patient Activation verhoogd worden, waardoor een beter management van het zorgproces plaats kan vinden en de patiënt een grotere verantwoordelijkheid op zich kan nemen. Dit zelfmanagement en verantwoordelijkheid kunnen een belangrijke rol spelen in diabetes type 2, omdat op deze manier de kwaliteit van leven en het gevoel van autonomie bij de patiënt kan stijgen. Voor u kan een verantwoordelijke patiënt voordelen hebben, want deze patiënt kan bijvoorbeeld betere gezondheidsuitkomsten tonen, beter aangeven wat hij of zij wil bereiken binnen de diabetes zorg, en meer therapietrouw zijn. Op deze manier kan een check-up consult zo efficiënt mogelijk verlopen voor zowel u als de patiënt.

Dit onderzoek is echter te kort om deze lange termijn effecten te onderzoeken. Het is allereerst van belang of u de PAM® een prettige methode vind om mee te werken. Om dit te onderzoeken vragen we aan patiënten om de Nederlandse PAM® in te vullen. Deze scores zullen verwerkt worden, zodat u een klein informatiepakket krijgt over de desbetreffende patiënt (zie Bijlage 2 voor het format). Dit kunt u voorbereiden en gebruiken tijdens het consult. Het is hiermee niet de bedoeling dat het consult op een compleet andere manier verloopt dan een huidig consult. Bepaalde items en protocollen moeten nu eenmaal besproken worden en de tijd van een consult is natuurlijk maar beperkt. Echter zou het mogelijk zijn om binnen de items die besproken moeten worden, vragen op een bepaalde manier gesteld kunnen worden en eventueel gekoppeld kunnen worden aan de PAM® score van de patiënt. Tabel 1 geeft een globaal overzicht over hoe patiënten gekarakteriseerd kunnen worden op basis van hun PAM® niveau. Dit overzicht is door Insignia Health geleverd, de organisatie verantwoordelijk voor het ontwikkelen van de Amerikaanse PAM® en de organisatie die verantwoordelijk is over de PAM® licentie. (Dit figuur is geleverd in het Engels en vertaald in het Nederlands. De Engelse versie is te vinden in Bijlage 3). Deze tabel geeft slechts suggesties voor bepaalde acties die u mogelijk kunnen assisteren in het gebruik van de PAM®.

Tabel 1 – Mogelijke patiënt karakteristieken en mogelijkheden op basis van PAM niveau

Niveau	Mogelijke karakteristieken	Zorg doel	Actie plan
1	Patient voelt zich niet verantwoordelijk over de eigen gezondheid en zorg. Het managen van gezondheid is overweldigend door alle andere levensuitdagingen heen. Patient heeft geen vertrouwen in de eigen vaardigheden om gezondheid te managen. Patient heeft slechts enkelen probleem oplossende vaardigheden en slechte copings-	Patient moet leren begrijpen dat ze zelf belangrijk zijn voor hun toekomstige gezondheid. Het begrijpen van het feit dat ze een positieve invloed op hun gezondheid kunnen hebben door eigen acties. Het creëren van het bewustzijn van de relatie tussen oorzaak en gevolg. Er kan gewerkt	Het monitoren van keuzes en uitkomsten: wanneer je X doet, hoe voel je je dan? Dit kan gedeeltelijk gedaan worden met zelf-monitoren. Mogelijk is het verstandig de patiënt meer te leren over de aandoening en wat één simpel aspect vinden wat de patiënt zelf kan doen (vb.: neem 3 vragen mee naar de volgende

	vaardigheden. Mogelijk is de patiënt zich niet bewust van eigen gedragingen.	worden aan probleem oplossende vaardigheden, gebruik makende van de kleine stapjes methoden. Om verantwoordelijkheid en motivatie te creëren, kan er gefocust worden op aspecten die de patiënt belangrijk acht	afsprak). Patiënten hebben aanmoediging nodig: ze kunnen betrokken worden, ze kunnen een verschil maken, ze kunnen dit! Er moet een begin gemaakt worden met het opbouwen van zelfvertrouwen.
2	Patient mist mogelijk basiskennis over de aandoening, behandelmogelijkheden of zelfmanagement opties. Ze hebben weinig ervaring of hebben succes met het toepassen van gedragsverandering. Er wordt naar de arts gekeken als degene die de touwtjes in handen heeft. Patient heeft weinig vertrouwen in eigen vaardigheden.	Het creëren van een goede kennisbasis voor het maken van goede keuzes. Het opbouwen van zelfvertrouwen door middel van het behalen van kleine successen. Succes kan behaald worden door gedragsverandering in kleine stappen op te breken. Een begin moet gemaakt worden met het opbouwen van stress-management en probleem oplossende vaardigheden	Bewustzijn en kennis moeten verder opgebouwd worden. Begin met kleine stappen maken, bv een koekje voor een banaan als snack vervangen. Vervang niet de hele routine, maar alleen een klein aspect waarin succes te verwachten is. Snappen patiënt de redenen achter hun medicatie en wat het voor hen doet? Wat zijn de bijverschijnselen en waar moeten ze voor uitkijken? Patiënten kunnen zelf een lijst maken wat ze wel en niet begrijpen over hun behandeling.
3	Patiënten begrijpen de basiskennis van hun aandoening en behandeling. Ze hebben wat ervaring en succes gekregen in het maken van gedragsveranderingen. Ze hebben wat vertrouwen gekregen verantwoordelijk te krijgen/nemen over een beperkt aantal aspecten van hun gezondheid	Bouw vanaf eerdere ervaringen en successen om zelfvertrouwen en verantwoordelijkheid over alle aspecten van hun gezondheid te vergroten. Vergroot en behoud gedragsveranderingen (nog steeds stap-voor-stap). Werk aan probleem oplossende vaardigheden en stress management	Begin met het creëren van een gevoel wat wel en niet werkt voor de specifieke patiënt door het nemen van kleine stappen die gerelateerd zijn aan doelen over kwaliteit van leven of klinische indicatoren. Ga door met het creëren van een sterke en bredere kennisbasis over nieuwe gedragingen
4	Patiënten hebben de meeste noodzakelijke gedragsveranderingen gemaakt, maar vinden het moeilijk deze te blijven hanteren wanneer de tijd verstrijkt of wanneer ze stress ervaren	Focus op het vergroten van zelfvertrouwen en vaardigheden die assisteren in het volhouden van gedrag en vaardigheden hoe er met stress om kan worden gegaan. Ontwikkel	De focus is op het volhouden van gedrag. Start met het creëren van vaardigheden en zelfvertrouwen hoe de patiënt om moet gaan met probleem situaties die moeilijkheden met zich mee brengen. Situatie

