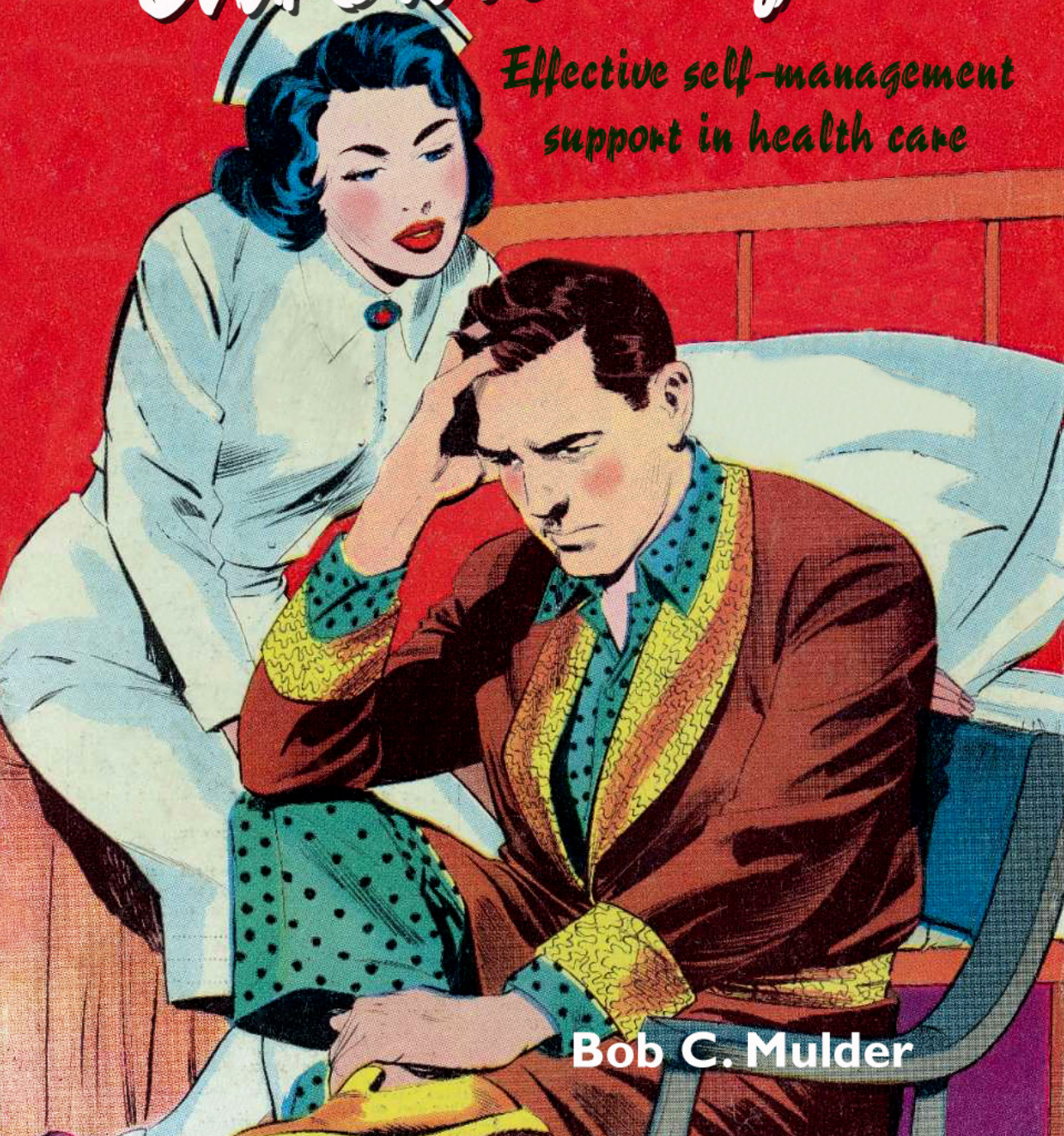# Communicating with the chronically ill

Effective self-management support in health care

Bob C. Mulder

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Thesis committee

Promotor
Prof. Dr C.M.J. van Woerkum
Emeritus Professor of Communication Strategies
Wageningen University

Co-promotors
Dr A.M. Lokhorst
Assistant professor, Strategic Communication Group
Wageningen University

Prof. Dr M. de Bruin
Chair in Health Psychology, Health Psychology Group, Institute of Applied Health Sciences
University of Aberdeen, UK

Other members
Prof. Dr M.A. Koelen, Wageningen University
Prof. Dr P. van 't Veer, Wageningen University
Prof. Dr J.M. Bensing, Utrecht University
Dr A.E.R. Bos, Open University of the Netherlands, Heerlen

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Wageningen School of Social Sciences

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Introduction

1.1 Background

Today's world shows a high prevalence of chronic diseases such as HIV (WHO, 2013), and diabetes (Danaei et al., 2011) and cardiovascular diseases (Smith et al., 2012), with particularly the latter two diseases showing a clear prevalence increase over the last few decades. Moreover, estimates of future prevalence show a continuing upward trend (Shaw, Sicree & Zimmet, 2010; Smith et al., 2012). This so called epidemic of chronic diseases has led to global societal and scientific attention for the main causes thereof, which are health behaviors such as smoking, too little physical activity, unhealthy diets, and unsafe sexual intercourse (Bajos et al., 1995; WHO, 2002; 2003). Therefore, in theory, as much as 80% of premature heart disease, stroke and diabetes can be prevented if people change their health behavior (WHO, 2014).

Over the past few decades, much time, energy and money have been spent on the development of interventions that aim to change health behaviors among the general population or in specific target groups. However, current efforts to prevent the increase in chronic diseases are not expected to turn the tide on the population level. To illustrate, the rising obesity prevalence has been known for

decades, but no country has been able to stop it (Ng et al., 2014). One reason for this is that scientific evidence for health behavior change interventions generally indicates small-to-medium effect sizes immediately following interventions, but those effects often diminish after interventions are ended and follow-up contact ceases (Conn, Hafdahl & Mehr, 2011; Fjeldsoe, Neuhaus, Winkler & Eakin, 2011; Jepson, Harris, Platt & Tannahill, 2010). Also, multiple unhealthy behaviors have an added negative effect on health, and thus should be targeted simultaneously (Prochaska & Prochaska, 2011). However, it has been proven difficult to effectively target multiple health behaviors at the same time (Artinian et al., 2010).

In addition, interventions that have proven to be effective in controlled circumstances can be difficult and costly to implement, and often are less efficacious in the general population (Glasgow, Vogt & Boles, 1999). This may be even stronger for those groups who have the worst health status (Spadea, Bellini, Kunst, Stirbu & Costa, 2010). For example, notable socioeconomic equalities have been found in the utilization of preventive services such as colon cancer screening (Stirbu, Kunst, Mielck & Mackenbach, 2007) and breast cancer screening (Peek & Han, 2004). Therefore, groups with lower socioeconomic position are disproportionately more affected by chronic diseases (e.g., Mackenbach et al., 2008), and for a large part, this is the result of health behaviors of such groups (Stringhini et al., 2010). Research on socioeconomic health disparities suggests that a set of common determinants, related to structural socioeconomic factors, underlies differences in health behaviors between groups within society (Gallo, de los Monteros & Shivpuri, 2009). Identifying and addressing these factors is thus expected to be beneficial for lower socioeconomic groups, and potentially for the population as a whole.

Despite preventive efforts, an increasing number of people will be inflicted with chronic diseases, meaning they will become patients who are treated in the health care system (Wang et al., 2011). Once people become patients, they are required to effectively self-manage their disease in order to prevent the disease to progress (Bodenheimer, Lorig, Holman & Grumbach, 2002). For health professionals, this means working on tertiary prevention. Chronically ill patients regularly visit one or more health care providers (henceforth called providers), and this stages a professionally organized setting in which health behavior is often discussed. Such settings provide an important opportunity for guiding patients towards health behavior change, and reviews indicate that physician advice may have beneficial effects on several health behaviors, including smoking, physical activity and diet (Jepson et al., 2010). In addition, face-to-face contact is more effective than contact mediated through, for example, telephone or email (Conn et al., 2011);

and frequent and prolonged contact, which is typical of health care for chronic diseases, is beneficial for change and maintenance of change (Artinian et al., 2010; Fjeldsoe et al., 2011). Taken together, chronically ill patients are posed for lifelong self-management issues, and health care professionals have an important role in providing self-management support to these patients (Bodenheimer et al., 2002). How providers can support self-management is an important practical and scientific matter that still raises questions. For example, a recent trial testing the effectiveness a self-management support program in primary care yielded no significant differences between intervention and control practices (Kennedy et al., 2013). This indicates the need for better understanding of what is required to effectively support self-management, both from the perspective of the patient's everyday life and from the perspective of current health care practices.

1.2 Self-management

Self-management is a broad concept, and therefore it may have different meanings according to different researchers, or in different contexts. When a person is diagnosed with a chronic disease, this person's health behaviors become relevant in terms of affecting the disease, its outcomes, and the disease course over time. In other words, as a patient, this person becomes responsible for managing the disease, regardless of whether the patient takes this responsibility, or what healthy or unhealthy management style is chosen (Lorig & Holman, 2003). Not only do chronically ill patients become responsible for self-management, but their self-management presents the vast majority of the day-to-day care they receive. For example, type 2 diabetes patients are required to make dietary changes, be physically active on a regular basis, and in many cases use medication to control their blood glucose and other clinical outcomes (Inzucchi et al., 2012). Together, these health behaviors amount to about 98% of the total care (Anderson & Funnell, 2010).

Where it seems clear that all chronically ill patients self-manage, it is less clear exactly what self-management is, because there is no single and universally accepted definition. Rather, self-management definitions may overlap or complement each other by describing different dimensions of self-management, such as disease specific behaviors or activities (e.g., Toobert, 2000), the patient's overall ability to self-manage (Barlow, Wright, Sheasby, Turner & Hainsworth, 2002), specific skills related to problem-solving that underlie self-management (Lorig & Holman, 2003), or even patient education itself (Alderson, Starr, Gow, Moreland, 1999).

Obviously, the 'self' in self-management refers to the patient, and what the patient does, or should do, to manage the disease. Importantly, 'what the patient does' versus 'what the patient should do' conveys the fact that self-management can be studied from a descriptive or from a normative point of view. As the patient is responsible, it is essential to begin the study of self-management from the patient's perspective as to what it is, what it aims for, what is needed for it, and how it can best be supported in health care. In their landmark book, Corbin and Strauss (1988) are among the first to describe self-management from the patient's perspective, and they identify three different tasks. The first task is the medical management of the disease, which involves adhering to medical recommendations such as diet or medication intake. Medical management is closely tied to the normative perspective of what the patient should do to avoid progression of the disease. The second task is changing and maintaining new life roles, for example, as a result of the functional limitations that result from having the disease. Third, having a chronic disease, and having to reconsider your life roles and accept functional limitations, has all kinds of emotional consequences that have to be dealt with (Corbin & Strauss, 1988). From these main tasks it becomes clear that patients not only self-manage to maintain their health, but that in the end they strive for wellbeing and quality of life (Lorig & Holman, 2003).

If self-management is aimed at wellbeing, the next question is what patients need for effective self-management. Lorig and Holman (2003) describe how, much to their surprise, it was not a change in health behaviors that predicted change in rheumatic patients' self-reported health status, but rather a change in their sense of control over the illness. This led these authors to apply Bandura's (1997) social cognitive theory as the base for studying and explaining self-management, with self-efficacy as its core concept (Lorig & Holman, 2003). Self-efficacy is defined as the belief a person has in his or her own capabilities to perform a certain behavior that is required to produce a desired goal (Bandura, 1997). According to Bandura (1998), there are two ways through which self-efficacy influences health and wellbeing. First, self-efficacy affects biological stress reactions to perceived stressors. Low self-efficacy leads people to perceive stressors as much more stressful, because they believe they are unable to cope with them, and this negatively affects the immune system through neuroendocrine reactions. Conversely, people with high self-efficacy are much less distressed, if at all, by threats and other environmental demands. Second, self-efficacy influences health behaviors through its effect on motivation and behavior. The confidence people have in their ability to perform a behavior affects how much they are willing to perform that behavior, how they perceive impediments to perform that behavior, affecting their perseverance under difficult circumstances, and how well they are able to maintain behav-

ioral change (Bandura, 1998). Thus it seems that control perceptions are an important cause for self-management, but also that control perceptions may increase as a result of effective self-management.

1.3 This thesis

With exercising control as a central issue, self-management support can be seen as supporting patients' actual and perceived control over their disease. From this perspective, this thesis aims to contribute theoretically and empirically to knowledge on how to effectively support self-management. To date, self-management support has been studied or discussed under diverse headers such as patient-centered care (Bensing, 2000), patient empowerment (Anderson & Funnell, 2010), and self-management support itself (Glasgow, Davis, Funnell & Beck, 2003). To a varying extent, patient control plays a role in all of these approaches; however, the central and common components of self-management support in these approaches are conceptually not clear. Empirical study of communication between chronically ill patients and providers in current health care can help to clarify conceptual issues, as well as provide practical insights into how provider communication can support patient self-management. Therefore, the aim of the present thesis is to examine how self-management can be supported in health care by studying patient-provider communication. As such, the focus will be on identifying barriers and opportunities for effective self-management support from a patient perspective, starting from current health care communication practices. Specifically, this thesis addresses the following research questions:

- How can patient self-management be supported in health care during standard consultations?
  a. What general factors related to control may help to explain variation in health behaviors?
  b. What do patients prefer in provider communication that ultimately aims to support self-management, and how can providers meet these preferences?
  c. What hinders or helps providers to provide effective self-management support?

1.4 Disease cases

The studies in this thesis will address patient self-management of two different chronic diseases: HIV and type 2 diabetes mellitus. For both diseases, the importance of patient self-management and provider self-management support has been acknowledged. With the introduction of powerful antiretroviral therapies in

the 1990s, HIV transformed from an acute – and lethal – disease into a chronic disease (Mahungu, Rodger, & Johnson, 2009). This transformation caused HIV patients to become self-managers, because now they have lifelong responsibility for their own day-to-day care. HIV care thus has let go of the acute care model and provide appropriate self-management support (Gifford & Groessl, 2002). In line with Corbin and Strauss (1988), HIV self-management involves, for example, proper use of antiviral medications (medical self-management), dealing with disclosure, sex and intimacy (functional adaption to the disease), and dealing with difficult emotions, depressed feelings, and negative thinking (emotional self-management). Often, self-management is seen as serving the overall medical goal of optimal medication adherence (Gifford & Groessl, 2002). This is because suboptimal adherence may cause the virus to replicate and become resistant to treatment (Sethi, Celentano, Gange, Moore, & Gallant, 2003), and can even lead the disease to progress to AIDS and increase HIV transmission risk (Bangsberg et al., 2001). Unfortunately, up to 50% of HIV patients do not maintain optimal adherence (Catz, Kelly, Bogart, Benotsch & McAuliffe, 2000; Deschamps et al., 2004; Nachega et al., 2011). Health care is one of the factors affecting patient medication adherence (Vervoort, Borleffs, Hoepelman & Grypdocnk, 2007). In fact, in fact, meta-analyses have found that variability between health care providers in the active content of self-management support (focused on adherence to medication) they provide to patient with HIV, explained about 50% of the differences in adherence and treatment success rates between patients (de Bruin, Viechtbauer, Hospers, Schaalma & Kok, 2009; de Bruin et al., 2010).

Whereas approximately 0.1% of the Dutch population has been diagnosed with HIV infection (Op de Coul & Harbers, 2011), diabetes mellitus affects about 5% of the population, and annually about 50.000 patients are newly diagnosed (Baan & Spijkerman, 2014). Due to a combination of an ageing population, unhealthy diets, and physical inactivity, the prevalence of diabetes is expected to be around 439 million people worldwide in 2020 (International Diabetes Federation, 2010). Of all diabetes patients, about 90% are affected with type 2 diabetes mellitus (T2DM). Diabetes is an endocrine disorder that is characterized by high blood glucose levels (hyperglycemia), due to a combination of low insulin production and insulin resistance. Chronically high glucose levels will damage blood vessels and nerves, resulting in a greatly increased risk of micro-and macrovascular complications such as heart disease, blindness, kidney disease, and numbness or pain in the limbs, up to the point that lower limb amputation is required (Arend, Stolk, Krans, Grobbee & Schrijvers, 2000). Therefore, treatment focuses on maintaining a low and stable level of blood glucose (glycemic control), as well as controlling lipid levels and blood pressure. Patients must achieve this by self-managing their

diabetes by eating healthily, having regular physical activity, and taking antidiabetic medication (Stone et al., 2010; Toobert, Hampson, & Glasgow, 2000). However, less than 20% of patients reaches all clinical goals (Casagrande, Fradkin, Saydah, Rust, & Cowie, 2013), and many do not achieve glycemic control (Barnett, 2004; Cleveringa, Gorter, van den Donk, & Rutten, 2008). An important reason is that patients find it hard to self-manage, because of the multiple behavioral changes that are required (Gorter et al., 2010). Many patients have difficulties changing their diet (Rubin & Peyrot, 2001) and increasing activity patterns such that they are sufficiently active (Plotnikoff et al., 2006). In addition, medication adherence can be problematic for diabetes patients as well (Cramer, 2004). Fortunately, also for diabetes, health care activities are associated with better clinical outcomes, such as average blood glucose levels (den Engelsen, Soedamah-Muthu, Oosterheert, Ballieux & Rutten, 2009).

The quality of communication affects health and wellbeing of chronically ill patients through various pathways. For example, when a provider shows understanding, provides comfort and reduces anxiety, patient health and wellbeing can be directly improved (Bensing & Verheul, 2010; Street, Makoul, Arora, & Epstein, 2009). Provider communication may also improve patient health by providing information and increasing patient self-efficacy, thus supporting patient self-management. For example, the quality of provider communication is predictive of treatment adherence (Zolnierik & DiMatteo, 2009). Therefore, and in line with Corbin and Strauss (1988), self-management in this thesis refers to behaviors that focus on the medical management of the disease, as well as managing wellbeing through emotional and functional adaptation to the disease. Both for HIV and diabetes it is not fully clear how providers should communicate during consultations to effectively support self-management. Furthermore, exploration of self-management support for these two distinct diseases enables broader examination of concepts and how they are applied in practice. By rooting concepts in a broad empirical base, our understanding of theoretical concepts can be enhanced. This will also help generalization of the findings to chronic disease self-management.

1.5 Overview of studies

This thesis consists of four studies that are described in Chapters 2-5. Chapter 2[1] reports the findings of a cross-sectional study on the associations between a set of general psychosocial factors, termed stressors and resources, and various

1   This chapter is based on a paper that is written in British English, due to the author guidelines of the journal in which it was published. The other chapters are written in American English.

health behaviors. Recent studies in the field of socioeconomic health disparities suggest that people from lower socioeconomic strata have less reserve capacity and at the same time have to deal with more stressors that deplete this capacity. Having less resources while coping with more stressors places these groups at disadvantage, which may help to explain their worse objective and self-reported health. Also, stressors and resources may affect health behaviors as an intermediate pathway to health. In Chapter 2, specific resources such as perceived life control and social support, and stressors such as financial stress and psychological distress, are tested as mediators in the association between socioeconomic position and health behaviors. As such, this chapter shows whether these factors are important predictors of health behaviors, and thus need to be addressed when supporting patient self-management.

Chapter 3 describes the findings from a study for which HIV-patient were interviewed about their preferences for communication with their providers. The providers of these patients were also interviewed to examine their beliefs about patient communication preferences. Prior studies indicate that patients may have widely differing individual preferences when it comes to exchanging information with their provider, sharing control over medical decisions, and establishing a relationship (Ong, De Haes, Hoos, & Lammes, 1995). Matching patient preferences through provider communication is beneficial for various patient outcomes, including treatment satisfaction, adherence, and wellbeing (Kiesler & Auerbach, 2006). Because little is known about communication preferences of HIV patients, eliciting these preferences is one of the aims. In addition, the meaning of matching their preferences is explored, with the aim of gaining insight in how patients may feel supported or not. Finally, providers were interviewed with the aim of establishing the extent to which provider beliefs correspond with patient preferences, to enable recommendations for practice.

Chapter 4 presents a literature review about effective nurse communication with T2DM patients. Although the importance of nurse self-management support for these patients is quite clear, issues remain about how nurse communication can effectively support self-management. Nurses themselves often struggle with communication, indicating that certain barriers may hinder effective communication. The first aim of this review is to provide an overview of communication barriers. Next, an overview is provided of studies that provide insights into effective methods for nurse communication, based on either experimental or observational research. Taken together, knowledge about barriers and effective methods may help to formulate recommendations for communication in clinical practice as well as provide avenues for further research.

Chapter 5 reports on an observational study that is based on the review from Chapter 4. Research indicates that theory-based behavior change techniques are superior to non-theory based methods. This also holds for behavior change counseling to T2DM patients as applied by practice nurses. The 5As Model describes the key elements of self-management support and can be used to evaluate health care counseling to support behavior change. In this chapter, the 5As Model is used to evaluate nurse communication practices related to health behavior change.

Finally, in Chapter 6, the findings of these four studies are discussed and synthesized to answer the central research questions. Findings will be compared with the literature to provide conclusions, directions for future research, and implications for practice.

Abstract

Background

Variability in health behaviours is an important cause of socioeconomic health disparities. Socioeconomic differences in health behaviours are poorly understood. Previous studies have examined whether (single) stressors or psychosocial resources mediate the relationship between socioeconomic position and health or mortality. This study examined: 1) whether the presence of stressors and the absence of resources can be represented by a single underlying factor, and co-occur among those with lower education, 2) whether stressors and resources mediated the relation between education and health behaviours, and 3) addressed the question whether an aggregate measure of stressors and resources has an added effect over the use of individual measures.

Methods

Questionnaire data on sociodemographic variables, stressors, resources, and health behaviours were collected cross-sectionally among inhabitants (n=3050) of a medium-sized Dutch city (Utrecht). Descriptive statistics and bootstrap analyses for multiple-mediator effects were used to examine the role of stressors and resources in mediating educational associations with health behaviours.

Results

Higher levels of stressors and lower levels of resources could be represented by a single underlying factor, and co-occurred among those with lower educational levels. Stressors and resources partially mediated the relationship between education and four health behaviours (exercise, breakfast frequency, vegetable consumption and smoking). Financial stress and poor perceived health status were mediating stressors, and social support a strong mediating resource. An aggregate measure of the stressors and resources showed similar associations with health behaviours compared to the summed individual measures.