	<p>vaardigheden op het gebied van coping en probleem oplossing</p>	<p>waarin de patiënt moeite heeft met het volhouden van gedrag kunnen worden geïdentificeerd en vaardigheden om dit te voorkomen kunnen worden ontwikkeld (vb., vooraf plannen, stress management vaardigheden etc.)</p> <p>Ga door met het creëren van een bredere kennisbasis die relateert aan aspecten die komen kijken bij gedragsdoelen. Creëer samen nieuwe doelen die steeds een stap dichter bij komen bij de optimale gezondheid van een patiënt.</p> <p>Focus op eventuele achterblijvende gedragingen</p>
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Toe te passen technieken

Er zijn natuurlijk heel veel manieren om vragen te stellen en erachter te komen wat er anders kan binnen het zorgproces. Er zullen twee methodes uitgelicht worden, die u kunnen assisteren om de PAM® naar uw inzicht in te zetten. De eerste methode is Motivational Interviewing (MI). Deze methode past goed bij het concept van Patient Activation, omdat beide gebaseerd zijn op het idee dat mensen zich in verschillende fasen van motivatie en verandering kunnen beginnen (transtheoretisch model). De tweede methode is oplossingsgericht werken, een methode die ook toegepast zal worden in andere projecten zoals Gezondhuizen. Om eventueel al te oefenen met deze methode, zullen wat basisbeginselen, tips en voorbeelden gegeven worden.

Motivational Interviewing

Motivational Interviewing is een methode die persoon centraal stelt en non-directief is. De methode beoogt een samenwerking met als doel een verandering in de autonome motivatie voor individuele gedragsverandering. Autonome motivatie resulteert uit intrinsieke motivatie (motivatie komt voort uit interesse voor het gedrag), identificatie met een gedraging (het belang van een bepaald gedrag wordt door het individu als belangrijk voor zichzelf gezien) en integratie met een gedrag (het gedrag wordt geïntegreerd met andere belangrijke aspecten van het individu). Het stimuleren van autonome motivatie met behulp van MI kan in het geval van diabetes patiënten belangrijker zijn dan slechts intrinsieke motivatie, omdat bepaalde gedragingen die van patiënten worden gevraagd niet zozeer interessant zijn, maar wel van essentieel belang. Patiënten kunnen wel het belang van een gedrag inzien en het gedrag integreren.

Allereerst is het bij MI van belang dat er gekeken wordt in welke fase van gereedheid tot verandering (readiness to change) een patient zit. Het transtheoretische model identificeert vijf fases, die te zien zijn in Tabel 1. Deze fases hangen samen met het niveau van Patient Activation: iemand die een lagere PAM® score heeft, legt de verantwoordelijkheid deels buiten zichzelf en zal dus in mindere mate willen veranderen als wanneer deze patiënt zichzelf als een belangrijk deel ziet van het zorgproces. Zowel om van veranderingsfase als Patient Activation niveau te veranderen, is het hebben van motivatie tot verandering en het vertrouwen in de eigen vaardigheden (self-efficacy). Hierin kan MI een uitkomst bieden¹.

Tabel 2 – Fases van het trans-theoretische model.

Fase	Beschrijving
Pre-contemplatie	Men is zich nog niet helemaal bewust van de risico's die het gedrag met zich mee brengt. Men overweegt nog geen verandering
Contemplatie/ afweging	Voor- en nadelen van gedrag worden afgewogen. In deze fase is men nog niet van plan ook echactie te ondernemen. Wanneer dit wel het geval is, begint de volgende fase
Determinatie	Voorbereiding: men ziet het nut in van het veranderen van het eigen gedrag en wil dat uitproberen
Actie	Men probeert het nieuwe gedrag daadwerkelijk uit
Gedragsbehoud	Nieuw gedrag wordt gedurende minimaal 6 maanden uitgevoerd en is een gewoonte geworden

Er zijn een aantal dingen mogelijk om MI in de praktijk te gebruiken. Allereerst geeft de PAM® score u al een inzicht in hoe de patiënt zijn of haar verantwoordelijkheid ziet. Daarnaast is het mogelijk om tijdens een consult open vragen proberen te stellen (geen ja/nee vragen). Bij dit soort vragen moet de patiënt meer vertellen over hun proces. Een tweede manier in MI is een reflectieve luisterstijl, die checkt of de boodschap is overgekomen in plaats van aanneemt (begrijp ik dat u bedoelt?). Een derde manier is het checken naar hoeveel vertrouwen een patiënt heeft om een bepaalde verandering te maken (mits het nut voor verandering al wordt ingezien). Dit kan goed passen in de huidige protocollen. Als beiden (u en de patiënt) het erover eens zijn dat een bepaalde waarde anders moet worden, zou de volgende vraag gesteld kunnen worden: wat zou er voor u/volgens u moeten veranderen als we van waarde X naar Y willen? Een antwoord