Conclusions

Lower educated groups are simultaneously affected by the presence of various stressors and absence of multiple resources, which partially explain socioeconomic differences in health behaviours. Compared to the direct associations of stressors and resources with health behaviours, the association with socioeconomic status was modest. Therefore, besides addressing structural inequalities, interventions promoting financial management, coping with chronic disease, and social skills training have the potential to benefit large parts of the population, most notably the lower educated. Further research is needed to clarify how stressors and resources impact health behaviours, why this differs between behaviours and how these disparities could be alleviated.

2

Stressors and resources mediate the association of socioeconomic position with health behaviours

2.1 Background

Indicators of socioeconomic position, such as education, occupation, income and wealth, are negatively related to morbidity and mortality (Cesaroni, Agabiti, Forastiere, Ancona & Perucci, 2006; Dalstra et al., 2005; Davies, Dundas & Leyland, 2009; Mackenbach, Kunst, Cavelaars, Groenhof & Geurts, 1997; Mackenbach et al., 2008; Menvielle, Leclerc, Chastang & Luce, 2010; Pamuk, 1985; Schalick, Hadden, Pamuk, Navarro & Pappas, 2000). In order to intervene in these disparities, it is important to understand how lower socioeconomic position leads to increased morbidity and mortality. Previous research suggests that an important cause lies in the higher prevalence of risky behaviours such as smoking, drinking, physical inactivity and unhealthy dietary habits (Fukuda, Nakamura & Takano, 2005; Hulshof, Brussaard, Kruizinga, Telman & Löwik, 2003; Kavanagh et al., 2010; Kershaw, Mezuk, Abdou, Rafferty & Jackson, 2010; Kim & Ruger, 2010; Koster et al., 2006; Lantz, Golberstein, House & Morenoff, 2010; Poortinga, 2007; Purslow et al., 2008; Sharma, Lewis & Szatkowski, 2010; Stringhini et al.,

2010). But then, how does socioeconomic position translate into differences in health behaviours? The observation that socioeconomic position is negatively correlated with morbidity, mortality and health behaviours suggests that there is a set of common, general determinants of health behaviours that is related to socioeconomic position. A perusal of the literature suggests that stressors, such as financial stress and psychological distress (e.g., Munster, Ruger, Ochsmann, Letzel & Toschke, 2009; Schulz et al., 2008), and a lack of psychosocial resources such as perceived life control (e.g., Wardle & Steptoe, 2003) may group among those with a lower socioeconomic status. Moreover, many studies have found an impact of stress (Almeida, Neupert, Banks & Serido, 2005; Bailis, Segall, Mahon, Chipperfield & Dunn, 2001; Baum, Garofalo & Yali, 1999; Caplan & Schooler, 2007; Droomers, Schrijvers, van de Mheen & Mackenbach, 1998; Giskes et al., 2009; Lantz, House, Mero & Williams, 2005; van Lenthe et al., 2004; Schulz et al., 2008) and resources (Bosma, Schrijvers & Mackenbach, 1999; Franzini, Caughy, Spears & Eugenia Fernandez Esquer, 2005; Gallo, de los Monteros & Shivpuri, 2009; Gorman & Sivaganesan, 2007; van Lenthe et al., 2004; Marmot et al., 1998; van Oort, van Lenthe & Mackenbach, 2005) on morbidity and mortality. Hence, stressors and resources may be good candidates when looking for general determinants that explain how socioeconomic status translates into health behaviours. For example, financial stress may lead to feelings of anxiety and depression (Lantz et al., 2005; van Oort et al., 2005; Schulz et al., 2008). In turn, anxiety and depression have been found to predict smoking and waist circumference (Schulz et al., 2008). Over time, worsening physical and mental health as a result of stress and unhealthy lifestyle may thus become additional stressors themselves. Therefore, stressors under scrutiny in the present article are financial stress, poor physical health and psychological distress.

At the other side of the balance a reserve capacity of several resources such as perceived control (i.e. mastery), social cohesion and social support may positively impact health behaviours (Franzini et al., 2005; Gallo et al., 2009; Gorman & Sivaganesan, 2007; van Lenthe et al., 2004; van Oort et al., 2005). Perceived control is an important resource for coping with stress, because the belief that one has a certain degree of control over the outcomes in one's life determines emotional and behavioural responses to negative events (e.g. Gallo et al., 2009; Hoffmann, 2008). It has indeed been shown that lower education is associated with lower scores on measures of control, and that, in turn, these are related to either worse health or unhealthy behaviours (Bosma et al., 1999; Leganger & Kraft, 2003; Marmot et al., 1998; Schulz et al., 2008; Wardle & Steptoe, 2003). Similarly, individual social support and neighbourhood social cohesion are resources that vary with measures of socioeconomic position, and that provide tangible, emotional or

informational support when dealing with problems (Franzini et al., 2005; Gallo et al., 2009; Gorman & Sivaganesan, 2007). Hence, perceived life control, social support and neighbourhood cohesion are the psychosocial resources examined in the present article.

Although many studies have looked at the impact of stress and resources in relation to morbidity and mortality, fewer studies examine their impact on health behaviours (Leganger & Kraft, 2003; Ng & Jeffery, 2003; Nguyen-Michel, Unger, Hamilton & Spruijt-Metz, 2006). Moreover, these studies have typically focused on either a single stressor or a single resource, while it is likely that the absence of multiple resources and the presence of multiple stressors co-occur among the lower educated. Other studies have combined stressors and resources into one measure, leaving questions as to what extent specific factors contribute to health disparities, or whether such an aggregate measure can be preferred above examining the specific effects of individual mediators (Gallo et al., 2009; Matthews, Gallo & Taylor, 2010). The objectives of the present study are therefore, first, to examine whether high levels of stressors and a lack of resources co-occur among the lower educated. A related objective is to examine whether stressors and resources can be represented by a single underlying factor, as is expected, because the absence of a resource such as life control can well be considered a stressor; and second, to examine whether the relation between educational level and four health behaviours (i.e., exercise, vegetable consumption, breakfast frequency and smoking) is mediated by stressors and resources simultaneously. The final aim is to examine whether an aggregate measure of stressors and resources has stronger associations with the health behaviours than the sum of the individual associations, as has been suggested but, to our knowledge, has not been tested empirically (Gallo et al., 2009).

2.2 Methods

Study design and sample
In 2008, cross-sectional data were collected in the Dutch city of Utrecht using the Health Survey (HS). The HS consists of a self-administered questionnaire which is distributed every 2 or 3 years among a sample of the city population of 16 years and older. This sample is stratified according to neighbourhood of residence. Inhabitants (n=7500) were approached by postal mail to participate in the survey, 2413 (32.4%) of whom returned the filled-out questionnaires within two weeks. After two weeks, non-respondents were contacted by telephone providing an additional 787 respondents (10.1%). Another two weeks later, remaining non-respond-

ers were contacted personally at their home address to prompt them to return the filled-out questionnaire, yielding the final 649 (8.7%) respondents. This resulted in a total of 3916 respondents (response rate 52.2%; including 67 respondents for whom it was not registered at what step their questionnaire was included). The present study is based on a secondary analysis of these data.

Measures
Educational level was used as an indicator for socioeconomic position (Van Kippersluis, O'Donnell, van Doorslaer & Van Ourti, 2010; Herd, Goesling & House, 2007), and respondents whose main occupation was studying (n = 419, 10.7%) were omitted from the analysis, since they had not yet achieved their final education level. Educational attainment was categorized in four levels: 1) no education and primary school, 2) lower vocational school and intermediate secondary school, 3) intermediate vocational school and higher secondary school, and 4) higher vocational school and university.

Three stressors and three resources were measured. First, financial stress was measured with two items: 1) 'Have you had any difficulty getting by on the household income?' (1 = 'No difficulty whatsoever', 4 = 'Great difficulty'), and 2) 'How is the current financial situation of the household?' (1 = 'Have to go into debt', 5 = 'Still have a lot of money left'). Both items correlated satisfactorily (r = .65), corresponding with a Cronbach's alpha of .79. Second, suboptimal physical health was included as a stressor. Since people cope differently with disease (Dell Orto & Power, 2007), rather than using the absence/presence of chronic disease as a stressor, we used perceived health status. This was measured with the single validated item 'How would you rate your health in general?' (1 = 'excellent', 5 = 'poor') (Mackenbach, Simon, Looman & Joung, 2002). Chronic disease itself was treated as a confounder rather than a stressor, since it may directly cause differences in health behaviours, for instance, through disability. Third, psychological distress was measured with the 10-item Kessler Psychological Distress Scale (Cronbach's α = .92) (Kessler et al., 2002). Although psychological distress could be both a stressor or an indicator of stress, it is argued – similar to perceived health status – that psychological distress is an indicator of how stressed someone is by their circumstances, and this may vary across individuals in similar circumstances (Schulz et al., 2008).

We also measured three resources. Perceived life control was measured with the Pearlin & Schooler Mastery Scale (Cronbach's α = .83) (Pearlin & Schooler, 1978). Examples of items are 'I have little control over the things that happen to me' or 'Whatever happens in the future largely depends on myself'. All 7 items are scored on a 5-point scale from 'totally agree' to 'totally disagree'. The second resource was perceived social support, measured with 11 items on a 3-point scale ('yes', 'more or less', 'no'; Cronbach's α = .89). Examples of items are 'I have a lot of people I can trust completely' and 'When I feel the need, I can always contact my friends'. Third, social cohesion in the neighbourhood was measured with 5 items on a 5-point scale (1= 'totally agree', 5 = 'totally disagree'), such as 'The people in my neighbourhood help each other' (Cronbach's α = .81).

All behavioural measurements were self-reported. Exercise was measured in minutes per week by asking participants to indicate the typical number of exercise days per week during the last few months and the average duration of exercise on such a day. Vegetable consumption was expressed in serving spoons per day, and measured by asking how many days in the week they normally ate boiled, fried or raw vegetables and salads, and the number of serving spoons they normally consumed on such a day. Breakfast frequency was added since many studies have found an inverse association with obesity and chronic disease, which may be explained by several mechanisms, such as through metabolic pathways that help control appetite throughout the day (Timlin & Pereira, 2007). Breakfast frequency was assessed with one item: 'How many days a week do you usually eat breakfast?'. For smoking, people were asked to report the daily number of cigarettes and weekly number of cigars they typically smoke. Demographic characteristics such as age, gender and ethnicity, were also measured. Finally, respondents reported whether they suffered from cardiovascular diseases, lung diseases, musculoskeletal disorders, cancer or diabetes.

Statistical analysis
For all stressor and resource scales (mediators) the mean item score was calculated. The original response scales varied in ranges, which therefore had to be adjusted to enable comparison. All scales were thus converted to the smallest range of any of the mediators, which was 1 to 3 for social support. For all resulting scales, higher scores indicated higher levels of the particular stressor or resource. First, bivariate correlations were computed to explore whether educational level, mediators and health behaviours were associated in the expected directions. Next, co-occurrence of stressors and mediators within individuals was examined by performing a factor analysis, to test whether stressors and resources could best be explained by a single underlying factor. This was done through a principal components analysis with oblique rotation (because factors were expected to correlate), which retained all factors with an eigenvalue greater than 1.

The mediation of the education-health behaviour relations by the stressors and resources was tested directly with a bootstrapping method for multiple mediator models (Preacher & Hayes, 2008). This method allowed all mediational paths of the various stressors and resources to be included simultaneously in one model, and this was done separately for each health behaviour. The bootstrapping method yields a point estimate and a 95% confidence interval for each indirect (i.e., mediation) effect a*b in the model (see Figure 2.1), while c' represents the direct effect of X (i.e., educational level) on Y (i.e., health behaviours) that is independent of the pathways through the mediators (i.e., stressors and resources). The total effect of X on Y, represented by coefficient c, is thus comprised of direct effect c' and all indirect effects $a_{1-6}*b_{1-6}$. When the confidence interval for the indirect effect does not contain zero, the indirect effect is significant. The sampling distribution of the product term a*b is almost always skewed and bootstrapping is a method that involves a nonparametric resampling procedure to generate an empirical approximation of the sampling distribution of a*b, and thereby prevent the loss of statistical power. The number of bootstrap resamples was set to 5000, indicating that 5000 samples (with replacement) were taken from the data set to calculate a value for each mediation effect (Preacher & Hayes, 2008).The third research objective was accomplished by averaging all the separate measures of stressors and resources into one overall measure. This overall Stressors & Resources measure was entered as a single mediator in a separate model for each health behaviour.

All relations with education were controlled for possible confounding, by including demographic variables (i.e. gender, age, ethnicity, and neighbourhood of residence) and chronic disease status (since chronic diseases may impact health behaviour through routes other than stress, i.e. physical impairment) as covariates in all analyses. Alpha level for tests of significance was set a priori at $p = .05$. We used PASW statistical software version 19.0 (SPSS Inc., Chicago, USA) for all analyses.

Ethical considerations
Data for this study were collected by the Municipal Health Service Utrecht for purposes of public health promotion. The research was carried out according to national guidelines for survey research among the adult population. Data collection procedures assured confidentiality by the use of self-administered, anonymous questionnaires. Ethical approval was not required as the study was voluntary and confidentiality was fully guaranteed.

Figure 2.1 | Multiple stressors and resources mediate the education-health behaviour link.
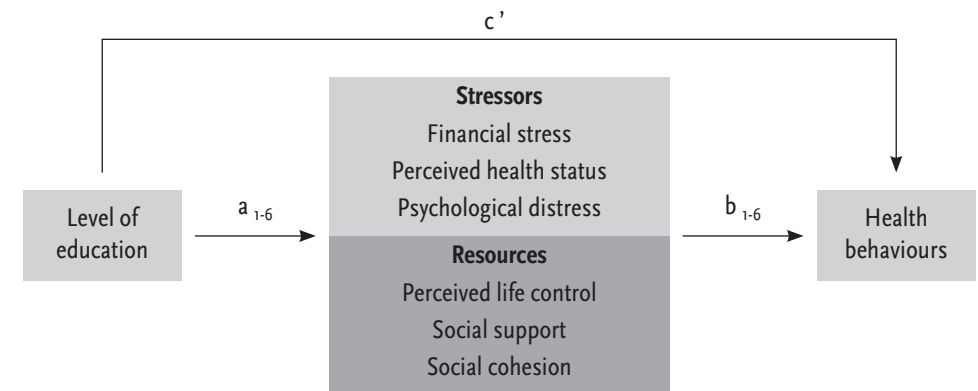
2.3 Results

From our sample of 3497 respondents, a total of 447 (12.8%) respondents were excluded from the analyses because they had missing data on educational level (*n* = 96), had missing data on one or more health behaviours (*n* = 264), or on one or more of the mediators (*n* = 249; these categories were not mutually exclusive). Results from a logistic regression showed that higher age, lower level of education, and a non-Western background (but not gender) was related to having missing data. The final sample counted 3050 respondents with complete data. The mean age of the sample was 44.9 years (SD = 15.9) and 56.3% were female (n= 1718). The majority was of Western descent (87.2%). The percentage of people with no education or primary school only was 10.9% (n = 332), 23.3% (n = 712) finished lower vocational school to intermediate secondary school, 19.0% (n= 579) intermediate vocational to higher secondary school, and 46.8% (n= 1427) received higher vocational to university education. Other descriptives are presented in Table 2.1.

We first explored the data through examining correlations between educational level, stressors and resources and the four health behaviours. All expected relations were observed, namely that level of education was correlated with the four health behaviours (range $r = .14$ to -.17, all *p*'s <.01); education was positively correlated with the three resources (range $r=.10$ to .29, all *p* values < .01) and negatively to all three stressors (range $r= -.20$ to -.36, all *p*'s < .01); and higher levels of stressors were associated with more risky health behaviours (range $r = -.05$ to -.21

Table 2.1 | Sample characteristics (N = 3050)

Variable		N (%)	Mean (SD)	Range
Age			44.9 (15.9)	17-96
Male		1332 (43.7)		
Level of education	• no education and primary school	332 (10.9)		
	• lower vocational/ intermediate secondary school	712 (23.3)		
	• intermediate vocational/ higher secondary school	579 (19.0)		
	• higher vocational school/ university	1427 (46.8)		
Non-Western background		389 (12.8)		
Chronic diseases [a]	• Cardiovascular disease	460 (15.1)		
	• Musculoskeletal disorder	775 (25.4)		
	• Diabetes	185 (6.1)		
	• Lung diseases	268 (8.8)		
	• Cancer	56 (1.8)		
Stressors	• Financial stress		1.6 (0.5)	1-3
	• Perceived health status		1.8 (0.5)	1-3
	• Psychological distress		1.3 (0.3)	1-3
Resources	• Perceived life control		2.5 (0.4)	1-3
	• Social support		2.7 (0.4)	1-3
	• Social cohesion		2.3 (0.4)	1-3
Health behaviours	• Exercise (minutes per week)		107.8(156.6)	0-750
	• Vegetable consumption (daily no. of serving spoons)		3.6 (1.9)	0-12
	• Breakfast frequency (per week)		5.9 (2.1)	0-7
	• Smoking (cigarettes/cigars per day)		3.0 (6.8)	0-30

[a] number of respondents indicating that they currently suffered, or had suffered during the last twelve months, the disease.

The stressors and resources intercorrelated in the expected direction (stressors positively, resources positively, stressors and resources negatively) from $r = -.11$

Table 2.2 | Correlation coefficients between scales and Factor 1

Scale	Correlation with Factor 1
Financial stress	.61
Perceived health status	.70
Psychological distress	.83
Perceived life control	-.81
Social support	-.73
Social cohesion	-.36

to $r = -.64$ (all p's < .01), providing a first indication that stressors and resources tend to co-occur. Results from the factor analysis revealed only one factor with an eigenvalue greater than 1, which explained 47.4% of the total variance. Examination of the factor loadings (see Table 2.2) showed that all stressors and resources correlated strongly with this single factor, except for social cohesion, which showed a moderate correlation.

These results indicate that the various stressors and resources co-occur within individuals, and can be represented by a single factor. This is further supported by the results from the mediation analysis.

Mediation by stressors and resources
Looking at the a weights in the bootstrap analyses (Table 2.3), it is evident that level of education was negatively associated with all three stressors (range $B =$ -0.04 to -0.16, all p's < .01) and positively with all three resources (range $B = 0.05$ to 0.09, all p's < .01) for all four behaviours while controlling for other demographic variables and chronic disease. This again indicates that higher levels of stressors and lower level of resources indeed co-occur among the lower educated. With regard to the second objective, results showed that level of education was positively associated with all four health behaviours (c weights in Table 2.3), and continued to have a direct relationship (c' weights) with health behaviours in the presence of the mediators, with the exception of exercise. For all four health behaviours the relationship between education and health behaviour was partially mediated by three or more stressors and resources.

To illustrate the results displayed in Table 2.3, the results of physical exercise are discussed in more detail. The total association of education with physical exercise is $B = 11.81$ ($p < .001$), meaning that one level increase in educational attainment

all p's <.01), and vice versa for resources (range $r = .07$ to .19, all p's <.01), with the notable exception of social cohesion that did not correlate with exercise.

is associated with almost 12 more minutes exercise per week. Of this association, little over 2 minutes is mediated by financial stress (*a**b weight, *B* = 2.20; 95% confidence interval [CI] = 0.73, 3.77), over 3 minutes by perceived health status (*B a**b path = 3.36; 95% CI 2.05, 4.95) and 1 minute by social support (*a**b weight, *B* = 1.00; 95% CI 0.19, 1.94). The other mediators are not significant (i.e., the confidence interval contains '0'). This means that about half of the relation between education and health behaviour can be explained through these mediators, leaving the direct relation of education with exercise not significant in the presence of resources and stressors (*c' *weight*, B* = 4.90, *p* = .13).

Although these mediation effects might not sound too spectacular, primarily because – contrary to what one would expect based on the literature on socioeconomic health disparities – the relation of education with the health behaviours is modest, the associations between health behaviours and the resources and stressors are notable. For example, the *b* weight from perceived health status to exercise is *B* = -44.27 (*p* < .001), indicating that a one-point increase (indicating worse health) is associated with 44 minutes less exercise per week (since the analysis is controlled for chronic disease, this association is unlikely to reflect physical disability). A 1-point increase in financial stress equals an additional 17 minutes in exercise. Hence, although stressors and resources co-occur among the lower educated, it seems that independent of educational level the direct associations between health behaviours and the stressors and resources are large relative to the total effect of education.

Note that psychological distress was not a significant mediator for any of the health behaviours when controlling for confounders and the other mediators in the model. Social cohesion only mediated the association between education and vegetable consumption. Furthermore, perceived life control is a significant mediator for vegetable consumption and smoking. In contrast to expectations and the univariate correlations, it is associated with more smoking. However, because all the mediating variables were to some extent correlated, entering them all in the same model, could have resulted in over-adjustment. All analyses were therefore repeated with all stressors and resources entered as a single mediator for all four health behaviours (data not shown). As opposed to the results from the full models, psychological distress was now a significant mediator for all four health behaviours. Perceived life control as a single mediator was no longer significant for smoking, but now showed a positive association with exercise and breakfast frequency. Finally, social support was a significant single mediator for vegetable consumption, while social cohesion became significant for breakfast frequency and smoking.

Finally, since it has been suggested that the aggregate effects of stressors and resources is stronger than the sum of the individual effects (Gallo et al., 2009), and the factor analysis confirmed that a single factor best explains the different stressors and resources measures, all six separate measures were averaged into a single measure of Stressors and Resources. This overall measure was entered as a single mediator into the bootstrap analyses. Results revealed (Table 2.4) that the mediational relations of the separate mediators were comparable with the mediational relations of the overall measure for all four health behaviours. Although the *B* values of the direct associations of the overall measure with the health behaviours appear to be somewhat stronger, the overall measure has a smaller range than the individual stressors and mediators. As a result, direct and indirect effects of the overall Stressors & Resources measure are of similar size as the direct and indirect effects of the significant individual stressors and resources added together.

2.4 Discussion

Recent studies indicate that differences in health behaviours largely account for the socioeconomic health disparities observed in a range of studies (Lantz et al., 2010; Kershaw et al., 2010; van Oort et al., 2005; Stringhini et al., 2010). How exactly socioeconomic position translates into health behaviours is not that clear. It has been suggested that differences in health behaviours may, at least partially, stem from differences in stressors and psychosocial resources. Although some studies support this idea, it remains to be examined whether stressors and resources co-occur among the lower educated, simultaneously impact health behaviours, mediate the relation between education and behaviour, and whether co-occurring stressors and resources are better examined separately or in one or two overall measures (Gallo et al., 2009; Matthews et al., 2010). The aim of the present study was to investigate these issues.