A core belief within the process of MI is the innate capacity of individuals to naturally evolve in a healthful direction under conditions of acceptance and support, where people use their own positive, creative energy and insight to discover the best solutions for themselves

Passmore & Whybrow, in Palmer & Whybrow, 2008: 160

¹ De link tussen MI en Patient Activation is in meerdere studies onderzocht en geconcludeerd is dat MI Patient Activation kan verhogen. Voorbeelden van deze onderzoeken zijn:

- Linden et al. (2009) – Motivational interviewing-based health coaching as chronic care intervention
- Hibbard et al. (2009) – Improving the outcomes of disease management by tailoring the care to the patients' level of activation

kan natuurlijk aangevuld worden met de medische kennis die patiënten niet hebben, maar het geeft u wel een inzicht in waar de patiënt toe bereidt is en dus ook beter zal volhouden. Een vierde manier in MI is het geven van bevestigingen. Dit helpt een goede relatie en het vertrouwen van de patiënt te vergroten. Een optie kan zijn om aan te geven wat de patiënt al goed doet met daarbij een duidelijk voorbeeld. Een andere optie is om een bevestiging te geven van een suggestie die de patiënt doet tot verandering. Tot slot is het belangrijk om samen naar een duidelijk doel toe te werken. Dit doel moet echter wel realistisch zijn, omdat een te groot verschil tussen werkelijkheid en doel het vertrouwen doet verminderen. Ook hierin kan de PAM® score u assisteren, omdat deze score aangeeft wat de werkelijkheid van de patiënt is.

Oplossingsgericht werken

Problemen kunnen ook gezien worden in de positieve zin en zo uitdagingen worden. Dit is de basis van oplossingsgericht werken. Net als MI is het een methode waar de patiënt (of cliënt) centraal staat en een positieve insteek heeft. Oplossingsgericht werken is niet op één theoretisch model gericht zoals MI, maar stelt wel een aantal aannames vast:

- Analyse van problemen is niet nodig om tot oplossingen te komen, analyse van oplossingen juist wel
- De patiënt/cliënt is de expert (In dit geval weet de patiënt het beste wat de chronische ziekte met hem of haar doet, hun beleving maakt hun expert)
- Wat niet stuk is, moet je niet maken
- Als iets werkt, ga er mee door
- Ga in op uitzonderingen op de regel van problemen (wanneer is het probleem even niet het probleem?)
- Als iets niet werkt, doe dan iets anders

Overeenkomsten tussen MI en oplossingsgericht werken zijn dat er (a) altijd sprake is van een samenwerking, (b) verandering is onvermijdelijk (het doorlopen van fases van verandering), en (c) slechts een kleine verandering is nodig omdat dit zelfvertrouwen oplevert. Oplossingsgericht werken voegt hier aan toe dat de meeste patiënten/cliënten zelf al in het bezit zijn van hulpbronnen die nodig zijn voor verandering en problemen zijn niet-succesvolle pogingen om moeilijkheden op te lossen.

Zoals u merkt is deze methode radicaal anders dan het medische model. In sommige gevallen zal oplossingsgericht werken dan ook niet van toepassing zijn of moeilijk te implementeren zijn binnen het consult. Oplossingsgericht werken is immers ontworpen om een traject met een cliënt te doorlopen en als het einddoel behaald is dit traject af te sluiten. Binnen de diabeteszorg zal het zorgtraject nooit volledig afgesloten worden, waardoor de persoon meer een patiënt als cliënt blijft. Echter kunnen er wel gezamenlijke doelen gesteld worden met de patiënt en waar mogelijk oplossingsgerichte vragen te stellen om de patiënt deze doelen te laten bereiken. In oplossingsgericht werken worden verschillende typen vragen onderscheiden:

- Uitlokende vragen of doel vragen: wat wilt u voor dit probleem in de plaats?
 - o Een voorbeeld is de wondervraag: *stel dat u vannacht ligt te slapen en er een wonder gebeurt. Door dit wonder zijn uw problemen opgelost, maar u weet dit niet omdat u*

*lag te slapen. Waaraan merkt u dat de volgende ochtend het wonder is gebeurd?
Wat is er anders? Etc.*

- **Detail vragen:** Hoe deed u dat precies? Kunt u beschrijven wat u deed waardoor het beter ging?
- **Uitzonderingsvragen:** wanneer was uw probleem even geen probleem? Wanneer was of is er al even iets van het wonder aanwezig?
- **Schaalvragen:** vragen gericht op vooruitgang, motivatie en vertrouwen. Zie hierbij ook de uitgangspunten van MI: wat zou er voor u/volgens u moeten veranderen als we van waarde X naar Y willen?
- **Het geven van beloningen en competentie vragen:** een compliment geven en bijvoorbeeld vragen: hoe kwam u op dat goede idee? Hoe krijgt u het voor elkaar om...?

Oplossingsgericht werken is een lastige methode, omdat vrijwel iedereen in de maatschappij leert om eerst problemen te identificeren en vervolgens oplossingen te formuleren. Het vraagt daarom veel oefening, maar kan mooie resultaten opleveren. Mocht u een poging willen wagen met oplossingsgericht werken, kunt u in Tabel 3 een lijst met voorbeelden vinden van oplossingsgerichte vragen. Voor meer voorbeeld vragen, wil ik u verwijzen naar het boek van Frederike Bannink: oplossingsgerichte vragen – handboek oplossingsgerichte gespreksvoering. In Tabel 4 vind u suggesties voor oplossingsgerichte vragen specifiek gericht op medicatie gebruik.

Tabel 3 – Voorbeelden van oplossingsgerichte vragen

Doel vragen	Wat zou een goed resultaat voor u zijn? Hoe zou die verandering een verschil voor u maken? Welke manieren zijn er (nog meer) om uw doel te bereiken? Als uw probleem is opgelost, wat zou er dan anders zijn? Wat wilt u aan het eind van deze behandeling bereikt hebben, om te kunnen zeggen dat het zinvol en nuttig was? Stel dat u de gewenste situatie hebt bereikt, wat en wie heeft dat dan mogelijk gemaakt?
Uitzonderingsvragen	Wat zou u nu al anders kunnen doen? Welke momenten lijken al een heel klein beetje op de gewenste uitkomst? Weke successen waren er nog meer in het verleden? Wat denkt u dat u deed om dat te laten gebeuren? In welke situaties voelt u zich al beter? Wanneer is het probleem geen probleem? Wat is er dan anders?
Competentie vragen	Hoe lukt het u om..? Hoe wist u wat er nodig was? Hoe denkt u dat u dit gedaan heeft? Wat denkt u dat u deed om dit te laten gebeuren? U hebt veel goede ideeën, hoe komt u daaraan? Hoe kan ik u helpen? Welke rol ziet u mij hierin spelen? Hoe lukt u het om op het goede spoor te blijven? Hoe vindt verandering meestal plaats in uw leven?
Schaal vragen	Wat zou naar uw idee een klein stapje vooruit zijn? Hoe ziet dat stapje er precies uit? Wat doet u dan anders? Hoeveel vertrouwen hebt u erin dat het u gaat lukken?

Tabel 4 – Voorbeelden van oplossingsgerichte vragen voor patiënten met medicatie

Oplossingsgerichte vragen over medicatie
Wat zijn uw gedachten over het nut van deze medicatie voor uzelf
Stel dat deze medicatie aanslaat, welke veranderingen zou u dan zien waardoor u kunt zeggen dat deze medicatie goed werkt bij uzelf?
Stel dat deze redactie aanslaat en het goed gaat met u, hoe zou uw lever er dan uitzien?
U zult een goede reden hebben om kritisch naar het gebruik van medicatie te kijken, vertelt u eens?
Wat weet u al over de werking van deze medicatie?
Wat is ervoor nodig om het gebruik van deze medicatie vol te houden?
Hoe kunt u controle over uw leven houden, ook al gebruikt u deze medicatie

Appendix 5 – Questionnaire intervention



ENQUETE



Beste meneer/mevrouw,

Deze enquête zal bestaan uit verschillende onderdelen. Als eerst vragen wij enkele algemene gegevens van u. Daarna worden enkele uitspraken voorgelegd, die mensen kunnen doen over hun gezondheid. Aan u wordt gevraagd in welke mate u het met deze uitspraken eens bent. Uw gegevens zullen anoniem verwerkt worden en er zijn geen goede of foute antwoorden.

Hartelijk dank voor uw medewerking.

Met vriendelijke groet,

Huisartsenpraktijk Veldhuizen

Deelnemersnummer:

In te vullen door onderzoeker

Algemene gegevens

Naam: _____

Geslacht:

- Man
- Vrouw

Geboortedatum: ____(Dag)-____(Maand)-_____ (Jaar)

Hoe ervaart u uw huidige gezondheid?

Omcirkel een cijfer van 0 tot 10, waarbij 0 staat voor een zeer slechte gezondheid en een 10 voor een uitstekende gezondheid.

0 1 2 3 4 5 6 7 8 9 10

Z.O.Z. ----->

Uitspraken over gezondheid

Hieronder staan enkele uitspraken die mensen soms doen over hun gezondheid. Geef voor elke uitspraak aan, in hoeverre u het ermee eens of oneens bent. Doe dit door het antwoord te omcirkelen dat het meest op uw persoonlijke situatie van toepassing is. **We willen dus weten wat u zelf vindt en niet wat u denkt dat de dokter of onderzoeker wil horen.**

Als de uitspraak niet op u van toepassing is, omcirkel dan 'n.v.t.'