The current study revealed that the presence of stressors and the absence of resources co-occur among those with lower educational levels. A lower education thus placed people at a disadvantaged position for all the stressors (i.e. financial stress, worse perceived health status and psychological distress) and resources (i.e. perceived life control, social support and social cohesion) examined here. Whereas the focus of our study was on the association of this accumulated disadvantage with health behaviours, it is important to note that exposure to stressors and having limited resources also have a direct negative impact on quality of life and health (Almeida et al., 2005; Cohen, Tyrrell & Smith, 1993).

Subsequent analyses showed that, as others have previously observed (e.g., Purslow et al., 2008; Sharma et al., 2010; Stringhini et al., 2010), higher educational level is associated with more exercise, a higher vegetable consumption and breakfast frequency, and less smoking. But most notably, as we proposed, stressors and resources were associated with health behaviours and partially mediated the association with education. Lower education was associated with higher exposure to stressors and less availability of resources, which, in turn, predicted less healthy behaviours irrespective of education.

Examining the mediation and direct associations of individual stressors and resources, different relations were observed for each of the health behaviours. The educational relation with vegetable consumption was mediated by perceived health status, perceived life control and social cohesion, while the relation with smoking and breakfast frequency was mediated by four out of the six stressors and resources, i.e. financial stress, perceived health status, perceived life control and social support. For exercise financial stress, perceived health status, and social support were significant mediators. Depending on the behaviour, financial stress and perceived health status were significant mediating stressors, and perceived life control and social support were significant mediating resources. Surprisingly however, perceived life control showed a negative relation with breakfast frequency and smoking (but not with vegetable consumption), and psychological distress was not a mediator for any of the health behaviours. However, when mediators are highly correlated, entering them together in the model may lead to suppression or over-adjustment of the effects of the single mediators. Therefore, all analyses were rerun with the single stressors and resources. The pattern of results was largely the same, with notable exceptions for psychological distress and perceived life control. Psychological distress was now a significant mediator for all four health behaviours. Perceived life control was no longer a significant mediator for smoking, but it did become a significant mediator for exercise and breakfast frequency, having positive associations with both behaviours. These deviations from the previous results could be a sign of suppression or over-adjustment in the full model, but findings are ambiguous. Taken together, the results from the mediation analysis suggest that level of education is predictive of the degree to which people experience financial, emotional and physical stressors, or accumulate perceived life control, social support and neighbourhood social cohesion, and that these stressors and resources explain – at least to some extent – how educational level is predictive of health behaviours.

When interpreting these results, it must be noted that, although it has been shown that unhealthy behaviours indeed co-occur among lower socioeconomic

Table 2.3 | Mediation by stressors and resources of the education-health behaviours relationships.

Dependent variable Mediating variables	Association between education and mediator (a)	Association between mediator and health behaviour (b)	Direct association (c')	Indirect association (a*b)	95% CI for a*b	Total association (c)
Exercise			4.90			11.81**
Financial stress	-0.12**	-17.65*		2.20	0.73, 3.77	
Perceived health status	-0.08**	-44.27**		3.36	2.05, 4.95	
Psychological distress	-0.04**	6.08		-0.23	-1.17, 0.62	
Perceived control	0.06**	11.00		0.61	-0.55, 1.85	
Social support	0.06**	16.26+		1.00	0.19, 1.94	
Social cohesion	0.05**	-0.38		-0.02	-0.74, 0.67	
Vegetable consumption			0.36**			0.41**
Financial stress	-0.12**	0.04		-0.01	-0.03, 0.01	
Perceived health status	-0.08**	-0.36**		0.03	0.01, 0.05	
Psychological distress	-0.04**	0.18		-0.01	-0.02, 0.00	
Perceived control	0.06**	0.33+		0.02	0.00, 0.04	
Social support	0.06**	0.15		0.01	0.00, 0.02	
Social cohesion	0.05**	0.23*		0.01	0.00, 0.02	
Breakfast frequency			0.26**			0.41**
Financial stress	-0.16**	-0.46**		0.08	0.05, 0.11	
Perceived health status	-0.11**	-0.30*		0.03	0.01, 0.06	
Psychological distress	-0.06**	0.07		0.00	-0.03, 0.02	
Perceived control	0.08**	-0.29+		-0.02	-0.05, 0.00	
Social support	0.09**	0.68**		0.06	0.04, 0.08	
Social cohesion	0.05**	0.17		0.01	0.00, 0.02	
Smoking			-1.14**			-1.45**
Financial stress	-0.12**	1.74**		-0.22	-0.32, -0.14	
Perceived health status	-0.08**	1.06*		-0.08	-0.14, -0.03	
Psychological distress	-0.04**	0.52		-0.02	-0.07, 0.03	
Perceived control	0.06**	1.33*		0.07	0.02, 0.14	
Social support	0.06**	-0.89+		-0.05	-0.12, -0.01	
Social cohesion	0.05**	-0.16		-0.01	-0.03 , 0.02	

+ p <.05; * p < .01; ** p < .001

All analyses were controlled for age, gender, ethnicity, neighbourhood of residence, and chronic disease status.

Table 2.4 | Mediation of the education-health behaviours relationships by the overall Stressors & Resources measure

Dependent variable	Association between education and mediator (a)	Association between mediator and health behaviour (b)	Direct association (c')	Indirect association (a*b)	95% CI for a*b	Total association (c)
Exercise	-0.05**	-108.33**	6.53	5.29	3.75, 7.12	11.81**
Vegetable consumption	-0.05**	-0.89**	0.37**	0.04	0.03, 0.06	0.41**
Breakfast frequency	-0.07**	-2.06**	0.27**	0.14	0.11, 0.17	0.41**
Smoking	-0.05**	5.41**	-1.18**	-0.26	-0.36, -0.19	-1.45**

groups (Poortinga, 2007), and the combination of several less healthy behaviours add up to explain a large part of the socioeconomic health gap (Stringhini et al., 2010), the association of education with each of the health behaviours is modest. Another issue is that level of education remains associated with three of the four health behaviours when the Stressors and Resources are taken into account. Hence, the stressors and resources examined here do not offer a comprehensive explanation of the education-health behaviour link. Other variables that we did not measure may underlie the remaining direct relation with education, such as knowledge, awareness, social norms or health literacy (Layte & Whelan, 2009; Von Wagner, Steptoe, Wolfs & Wardle, 2009; Godin et al., 2010).

In a final analysis, we found that combining stressors and resources in a single measure hardly changed the pattern of direct and indirect associations between education and health behaviours, as compared to using the individual variables. This confirmed the findings from the factor analysis and mediation analysis that stressors and lack of resources can be viewed as conceptually similar.

Besides their co-occurrence and mediation effects, a considerable *direct* relationship between stressors and resources, and health behaviours was observed. For example, by multiplying the *B* value of financial stress for exercise with the range of the financial stress scale (i.e. 2), it was found that the difference between a minimum and maximum score on the financial stress scale was associated with a reduction of approximately 35 minutes exercise per week, and an increase of 3.5

cigarettes per day. This observation implies that although stressors and resources cluster among lower educated people, part of their influence on behaviour is independent of educational attainment. Interventions directed at alleviating stressors and building psychosocial resources, like financial management, coping with chronic disease, or training of social skills may therefore have beneficial consequences for everyone, including those in disadvantaged groups who experience higher rates of difficulties. Interventions that aim to disproportionately reduce stressors and resources among the lower educated may relieve some of the inequalities in health behaviours, but this is limited to the extent stressors and resources explain these inequalities. This impact may be considerably larger, and easier to accomplish, compared to interventions to promote socioeconomic position. Although by no means we mean to imply that measures to decrease socioeconomic inequalities have no effect on health inequalities, studies indicate that with smaller income inequalities, health behaviours may become even more important in determining health inequalities (Mackenbach et al, 2008; Stringhini et al., 2010). That is why we propose that measures to narrow structural inequalities should be accompanied by health communication programs that address psychological and behavioural factors in disadvantaged groups.

Strengths and Limitations

The strengths of the present study are the use of reliable and valid measures in a large sample and the testing of relations across multiple behaviours. A limitation is the response rate of 52.2%. In addition, 12.8% of the respondents eligible for the analysis had missing data, and having missing data was associated with lower education, older age, and having a non-Western background. This may indicate a selection bias, although recent studies suggest that lower response rates do not necessarily affect survey results (Holbrook, Krosnick & Pfent, 2007; Keeter, Kennedy, Dimock, Best & Craighill, 2006). In addition, people with lower education were still well represented (34.2% in our sample against approx. 30% for the population). With 12.8% in our sample against 21% in the population of Utrecht, however, respondents with a non-Western background were somewhat underrepresented. Although more than sufficient participants were available from all educational levels and ethnic background to conduct the analyses, there may be limitations in generalizability of the findings. Other limitations of this study are that the data are cross-sectional so that causal inferences cannot be made. It is possible, for example, that health behaviours influence people's level of stressors and resources. However, it is very likely that educational level preceded the other measures in this adult sample (mean age 44.9 years). Moreover, since the resources and stressors measured here are relatively stable factors (Ng & Jeffery, 2003; Gallo et al., 2009), they are very likely to have preceded the behaviours measured in

the week prior to the completion of this questionnaire. A second limitation is that behaviour was measured subjectively and may therefore be subject to social desirability bias or memory impairments. Finally, averaging all the stressors and resources into one overall measure weights them all equally, although our results imply that some mediators are more meaningful than others.

Conclusions
Stressors and lack of psychosocial resources accumulate among those with lower socioeconomic position, are related with health behaviours, and partially explain how lower education translates into less healthy behaviours. Although longitudinal studies are needed to clarify exactly how stressors and resources accumulate among the lower-educated and affect health behaviours, this study suggests that both stressors and resources could be relevant intervention targets for bridging the health gap between people with different socioeconomic backgrounds.

Abstract

Since the introduction of cART (combination antiretroviral therapy), HIV has evolved into a chronic disease such that it requires lifelong medical treatment, to which patients must adhere. Communication with health care providers is pivotal in supporting patients to adapt to having HIV and adhering to treatment, in order to maintain health and quality of life. Previous research indicates that communication is optimal when it matches patient preferences for information exchange, relationship establishment and involvement in treatment decisions. The aim of the present study is to explore HIV patient communication preferences, and their experiences with their providers (not) matching their preferences. A second aim is to explore provider beliefs about patient preferences, and their views on optimal communication. Data was collected through interviews with 28 patients and 11 providers from two academic hospitals. Results indicate that patient preferences reflect their cognitive, emotional and practical needs such that patients look to increase their sense of control over their HIV. Patients aim to further increase their sense of control (by proxy) through their relationship with their providers, and their decisional involvement preferences. Providers are well aware of patient communication preferences, but do not explicate underlying control needs. Implications for clinical practice are discussed.

3

Communication between HIV patients and their providers: A qualitative preference match analysis

3.1 Background

The introduction of combination antiretroviral therapy (cART) in 1996 has dramatically increased the life expectancy of patients infected with the Human Immunodeficiency Virus (HIV) (Egger et al., 2002; Pérez-Hoyos et al., 2006). HIV can now be seen as a chronic rather than a lethal condition (Mahungu, Rodger, & Johnson, 2009). However, for cART to be effective (i.e. suppress viral loads to undetectable levels), patients need to carefully adhere to their medication. Non-adherence, and particularly missing consecutive doses, allows the virus to replicate with the risk of developing viral resistance (Sethi, Celentano, Gange, Moore, & Gallant, 2003), and even progression to AIDS (Bangsberg et al., 2001). Studies reveal, however, that about 25%-40% of HIV patients does not succeed in achieving and maintaining the high level of adherence generally considered adequate for the treatment of HIV (95% or more of the pills taken (Bangsberg et al., 2001; Deschamps et al.,

2004; Sethi et al., 2003). Causes for non-adherence include patient-related determinants such as depression, low self-efficacy, or denial of HIV status (Ammassari et al., 2002; Deschamps et al., 2004; Ickovics et al., 2002; Luszczynska, Sarkar, & Knoll, 2007; Nam et al., 2008; Vervoort, Borleffs, Hoepelman, & Grypdonck, 2007); treatment related variables such as regimen complexity or side-effects (Ammassari et al., 2002; Deschamps et al., 2004; Mills et al., 2006); and interpersonal factors such as social support or stigma (Luszczynska et al., 2007; Rintamaki, Davis, Skripkauskas, Bennett, & Wolf, 2006; Simoni, Frick, & Huang, 2006). Health care providers (henceforth referred to as 'providers'), however, can play a major role in helping patients cope with these challenges. Various studies have shown that providers, by offering trust, support and information within a caring patient-provider relationship, can have a positive influence on adherence (Schneider, Kaplan, Greenfield, Li, & Wilson, 2004; Vervoort et al., 2007). Meta-analyses have also offered strong evidence of the importance of adherence support, showing that whether patients achieved an undetectable viral load (a key indicator for treatment success) strongly depended on the quality of the instrumental provider communication (de Bruin, Viechtbauer, Hospers, Schaalma, & Kok, 2009; de Bruin, Viechtbauer, et al., 2010). Communication thus seems to be a key factor to the success of HIV treatment, and can be seen as the central tool through which providers care for patients (Bensing, 2000; Bensing & Verhaak, 2004).

Indeed, quality of provider communication positively affects patient adherence, because good communication informs patients about risks and benefits of their treatment, and encourages and motivates patients to adhere while offering support to gather and use resources for adherence. Providers may achieve this by enabling open discussion with patients about medical and psychosocial issues that may hamper adherence, and by involving patients in treatment decisions (Zolnierek & DiMatteo, 2009). However, although increasing patient autonomy and involvement in treatment decisions, referred to as shared decision-making, has been presented as ideal, large individual differences exist in patients' preferred level of involvement in decisions (Bensing, 2000; Charles, Gafni, & Whelan, 1997). Likewise, patients may differ, in the preferred type and amount of exchanged information, and in the preferred type of relationship with their provider (Ong, De Haes, Hoos, & Lammes, 1995). Evidence indicates that provider communication is optimal when it matches patient communication preferences in these areas (Kiesler & Auerbach, 2006). To date, no studies have examined communication preferences of HIV patients, which therefore is the focus of the current paper.

Communication goals

Patient-provider communication serves three goals: exchanging information, establishing a relationship, and involving the patient in decision making (Ong et al., 1995). For providers, information exchange is aimed at establishing a diagnosis and treatment plan, based on information from patients, such as perceived symptoms. In turn, patients need information to be able to know and understand their illness (Bensing & Verhaak, 2004; Charles et al., 1997). Patient preferences may vary as to the amount and type of information they want to receive about diagnosis, treatment options and related consequences, and prognosis. Patients may also vary in the type and amount of personal information they prefer to give (Bensing & Verhaak, 2004; Ong et al., 1995). Matching information exchange preferences has been shown to affect diverse outcomes such as adjustment during dental surgery, anxiety and treatment after breast cancer treatment, and coping after cardiac catheterization (Kiesler & Auerbach, 2006).

Patient-provider communication is also aimed at establishing a good working relationship. This can be seen as a prerequisite for medical care, because the relationship is the foundation for exchanging information and making decisions. Mutual trust is a central feature of this relationship. To varying degrees, patients prefer providers that are emphatic. Patients may also differ in their preference for the type of relationship, varying from egalitarian to paternalistic, pertaining to how much control the provider has over the interaction and the treatment (Ong et al., 1995).

Involvement in treatment decisions is the third communication goal. Evidence suggests that shared decision-making is beneficial (Kiesler & Auerbach, 2006), and is sometimes presented as an 'ideal' communication model, although it is also demanding for patients to be involved and take responsibility for decisions (Charles et al., 1997). Instead, matching patient decision-making preferences, which may vary according to personal and situational factors, appears to be more effective (Cvengros, Christensen, Cunningham, Hillis, & Kaboli, 2009; Jahng, Martin, Golin, & DiMatteo, 2005).

Thus, for all three communication goals, patient preferences may vary individually, and as a function of disease characteristics (Ong et al., 1995). Patient preferences can be matched to varying degrees by provider communication. Matching refers to the degree patient preferences are actualized within specific patient-provider interactions (Kiesler & Auerbach, 2006). To date, no studies have examined the communication preferences of HIV patients on cART. Therefore, the aim of the present study is to explore the communication preferences of HIV patients across

a culturally diverse sample, and to explore what it means to patients when providers match, or not match, these preferences. An additional question is whether patient preferences in these areas vary according to their cultural or ethnic background. Our second research aim is to examine provider beliefs about patient preferences across all three communication goals.

3.2 Method

A qualitative study was performed according to a 'grounded theory' approach (Strauss & Corbin, 1998).

Sample
Between August and November 2010, 31 HIV patients on cART were purposefully sampled from two large academic clinics in the Netherlands (the Academic Medical Center, Amsterdam; the Erasmus Medical Center, Rotterdam). Patients were eligible for selection if over 18 years, HIV infected and on cART. Initial selection focused on variation of the three largest cultural-ethnic groups on cART, i.e. Dutch, Caribbean, African; the aim was to include a comparable number of participants from each group.

During the study, three patients expressed their reluctance. Consequently their participation in the study was terminated. Of the resulting total sample of 28 patients, 10 patients were female, 11 patients from a Dutch background, 8 patients from a Caribbean background, and 9 patients from an African background (see Table 3.1 for other demographics). One Dutch female patient was pregnant at the time of the interview. Twelve providers who worked at the same two clinics, providing care to the interviewed patients, were interviewed: five physician-specialists, and six HIV nurses.

Procedure
After their regular visit to the clinic, patients were asked by their provider (i.e. either the specialist physician or the HIV-nurse) whether they would be willing to participate in the study. Patients were informed about the study objectives , were asked permission to audio-record the interview, and were informed that their anonymity would be guaranteed and that refusal to participate would not affect their care. Patients who agreed to participate signed an informed consent. The HIV-nurses and physicians who were primary care providers of the interviewed patients were also invited. Providers were approached by telephone or email to make an appointment for the interview. They were guaranteed anonymity, and provided informed consent.

Table 3.1 | Participant characteristics (n=28)

Variable		N (%)	Mean (SD)	Range
Gender	• Male	18 (64)		
Age		24 (86)	44.3 (10.3)	25-67
	• Unknown	4 (14)		
Ethnicity	• African	9 (32)		
	• Caribbean	8 (29)		
	• Dutch	11 (39)		
Level of education	• No education/primary school	4 (14)		
	• Lower vocational/intermediate secondary school [a]	5 (18)		
	• Intermediate vocational/higher secondary school	6 (21)		
	• Higher vocational school/university	10 (36)		
	• Unknown	3 (11)		
Marital status	• Single	14 (50)		
	• Married/living with partner	13 (46)		
	• Unknown	1 (4)		
Sexual orientation	• Homosexual [b]	8 (29)		
	• Heterosexual	20 (71)		
Years since diagnosis			7.5 (6.0)	1-25
Years since treatment initiation			5.8 (5.4)	0-19

[a] including non-western high school
[b] All eight homosexual patients were male; five were Dutch, and three were Caribbean.

Data collection
The data for this study were collected by ML through individual semi structured interviews. Based on a literature review, an interview schema was developed aiming to explore both patient communication preferences, and their perceived determinants of therapy adherence.

From the 28 patients, 25 were interviewed in a private room at the hospital immediately after a visit to their provider, while three were interviewed at their home. All providers were interviewed individually at the hospital. Patient interviews averaged 70 minutes per interview (range: 43-144 min), and provider interviews averaged 43 minutes (range: 18-88 min).

Patient communication preferences were explored during the first half of the interview. Patients were first asked when they were diagnosed with HIV, and when they had started treatment. Through the subject of how they had dealt with discovering their HIV status, and what their daily life currently looks like, they were asked how

satisfied they were with the care they received from the clinic. Then, three questions were used to elicit patient communication preferences. To explore preferences for information exchange, the main question was: 'What do you expect from your doctor/nurse during visits to the clinic?' For relationship establishment, the main question was: 'What do you feel are important conditions for you to talk about sensitive issues?' For decision making, the main question was: 'When a decision about your treatment needs to be made, what would you like the decision making process to look like?' Apart from these questions, the interview had an open character, to ensure that the subject of communicating with the provider could naturally arise. At the end of the interview, patients were asked about their age, marital status and education level.

Providers' beliefs about patient preferences were elicited by similar questions, i.e., 'What do you believe patients expect from you in treating or dealing with their HIV?', 'What do you believe are important conditions for patients to talk about sensitive issues?', 'According to you, what do patients find important to discuss decision making regarding their treatment or possible behavior change?'. A subsequent question for all three areas was whether providers perceived important ethnic or cultural differences: 'Do you perceive any differences between patients from Dutch, Caribbean or African backgrounds?'

Ethical considerations
This study was approved by the Medical Ethical Committee of the Academic Medical Center Amsterdam and the Medical Ethical Committee of the Rotterdam Erasmus Medical Center.

Data Processing and Analysis
All interviews were digitally recorded and transcribed verbatim. The first author (BM) immersed himself in the data by reading the interviews, and listening to the recorded interviews to pick up non-verbal cues, such as tone and strength of voice. Next, a data-driven analysis of patient interviews was carried out by labeling patient communication preferences using ATLAS.ti software, version 7.1.3. Information exchange, relationship establishment and decision making were used as a broad outline to categorize wordings and expressions. Within each communication goal, codes were added to identify patient preferences. During this process, new codes were added until no new preferences emerged, while at the same time codes were merged into higher themes. In a dynamic process of constant comparison (Strauss & Corbin, 1998), emerging themes were continually compared with the interview transcripts, to verify the interpretation, until no new themes were identified. Themes were connected across communication goals based on

associations between these goals when indicated by patients in the interviews. This allowed an overall model to emerge from the data. Two authors (BM and ML) independently analyzed the data according to this process, up to the point of thematic saturation and establishment of associations between themes. Then, the two separate analyses were compared, and showed a similar structure of associated themes. Further reliability was obtained by having one co-author (AML) read a selection of transcripts and themes to verify the analytic process.

3.3 Results

Our findings reveal main themes within the communication goals, which we will first discuss for patients. Overall, patients were very satisfied with the care they received, and with the communication with their providers, i.e. they expressed their preferences were being matched. For each communication goal, we will discuss patient preferences and explore the meaning of (not) matching. Next, we will present provider perceptions of patient preferences. Finally, we present a table with an overview of themes for patients and providers.

Patient Preferences for Information Exchange

Personal medical information and clinical feedback
Patients preferred to receive and to discuss clear and honest medical information, especially about their health status as shown by their viral load and CD4 cell count. This provided patients with the cognitive assurance that they are doing well physically, and the treatment is working. This indicates that patients wanted to control the virus, and thus receive feedback whether the virus was actually under control or not. Knowing this gave patients motivation and strength to deal with having HIV, which can be interpreted as an increase in their sense of control and self-efficacy.