1. Uiteindelijk ben ik zelf verantwoordelijk voor mijn gezondheid.	Helemaal niet mee eens	Niet mee eens	Mee eens	Helemaal mee eens	n.v.t.
2. Een actieve rol op me nemen in de zorg voor mijn gezondheid, heeft de meeste invloed op mijn gezondheid.	Helemaal niet mee eens	Niet mee eens	Mee eens	Helemaal mee eens	n.v.t.
3. Ik heb er vertrouwen in dat ik kan bijdragen aan het voorkomen of verminderen van problemen met mijn gezondheid.	Helemaal niet mee eens	Niet mee eens	Mee eens	Helemaal Mee eens	n.v.t.
4. Ik weet wat elk van mijn voorgeschreven medicijnen doet.	Helemaal niet mee eens	Niet mee eens	Mee eens	Helemaal mee eens	n.v.t.
5. Ik heb er vertrouwen in dat ik kan beoordelen of ik naar de dokter moet gaan of dat ik een gezondheidsprobleem zelf kan aanpakken.	Helemaal niet mee eens	Niet mee eens	Mee eens	Helemaal mee eens	n.v.t.
6. Ik heb er vertrouwen in dat ik een dokter mijn zorgen durf te vertellen, zelfs als hij of zij daar niet naar vraagt.	Helemaal niet mee eens	Niet mee eens	Mee eens	Helemaal mee eens	n.v.t.
7. Ik heb er vertrouwen in dat het mij lukt om medische behandelingen die ik thuis moet doen uit te voeren.	Helemaal niet mee eens	Niet mee eens	Mee eens	Helemaal mee eens	n.v.t.
8. Ik begrijp mijn gezondheidsproblemen en wat de oorzaken ervan zijn.	Helemaal niet mee eens	Niet mee eens	Mee eens	Helemaal mee eens	n.v.t.
9. Ik weet welke behandelingen er zijn voor mijn gezondheidsproblemen.	Helemaal niet mee eens	Niet mee eens	Mee eens	Helemaal mee eens	n.v.t.
10. Ik heb veranderingen in mijn leefstijl (zoals gezond eten of bewegen) kunnen volhouden.	Helemaal niet mee eens	Niet mee eens	Mee eens	Helemaal mee eens	n.v.t.
11. Ik weet hoe ik gezondheidsproblemen kan voorkomen.	Helemaal niet mee eens	Niet mee eens	Mee eens	Helemaal mee eens	n.v.t.
12. Ik heb er vertrouwen in dat ik zelf oplossingen kan bedenken voor nieuwe problemen met mijn gezondheid	Helemaal niet mee eens	Niet mee eens	Mee eens	Helemaal mee eens	n.v.t.
13. Ik heb er vertrouwen in dat ik veranderingen in mijn leefstijl (zoals gezond eten en bewegen) kan volhouden, zelfs in tijden van stress.	Helemaal niet mee eens	Niet mee eens	Mee eens	Helemaal mee eens	n.v.t.

Hoe makkelijk of moeilijk vond u deze enquête/stellingen?

Omcirkel een cijfer waarbij 1 staat voor zeer moeilijk en 10 staat voor zeer makkelijk

Zeer

moeilijk

1 2

3

4

5

6

7

8

9

Zeer

makkelijk

10

Heeft u nog opmerkingen naar aanleiding van deze enquête?

Bent u bereidt tot een kort interview over uw ervaringen van het diabetes consult zoals deze komende keer uitgevoerd zal worden, zet dan hier uw telefoonnummer neer:

Hartelijk dank voor het invullen van deze enquête.

U kunt deze enquête opsturen met de bijgeleverde enveloppe óf inleveren bij de receptie van de huisartsenpraktijk in de daarvoor bestemde afgiftekoos. Vergeet niet uw toestemmingsformulier toe te voegen.

Appendix 6 – Interview questions for caregivers

1. Naam: _____
2. Aantal PAM consulten: _____
3. Observatieverslag:
 Ja
 Nee

4. Kunt u kort beschrijven hoe een controle gesprek ging, waarbij de PAM werd gebruikt?
 Was er een verschil dan een gesprek waarin dit niet gebruikt werd?
 Heeft u bepaalde vragen direct met de patiënt besproken of bent u meer indirect te werk gegaan?
 Heeft u gebruik gemaakt van MI of oplossingsgericht werken? Welke en hoe?
 Was er verschil in een aanpak met een patiënt van een lage score (niveau 1-2) en een hoge score (niveau 3-4)?
 - i. Mijn observatie tijdens de interviews is dat mensen met een hoge score en een goede relatie met de huisarts, niet veel te bespreken hebben in relatie tot de PAM. Pas als de score lager is, of dat er dingen zijn in het zorgproces die niet helemaal soepel lopen, de PAM een meerwaarde kan hebben. Hoe denkt u hierover?
5. Wat waren positieve ervaringen bij het gebruik van de PAM?
 Vragenlijst zelf
 In relatie tot de patiënt
 Wel of niet zelf afnemen?
6. Wat waren barrières waar u tegenaan liep bij het gebruik van de PAM?
 Vragenlijst zelf
 In relatie tot de patiënt
 Wel of niet zelf afnemen?
7. Het doel van de vragenlijst is dat het u als zorgverlener iets meer inzicht geeft in de situatie van de patiënt en hoe de patiënt over bepaalde dingen denkt, zodat u de zorg daarop kan laten aansluiten. Heeft u het gevoel dat dit doel bereikt wordt?
 Zo ja, in welke mate? Wat zou er nog meer kunnen gebeuren?
 Zo nee, waar zit het knelpunt? Wat moet er eventueel verandert worden om dit doel te bereiken?
8. Hoe schat u de ervaring van uw patiënten in?
 In welke gevallen werkt het wel en in welke niet? Voor welke patiënt wel en voor welke niet?

9. U geeft aan geen/wel gebruik te maken van MI en/of oplossingsgericht werken

- Wat waren uw ervaringen?
- Waarom wel/niet? (volgende vragen ook als niet is geantwoord)
- Voorkeur voor één of ander?
- Past het bij de PAM?
- Past het bij u?
- Past het bij de patiënt?

10. Zou u in het vervolg vaker de PAM willen gebruiken?

- Waarom wel/ niet
- Wat zijn de voorwaarden?
- Moet er rekening gehouden worden met een bepaalde doelgroep?
 - i. Het verschil tussen zorgmijders en mensen die regelmatig komen?
- Ik heb zelf een aantal keer de vragenlijst persoonlijk afgenoem en heb een aantal interviews met patiënten gedaan. In mijn ervaring gaven patiënten vaak extra toelichting bij vragen hoe hun gedachte gang bijvoorbeeld ging. Dit opende vaak een gesprek over de individuele patiënt en zou daarom kunnen bijdragen aan zorg die specifiek op de individuele patiënt wordt gericht. Dit is ook tevens het doel van de vragenlijst. Hoe denkt u over de balans tussen tijd(gebrek)/ persoonlijke aandacht voor patiënt?