> Interview #4 (Dutch male, 50 years)
> *"Yes, yes I mean, otherwise it is haunting you like 'What is it? What do I have? Is that [virus] load all right or is it not all right?' Well, just tell me, and be done with it. Then I can deal with it. Otherwise it stays in your head."*

Receiving general medical information about the consequences and prognosis of having HIV can be also reassuring, especially for patients from African or Caribbean countries where HIV education is often absent, and having HIV is still viewed as a death sentence. No other cultural differences were apparent.

Psychosocial and behavioral issues
As a second theme, patients preferred to discuss all kinds of psychosocial and behavioral issues, from sexual behavior and medication intake, to issues of disclosing HIV status and romantic relationships. This provided patients instrumental support to deal with the practical side of these issues, and with emotional support to relieve themselves of the psychological burden of having HIV. Patients also realized that disclosing issues enabled their provider to help them deal with it, both instrumentally and emotionally. Patients preferred to be able to ask questions at any time, about any issue they were currently coping with, and they emphasized the importance of receiving thorough explanations from their provider, in 'normal' (i.e. non-medical) language.

Some patients stated they do not want to discuss any psychosocial or behavioral issues with their provider. These patients indicated feeling insecure or vulnerable when discussing personal or emotional issues, thus threatening their sense of control. Because they still experience these strong emotions, this might indicate these patients still have low disease acceptance. Paradoxically, patients who had fully come to terms with their status also expressed a preference for discussing the medical-technical side of their disease, precisely because they were done dealing with the emotional consequences.

Patient Preferences for Relationship Establishment

Conditions for relationship establishment
Several strongly interconnected themes emerged when patients talked about what they value in their providers, constituting a good relationship. Patients preferred to build a long-term relationship in which they feel they are being taken seriously, respected, and treated as equals, by a provider who is knowledgeable, genuinely involved in their wellbeing and who shows overall support. Patients would like their providers to be always available in times of medical or psychological need. No clear cultural differences were identified.

> Interview #9 (Dutch female, 35 years)
> *"But I know I can always call. And I won't [laughing], but that feels really good and, I feel, feel genuine involvement. (...) The feeling that they have time for it. The feeling... I strongly feel that the work they do... well yeah, that they really like this work, and that they are really interested in your wellbeing."*

Trust and disclosure
Matching patient preferences for relationship establishment resulted in patients feeling satisfied, known, and taken seriously. This is associated with a relationship in which trust is a central feature. When patients talked about trust, they refer to integrity-based trust, meaning their provider treats them with respect and confidentiality. Patients also refer to trust when talking about having confidence in the medical competency of the provider.

When patients trusted the provider's integrity and competence, it was easy for them to disclose their issues and problems. Disclosure and trust were seen as reciprocal, with trust resulting in disclosure, which in turn helped to build trust. Over time, this process resulted in the development of a trustful relationship. Ultimately, by being engaged in a trustful relationship with a physician who has the knowledge and expertise to control their HIV, patients gain a sense of control by proxy over their HIV. This was expressed by patients from all three cultural backgrounds.

> Interview #14 (Caribbean male, age unknown)
> *"The doctor... is someone I trust. To get [trust] from her, from her decisions or what she thinks. Someone so confident, that is doctor [name] too. I feel that when she says something, that she really does not doubt."*

Factors disturbing the patient-provider relationship
Factors patient mentioned that could disturb relationship establishment were switching providers, experiencing that the provider is under time pressure and has little time for the patient, and being pitied, judged, or not taken seriously by the provider. Patients understood the doctor may have limited time, but they knew they had more time to talk things through with their nurse. Patients distinguished between the doctor and the nurse as having different and complementary roles. The doctor is more involved in medical issues, and the nurse is more involved in psychosocial and behavioral issues. Some patients accepted or even preferred a more business-like relationship with their doctor (as compared to their nurse).

Patient Preferences for Decisional Involvement

Being involved by being informed
Most patients preferred a level of decisional involvement where decisions were taken by the provider, and the provider justified the treatment decision to the patient. Justification meant patients wanted to be informed about the pros and cons of the treatment preferred by the doctor, compared to alternative treatment op-

tions, such as potential medication side effects and the intake regimen. Patients preferred the provider to look for agreement over decisions, without being overly persuasive or using pressure. Similar to information and relationship preferences, patients preferred to have time to discuss decisions, asking questions and receiving thorough explanations.

Individual differences emerged in the preferred level of control over and responsibility for the treatment. However, few patients preferred responsibility for the medical treatment, but preferring control over the treatment by being thoroughly informed about treatment options and outcomes by a trusted provider.

High involvement in decision making
High involvement and responsibility was only preferred by some experienced patients, who were highly functioning socially and professionally, and who had fully come to terms with their HIV status. These patients often searched on the internet for information about treatment options, and stated their provider had a more advisory role instead of being the one taking the decisions.

Knowledge asymmetry and ambiguity
Most patients expressed a knowledge asymmetry, as a result of which especially Dutch patients expressed ambiguity towards their preferred level of decisional involvement. On the one hand, they wanted to have their say when it comes to decisions such as starting or switching treatment, or choosing a certain medication combination. On the other hand, patients felt they lacked the knowledge and expertise to make medical decisions themselves.

> Interview #5 (Dutch male, 36 years)
> *"You're allowed, you... it's being very strongly advised to do that. And yes, I am a person that... of course I follow that, because they have studied for it and they know. And you really have the feeling they want the best for you. So, but at the same time it's kind of, well, it's really, that is a good word, an agreement. And I like to join in."*

Besides this asymmetry being a limit to decisional involvement, treatment options offer limited choice. Patients are more likely to take the lead in decision making about behaviors such as determining the medication intake schedule, treatment adherence, and sexual behavior. That is probably because such behavioral decisions offer much more choice, and the patient is the one in control of behavior. For non-Western patients, ambiguity about decisional involvement was practically absent. African patients even had a hard time understanding the questions about

shared decision-making, because they could hardly imagine why a patient would go against physician advice, expressing that if you want to live, you have to follow the prescribed medical treatment, emphasizing their lack of knowledge. They took their good health as proof that the doctor is providing excellent medical treatment. Therefore, it seemed African patients preferred control by proxy over their disease through their provider, and experienced no control or other psychological benefits from decisional involvement.

Higher Order Goals of Communication Preferences

Establishing a sense of control
Patient preferences indicated that they wanted to increase their control over the physical and social threat (i.e. stigmatization) of being HIV positive. Therefore, patient communication with their providers was aimed at increasing their sense of control, and control by proxy over their disease through their relationship with their providers. We term the desired gain in these two forms of control as the second-order goals of patient communication preferences, because patients do not communicate these goals directly with their providers, nor do they mention these goals explicitly in the interviews.

Underlying the second-order control goals are the first-order communication goals. Indirectly, patient preferences revealed reciprocal interdependencies between the communication goals of exchanging information, establishing a relationship and involvement in treatment decisions. Open information exchange, particularly patients disclosing issues involving medication intake or sexuality, is enabled through a long-term relationship with a trusted provider. In turn, disclosure of issues elicits support from the providers, increasing trust. By being able to disclose issues to a trusted provider, patients gain a sense of control over their HIV.

> Interview #3 (Caribbean male, 45 years)
> *"[Discussing] it clears your head. I believe... it gives you... You're always terrified, there is always panic. That there are things in your head that make you think 'ah well, ah' [concerned tone of voice]. And [discussing] this eases your mind, and I like that a lot."*

Patient sense of control was further increased by sharing the responsibility for treating HIV with their providers. The preference to share responsibility was reciprocally associated with trust in provider competency, connecting decisional involvement with relationship establishment. Decisional involvement was further

established through information exchange. Patients preferred the providers to involve them in treatment decisions by looking for agreement. Patients preferred the providers to look for agreement by having the provider explaining and justifying treatment decisions.

Providers Beliefs about Patient Communication Preferences
Providers perceived two general patient needs, which are good medical treatment, and emotional support. Naturally, physicians addressed medical issues, and nurses addressed psychosocial issues, although this was not a strict distinction. Physicians discussed psychosocial issues, because they were aware that these issues may affect therapy adherence, or other treatment or behavioral factors. In turn, nurses discussed medical issues such as the medication intake schedule or how to deal with side effects. This was because nurses had more time to thoroughly explain matters than physicians.

Perceiving and matching information exchange preferences
Providers employed two overall strategies for exchanging information with patients: establishing patient disclosure, and patient education.

Establishing patient disclosure
Providers wanted patients to disclose their personal problems because of the potential negative consequences of personal issues for patient adherence. Providers used the word 'open' or 'openness' as a central goal they strived for in communication. Open communication referred to both the patient disclosing personal issues, such as having problems with medication adherence or having unsafe sex, as well as the process of facilitating this disclosure. Patient disclosure was seen as a patient communication preference, but also in the interest of the patient, even if the patient is reluctant to disclose certain issues. Non-disclosure was seen as something that the provider has to try to overcome.

Overall, providers believed that a trustful relationship was the basis for patient disclosure. According to providers, specific communication behaviors to facilitate disclosure (and to build trust in the long term) were having time for the patient, providing the patient the opportunity to ask questions, using non-medical language, asking open-ended questions, active listening, and looking patients in the eye. These communication behaviors together constituted an open attitude, conveying the message that the provider is there for the patient, authentic, accepting and non-judgmental, with matching body language. In search for patient information, providers asked questions about patients' lives, especially when patients did not come up with issues themselves. Sometimes this meant 'reading' non-verbal

signals of patients, such as a flat tone of voice, and using that as an entry point for eliciting issues. In the end, however, providers emphasized that patients decided whether to disclose personal issues.

> Interview #7 (female nurse, 54 years)
> *"You have to be able to listen carefully. And ask open questions, because as soon as you ask closed questions then... the conversation flags immediately. Then they go like 'Yes. No.' Good, then they're out of that. So uh... Well yes, your open attitude. And I literally consider my posture. Like, well yes, 'come on'. Those are the spearheads, I think."*

Patient education
Patient education is the second information exchange strategy, focusing on providing full information about HIV and its treatment, possibly but not necessarily as a response to patient questions. This pointed to ambivalence within this strategy. On the one hand, providers tried to motivate patients to adhere to treatment, by involving patients in treatment decisions, and by trying to elicit patient information about barriers to treatment adherence. More than just aiming to share responsibility, providers wanted to help patients control their disease by providing patients with tailored knowledge and other resources, such as social support and clinical feedback on behavior (i.e. lab results) to increase self-efficacy.

> Interview #6 (male nurse, 42 years)
> *"And the same goes for therapy adherence. (...) Yes, the patient has to be well able to make his own choice in that matter. And has to be aware of the consequences of what can go wrong if he for instance doesn't follow the advice that we give him. So if he, for example, if he is therapy non-adherent, it is important to explain to the patient... or to ask him, like 'What is the importance of taking [your pills] and what happens if you are non-adherent?' So first check 'Has he got the knowledge?' When he doesn't, give him that knowledge. When he does have that knowledge, then follow that path with him, like 'What do you want to achieve? And in what situations are you not able to manage and how in those situations could you apply the... tools that you will manage?' So creatively follow that path with him, that he gains that insight himself that he wants to change something, can change something. (...) And to motivate patients in that sense, like 'Gee yes, you're doing well, given your results we see that it's going well. Carry on like that!'"*

On the other hand, providers emphasized that all they could do was inform the patient and that, in the end, adhering to treatment was the patient's responsibility. When providers noticed that the patient was being non-adherent, providers used risk communication by informing patients about consequences of non-adherence in an effort to persuade them to adhere to treatment.