Appendix 7 – Interview questions for patients

1. ID nr. : _____
2. Huisarts : _____
3. Consult met : _____
4. Intro: anoniem, geen goede of foute antwoorden/ uw ervaringen, probeer zo eerlijk mogelijk naar deze ervaringen te antwoorden, interview wordt opgenomen
5. Kunt u kort voor mij beschrijven hoe een normale diabetes controle er bij de huisarts/praktijkondersteuner uit ziet?
 - a. Wat wordt er besproken?
 - b. Hoe lang duurt het gemiddeld?
 - c. Is er tijd voor vragen van uw kant?
6. Wat zijn de goede punten aan de manier waarop dit consult wordt gedaan?
7. Denkt u dat dit consult nog verbeterd kan worden? Zo ja, waar?
8. Voorafgaand aan de afgelopen diabetes controle, heeft u deze enquête ingevuld. De informatie uit deze enquête is teruggekoppeld naar de huisarts/praktijkondersteuner. Heeft u iets gemerkt tijdens dit consult in vergelijking tot een consult wat u hiervoor heeft beschreven?
 - a. Wel iets gemerkt:
 - i. Wat heeft u gemerkt? Slaat dit terug op het doel van de PAM: de zorg sluit aan bij de individuele patiënt, patiënt voelt zich/ wordt meer betrokken in het zorgproces
 - ii. Wat vond u hiervan?
 - iii. Voordelen
 - iv. Nadelen
 - b. Niets gemerkt:
 - i. Heeft de HP/poh vragen besproken uit de enquête? (enquête erbij)
 - ii. Reden?
 - iii. Wat vond u hiervan?
 - iv. Was dit een voordeel of nadeel?
 - v. Had u liever een andere ervaring gehad en hoe?
 - c. Heeft u het idee gekregen dat de HP/poh nu meer van uw individuele situatie weet dan voorheen? Kan de HP/poh nu beter inspelen op uw persoonlijke situatie?
 - d. De vragen uit de enquête geven aan dat u
 - i. Heeft de HP/poh hierop ingespeeld?
 - ii. Op welke manier?
 - iii. Wat vond u hiervan?

9. De vragen die gesteld zijn in de enquête hebben geen vaste antwoorden. Dit betekent dat op een ander tijdstip u een andere mening kunt invullen, omdat bijvoorbeeld uw situatie veranderd is. In hoeverre zou u het prettig vinden als de huisarts deze vragen vaker stelt, om meer inzicht te krijgen in uw persoonlijke situatie?
 - a. Hoe vaak?
 - b. Zijn er andere vragen die gesteld zouden moeten worden?
10. Zijn er dingen die u graag wilt zeggen over dit onderwerp?
11. Zijn er dingen die u graag wilt zeggen over dit interview?

Appendix 8 – Original Dutch quotes

1. "Het positieve ding is dat je door middel van die vragenlijst de mensen.. daar een gesprekje over kan beginnen: waar ze staan en wat ze belangrijk vinden in de begeleiding die ze krijgen. Dat is voor mij wat gemakkelijker, want je hebt die lijst en je zegt, ik zie dat u dit en dit heeft ingevuld: kunt u daar iets meer over vertellen, moeten we er iets mee, of ik stel voor om op korte termijn terug te komen. Dus op die manier kan je het gebruiken."
2. "Er is inderdaad een groep mensen die denken, krijg ik weer hetzelfde te horen. Voor die groep is het wel handig, want dan zien ze ook een keer dat er gekeken wordt naar waar zij behoeft aan hebben."
3. "En toen had ik zo in een keer echt een heel ander gesprek, want hij kwam hier altijd zo van: jij wilt het allemaal maar zo even weten en ik doe goed mijn best, en jij zeurt altijd dat ik het niet goed doe. Zo'n uitstraling had hij. Heel veel weerstand. Ik kom omdat het zo nodig moet, omdat ik anders nog meer gezeur krijg. Nou en toen had ik bij die meneer zo van he... Daar was ik verbaasd dat hij het had ingevuld en dan als je die techniek van MI bij toepast enzo, vult het elkaar aan. Dan stel je patiënt veel meer centraal"
4. Dat is wel een gegeven. Dan denk je wel van misschien moet ik daar toch wel eens iets over vertellen. Dat zijn hele duidelijke.. en dit ook, begrijpen wat de oorzaken ervan zijn, dub begrijpen wat je ziektebeeld is. Dat levert je informatie op als je daar niet mee eens ziet staan
5. Want je gaat er soms van uit dat mensen het weten, maar daar moet je niet altijd van uit gaan natuurlijk. Meestal kom je daar gedurende de tijd wel weer op, maar niet bij dat specifieke gesprek. Dus dat kon je meer op dat gesprek, wat ze miste eigenlijk
6. "Op een gegeven moment hoorde ik voor het eerst van het bestaan van PAM en ik las dat hele verhaal en begreep het onmiddellijk. Maar daarvoor was ik nooit met dat onderwerp bezig geweest en had ik ook niet zo goed in de gate dat je er iets mee kon doen. Ik wist wel dat er verschillen bestonden tussen patiënten, maar je gaat je dan in een keer realiseren dat we dan heel erg gewend zijn om een soort standaard verhaal te houden tegen iedereen hetzelfde en dat je dat ook anders kan aanpakken als je weet wat voor iemand je voor je hebt. Dat je dan een ander soort verhaal kunt doen. Wat is er verbeterd? Dan is er bij mij iets verbeterd dat ik dat inzicht dat inzicht ook zelf veel meer heb, dus er ook veel meer mee kan doen."
7. "Het goed is dat er vragen worden gesteld buiten de normale vragen die ik stel om dat ze over hun ziekte en eigen verantwoordelijkheid gaan nadenken... het feit dat bepaalde vragen gesteld worden, zet sommige mensen aan het denken. Het antwoord maakt dan ook niet eens zo veel uit."
8. "Nouja, die hele lage score bij bepaalde patiënt denk ik, nou ja dat klopt wel. Zo zie ik de persoon ook. Bij de hele hoge, daar zat er ook eentje bij, nou dat is ook een vrij hoog opgeleid persoon en die ook vrij zelfstandig is met z'n behandeling van diabetes. Dus voor mij was het op zich meer een bevestiging."

9. "Nou eigenlijk doe ik dat meestal al wel, maar nu zie het van de patiënt terug of het inderdaad zo is. Dat weet je niet altijd natuurlijk, je kan best wel inschatten hoe de patiënt met de ziekte bezig is en hoe ze voor je zitten, kun je best wel inschatten waar ze staan in hun ziektebeeld en in hoeverre ze begeleiding willen, dus dan speel ik daar al wel op in."
10. "Ik vind het prettig dat de mensen thuis al rustig naar de vragen hebben gekeken en in het onderwerp zitten. Dus als ze dan op het spreekuur komen, dat er dan voorwerk gedaan is. Wat voor mij enorm veel uitmaakt".
11. "Dat je van te voren dus weet waar mensen tegen aan lopen en dat je dus je gesprek daar een beetje op in kan richten, voor kan bereiden. Dat vond ik wel positief."
12. "Aan de hand daarvan ga je het niet allemaal bespreken, maar pik je er wat uit waarbij je denkt, o dat is misschien wel interessant om het over te hebben. Of je vraagt het aan de persoon of er iets was. Dus dan heb je het niet over al die vragen, maar dan heb je van te voren al een shifting: wat is wel of niet interessant."
13. "Om te begrijpen ook en überhaupt over het onderwerp te praten. Zelfs als je eenvoudige, de vragen zijn eenvoudig gesteld, maar als je probeert om woordgebruik nog simpeler te maken. Dan heeft het voor sommige mensen toch nog een behoorlijk hoog abstractieniveau, omdat ze vast zitten in het idee: ik ben ziek en tegenover mij zit de dokter, ik heb een klacht en die lost het even op. Dan is het voor die mensen nog heel lastig om de stap te maken naar het idee van ik heb ook een rol. Ja, als je vraag is of er verschil is tussen mensen met een hoge en een lage score: ja, de gesprekken met de mensen met een lage score lopen stroever, omdat dat het voor die mensen denk ik een moeilijk onderwerp is."
14. "Ik weet eigenlijk niet of ik dan een lijst zou uitdelen of dat ik dan als ik eraan denk van er is een chronische aandoening waarbij het van belang is hoe mensen hun eigen gezondheid ervaren en daar invloed op uit kunnen oefenen. Je zou het ook gewoon kunnen vragen zeg maar."
15. "Ik doe natuurlijk al een aantal jaar bij deze patiënten de jaarcontrole. Je ziet ze ook voor andere dingen, dus je krijgt wel door wat voor soort iemand dit is in de loop van de tijd en dat is natuurlijk veel meer tijd dan één vragenlijst. En dan weet je op een gegeven moment ook wel hoe mensen ermee omgaan en hoe je ze moet benaderen."
16. "Naar mijn idee is dat wel hoe ik mijn spreekuur doe, dat ik inspeel op de behoefte van de patiënt."
17. "Technisch gezien kan het gewoon dat in het systeem die vragen erin zitten. Ook bij de voeten moeten we bijvoorbeeld allerlei dingen nakijken [vb.]. dus dat zijn allemaal vragen, net zoals de PAM allemaal vragen zijn. Het kan gewoon in het systeem en dan hoef je het niet elke keer, maar dan kun je het ook persoonlijk, of bij de huisarts of de poh, of één vraag of 1x in de zoveel tijd alle vragen langslopen. En dan heb je tijd voor die wisselwerking."
18. "Op zich is zo'n jaarcontrole wel een geschikt moment ervoor, want het is, helemaal zoals we het nu georganiseerd hebben, bespreek je over het algemeen vrij weinig. Omdat je eigenlijk de gegevens even op een rijtje zet, en als dat allemaal goed loopt dan heb je tijd om dat te doen, dus dat is wel een goed moment. En dan kan je zelf eruit pikken wat je wilt omdat je dan wat meer tijd hebt."

19. "Ik denk dat de vragen zo gesteld zijn, dat mensen er ook goed over na... ja hoe moet ik dat zeggen... het zijn goede vragen, er is lang over nagedacht om dit op te stellen. Dus ik denk dat het goed werkt, dat het gaat waarover het moet gaan. Dat vind ik positief."
20. "en aantal, aangaven dat ze niet alle vragen goed begrepen. De meeste wat opvalt, is als er nieuwe problemen ontstaan met de gezondheid dat ze dan zeggen dat ze dat niet weten en weinig vertrouwen hebben om mee om te kunnen gaan."
21. "Dat is zo standaard, dat geld voor iedereen wel. Voor iedereen is dat zo natuurlijk. Dus dan voegt het niets toe. Het is niet specifiek genoeg voor mij dan."
22. "Sommige mensen zijn cognitief slechter, als ze echt dement zijn is het helemaal niet haalbaar. Als ze cognitief al een beetje minder of in aanleg zijn, mensen met een verstandelijke beperking kun je dit niet mee doen. Als mensen met hun leeftijd cognitief achteruit gaan en dat kan bij diabetes ook."
23. "En je moet kunnen reflecteren. Je moet dat wel kunnen. Je gaat een beetje op de middenmoot."
24. "Ik denk dat het heel veel tijd gaat kosten die we niet hebben. Het kan inderdaad, misschien krijg je wel meer informatie, dat wel. Maar ik denk dat het dan te veel wordt, want er zijn weinig mensen die het daar bij laten. Dan is het wel weer de kunst om bepaalde dingen af te kappen. Ik denk dat dat te veel tijd kost."
25. "Dus dat er toen bleek dat zij ineens een somatisch probleem naar voren kwam, wat acute aandacht nodig had. Dus die vragenlijst was uit beeld."
26. "De laatste keer stelde ze de vraag: wie is er verantwoordelijk voor mijn gezondheid. Ik zeg dat ben ik zelf. En daar hebben we samen even goed over zitten praten."
27. "Nou de laatste keer, was ze over en over en over vriendelijk. Het is onvoorstelbaar. Ze stelde me zelfs voor de keus, kom je weer of niet, want dat ligt aan jezelf. Het hoeft niet zegt ze. Ik denk wat krijgen we nou! Ze vroeg ook niet veel dingen, ze heeft gewoon gedaan wat ze eigenlijk moest doen."
28. "Tuurlijk draagt het iets bij, het zet je toch even aan het nadenken.. Als je in een preventief stadium periodiek eens mensen een spiegeltje kunt voorhouden, en je zou dat eens in de zoveel tijd doen, ik denk dat je dan hartstikke goed bezig bent.. Dat is het verhaal, het is een eyeopener. Gewoon een spiegeltje."
29. "Dat is de bedoeling van zo'n vragenlijst, om erachter te komen hoe de patiënt ertover denkt en hoe wij dat ervaren ... Hij begrijpt mij toch weer iets beter. Als er iets gebeurt, wanneer hij moet handelen of ingrijpen, als er iets niet klopt bij mij. Dan weet hij intussen ook weer hoe ik over het een en ander denk.... Dat is goed dat hij dat weet, vind ik tenminste. Dat dan weet hij tenminste hoe we tegenover elkaar staan."
30. "Het heeft voor mij op dit moment geen meerwaarde, maar in zijn algemeenheid is het natuurlijk helemaal niet verkeerd dat het periodiek zo iets nog eens plaats vind, nou ja laten we zeggen over 2 jaar. Dat je zegt van, nou er zijn nieuwe ontwikkelingen gaande, misschien zijn er nieuwe ideeën. Nou dat je daar weer op anticipiert, dat je de mensen weer eens benadert."
31. "Dus het is erg afhankelijk van de situatie, maar ja als er in mijn situatie niets verandert, zal dit ook niet veranderen... dan moet er echt wel iets heel drastisch veranderen".

32. "Ik denk dat de huisartsen mij al wel voldoende kennis om een beetje een idee te hebben hoe ik daar tegenover sta. Ik zit al een tijdje bij deze praktijk."
33. "Soort zelfde gesprek en ik ben er tevreden over en dat blijkt dan ook wel uit de antwoorden die ik gegeven heb. Ik ben er gewoon tevreden over, geen klachten, helemaal niets.. Het gaat zoals het gaat en het gaat goed. Ik ben er uitermate tevreden over en het is gewoon perfect."
34. "Het was wel een ander gesprek als daarvoor, maar niet dat hij nou uhm..... met een ander resultaat. er wordt ook niet echt met mij overlegd, ze vragen niet aan mij: wat doe je dan, laat eens wat zien of schrijf eens wat op."
35. "(I) Heeft u het gevoel dat dit doel een stapje dichter bereikt wordt of is dat nog wel ver?
Na die ene keer niet denk ik.
(I) En op langere termijn?
Misschien
(I) Als het op dezelfde manier doorgaat als op de laatste keer?
De laatste keer, ja dan wel."
36. Maar dat zou ik misschien zelf al eerder zeggen.
(I) U heeft er geen vragenlijst voor nodig?
Ja, niet alleen bij de huisarts maar ook bij andere zorginstellingen. Als ik iets niet goed vind zeg ik het ook gewoon. Je hebt ook goede contacten, je kunt er goed over praten. Je weet waarom dit en waarom dat. Maar dan weten ze ook van hun kant wat er aan de hand is."
37. "Goed, ik zie wel een samenspel en dat is nuttig, er komen wel meerdere van die dingen en die gooii ik weg, maar hier zie ik een samenspel in. Dat is teamwork. Misschien moet de apotheek er wel bij betrokken moet worden."
38. "Zoals het daar stond. Dat kon ik gewoon lezen. Dat stond er gewoon in het Nederlands.
(I) Soms kan de formulering toch lastig zijn
Ja, dat kan op heel veel verschillende manieren, maar dit stond er gewoon."
39. "Ik had ook vragen waar ik echt zat te dubben: wat moet ik daar nou mee aan. Moet ik nou mee eens of niet mee eens zeggen. Dan vond ik de vraagstelling voor mijn gevoel iets te onduidelijk."
40. "Het is natuurlijk allemaal vrij breed en je kunt op een aantal niet specifiek zeggen, ja of nee."