> Interview #6 (male nurse, 42 years)
> *"Listen, it's your choice, but be aware of the consequences (…) I can give the information, I can put the consequences on the table, I can try using motivational interviewing to change a certain thought or behavior, but yes, then it is up to him. So then it's his responsibility."*

Perceiving and matching relationship establishment preferences

Competence-based trust
Providers, especially physicians, expected trust to be mainly based on providing the right treatment, resulting in patient health and wellbeing. Providing clinical feedback – based on viral load and CD4 cell count – showed patients that the treatment is effective. This resulted in trust in provider competency, which was further increased, providers believed, by giving extensive and accurate information, for example about side effects and developments in medical treatments. Information should be up-to-date and detailed, because patients can get a lot of information on the internet.

According to providers, competence-based trust was further related to indicating to patients that they could always come up with questions or discuss certain issues, whenever they arise. This enabled patients to rely on the competence of the provider in times of need. This also built trust in the integrity of the provider by giving the message that the provider is there when needed, takes the patient seriously, and thus is genuinely involved and supportive.

Integrity-based trust
Providers believed that integrity-based trust was further built by talking about patients' everyday life, such as work or personal relationships. This served both to identify possible issues, and to establish trust. As mentioned under information exchange, trust is built by conveying empathy, honesty, taking the patient seriously, and being non-judgmental. Thus, providers built trust by communicating that patients would be fully accepted as they are, by a psychosocially and medically competent provider.

Providers realized that building trust is a process that takes multiple visits over time. According to providers, patients preferred to stay with the same provider to grow familiar. In the long term, providers and patients shared experiences and emotions during the ups and downs of the disease course, which could result in strong feelings of bonding and partnership. To further build integrity-based trust, providers aimed to give patients a sense of equality. Therefore, physicians might leave sensitive topics to the nurse, because they believe patients are more likely to experience equality when talking to the nurse. Nurses in particular said they functioned as a confidential advisor for patients, meaning counseling patients about sensitive issues while granting full confidentiality.

Perceiving and matching decision making preferences
Providers wanted to involve patients in decisions, because they expected this to increase treatment adherence as a result of commitment and shared responsibility. Also, treatment decisions that aimed to reduce intake barriers, such as side effects, require active input of patients. Adjusting the medication intake schedule to the patient's daily rhythm to facilitate adherence was the most common area for decisional involvement.

Shared decision-making dependent on patient
Providers believed that most patients do not like to be told what to do, and that being directive may hamper disclosure, trust and decisional involvement. Providers indicated that with most patients, the starting point was shared decision-making, and they then tailored the level of decisional involvement according to patient responses. According to providers, decisional involvement depended on patient preferences, and on patient health literacy.

Involving by informing
Providers said that most patients prefer to be involved by being informed about the reasons for treatment, and about consequences of the treatment, such as side effects and intake regime. Providers believed that most patients feel comfortable when the physician decides, and thus carries responsibility for the treatment, but at the same time justifies it to the patient. In their opinion, only a small minority of patients prefers to decide independently , for example based on internet information.

Cultural differences perceived by providers

Approaching cultural differences
Providers noted various cultural communication differences between Dutch, African and Caribbean patients, but emphasized that large individual differences exist

within groups. Providers indicated they had no special approach for each cultural group. Rather, their approach was basically the same for all patients, and tailored to the individual patient according preferences and capabilities.

Differences in disclosure
Concerning information exchange, providers noted that African patients were much less inclined to disclose personal issues about, for example, sexuality. This was because the stigma of having HIV is a much larger burden for African and Caribbean patients. Strong shame and guilt about having HIV hampered patients to talk about sensitive issues. As a result, providers needed to be much more active, e.g. through asking questions, to elicit personal issues. In addition, especially female providers noted that African men would never admit to having sexual problems, because of their pride towards women.

Language barriers
Providers also believed that language barriers might prevent patients to talk about personal issues, by preventing patients to speak freely about their thoughts and emotions. Also, providers said they had to be very clear when providing information or instructions, through repeating information and checking whether it had been understood correctly. Because Caribbean patients speak Dutch, providers perceived them to be culturally more similar to Dutch patients.

Little relationship differences
Although disclosure could be difficult, relationship establishment showed no large differences between cultural groups, according to providers. Especially for those feeling stigmatized, the provider acted as a confidential advisor, often because these patients talked to no one else about their HIV status. Providers realized that although African patients perhaps needed more stimulation, they were being open from their point of view. In addition, many African patients had been ill because of HIV, before they were being diagnosed and treated. Because they felt the physician had saved their life, they immensely trusted in provider competency.

Physician authority
Associated with high competence-based trust, African patients showed high reference for the physician as a medical authority. Providers expected this to lead to higher treatment adherence, but also to higher social desirability when answering questions, i.e. not disclosing non-adherence. African, but also Caribbean, patients are often religious and may express having faith in alternative treatments, such as herbs or faith healing, as a consequence of which they decide on their

own to stop following treatment. Providers indicated they had had to learn to take the religious perspective of patients into account during patient education.

Overview of themes
An overview of identified themes shows the different, but largely matching, approaches to communication goals of patients and providers (see Table 3.2). Moreover, themes interconnect such that openness and disclosure are important for information exchange, dependent on a trustful relationship, and enabling decisional involvement. Together, matching communication preferences helps patients to build and maintain a sense of control over their disease.

3.4 Discussion

Matching patient preferences through provider communication is beneficial to various patient outcomes, including treatment satisfaction, treatment adherence, and wellbeing (Kiesler & Auerbach, 2006). In this study we explored communication preferences of HIV patients on cART, and their experiences of matching or non-matching their communication preferences. We also explored provider beliefs about patient preferences, to compare patient and provider views on good communication practices.

Patient-provider communication is serves three broad goals: exchanging information, establishing a relationship, and involving patients in treatment decisions (Ong et al., 1995). Patient preferences regarding all three goals together indicated that patients communicate strategically with their providers, thus aiming to increase their sense of control over the physical and social threat of having HIV. Through relationships with their providers, patients further increase control over HIV by proxy. We termed these the second order goals of patient communication.

Matching information exchange preferences gave patients control by providing cognitive assurance, instrumental support and emotional relief. Matching relationship establishment preferences resulted in patients trusting their provider, disclosing their problems, and thus further increasing their control over issues currently on their mind. This is line with literature showing the importance of a good relationship, based on trust and support for HIV patient adherence (Vervoort et al., 2007).

When patients trusted the provider's medical competency, most patients preferred to diffuse responsibility for the treatment to the provider. Patients wanted

to be 'involved by being informed', having the provider to justify treatment choices and looking for agreement. This points to an ambiguity in patient preferences, because patients look for control but not responsibility, thus maximizing benefits and minimizing costs, a finding that has been described before (Ong et al., 1995). Similarly, providers were in two minds about patient involvement and responsibility. On the one hand, providers could be seen as trying to empower patients, by involving patients in treatment decisions, and trying to motivate, encourage and support patients to adhere to treatment, working from patient beliefs and preferences. On the other hand, when patients failed to adhere, providers shifted from a patient-centered approach to a more paternalistic approach, using risk communication about consequences of non-adherence. Providers justified this shift by stating that they work with the patient's best interest in mind. Apparently, a patient-centered approach worked for providers as long as it seemed to be effective, but they still communicated from the assumption that they know what is best for the patient, which is inconsistent with the tenets of the patient-centered approach (Bensing, 2000).

Further comparisons between patient preferences and corresponding provider perceptions showed many similarities. Providers were able to match patient preferences because providers were genuinely supportive and took the patient's life as the starting point for treatment and care. A minor discrepancy was that some patients preferred a provider that did not wear a white coat because it emphasizes asymmetry, while providers did not mention this. On the other hand, patients who did not mention this issue may associate the white coat with the doctor as a trusted authority.

When comparing preferences between patients from Dutch, Caribbean and African backgrounds, no strong cultural differences emerged, except for decisional involvement. Non-Western patients preferred their provider to make medical decisions, because they viewed their physician as a medical authority, and expressed high competence-based trust in provider and prescribed treatment.

Providers noted more cultural differences than a comparison of patient interviews indicated. At the same time, providers emphasized that individual differences were stronger or more important for communication. Providers generally perceived Caribbean and African patients to show more trust in medical authority. This may be associated with higher adherence; however, it may also lead to social desirable answering when being non-adherent. Faith in alternative treatments or religion as a cause of non-adherence is more common in non-Western patients. Another perceived cultural difference was the much greater burden

Table 3.2 | Themes of patient communication preferences and providers perceptions

Communication goal	Patients	Providers
Information exchange	• Personal medical information and clinical feedback • Psychosocial and behavioral issues	• Patient education • Establishing patient disclosure
Relationship establishment	• Trust and disclosure • Pat-provider relationship disturbing factors	• Competence-based trust • Integrity-based trust
Decisional involvement	• Being involved by being informed • High involvement in decision-making	• Involving by informing • Shared decision-making dependent on patient
Higher order goals of communications	• Establishing a sense of control	
		Cultural differences perceived by providers: • Approaching cultural differences • Differences in disclosure • Language barriers • Little relationship differences • Physician authority

of stigma for these patient groups, possibly hampering discussion of sensitive issues.

Our study contributes to the literature on several points, of which we will highlight the most important. The importance of sense of control, or mastery, for human behavior and wellbeing is well-known (Pearlin & Schooler, 1978). Sense of control is predictive of self-rated and objective health in late life, and consists of the perception that both outcomes (e.g., virus load), and thoughts and emotions (e.g., about being a HIV patient) can be controlled (Chipperfield et al., 2012). However, in the context of HIV, sense of control has not received much attention, but has been studied indirectly through the related concept of coping (Harding, Liu, Catalan, & Sherr, 2011; Moskowitz, Hult, Bussolari, & Acree, 2009). Coping, defined as efforts to deal with demands taxing or exceeding a person's resources (Lazarus & Folkman, 1984), is aimed at increasing sense of control over perceived stressors. Although the coping literature provides important knowledge about

effective and ineffective coping strategies, it does seem that the field may benefit from incorporating sense of control as an overarching concept. Theoretically, the coping literature is very heterogeneous (Moskowitz et al., 2009), and sense of control may help to integrate the multiple measures, outcomes and conclusions. Empirically, sense of control may be added to outcome measures, reflecting that it is a resource that negatively correlates with stressors (Mulder, de Bruin, Schreurs, van Ameijden, & van Woerkum, 2011).

Health locus of control is another control concept, referring to patients' beliefs whether their health is controlled by their own behavior (Internal), by fate or luck (Chance), or by important other people such as providers (Powerful Others) (Wallston, Wallston, & DeVellis, 1978). Although evidence indicates that a high Internal Health Locus of Control (IHLOC) is beneficial for adaptation to chronic illness and regimen adherence (O'hea et al., 2005), a recent study shows that HIV patients may benefit from a high Doctors Health Locus of Control (DHLOC), possibly depending on disease stage (Ruffin, Ironson, Fletcher, Balbin, & Schneiderman, 2012). Our study suggests that IHLOC and DHLOC may indeed be orthogonal, but interestingly, all patients value the sense of control by proxy over HIV through provider support. Moreover, patients try to balance internal control with provider control through their communication with providers. Thus, although high DHLOC may compromise IHLOC, from the patient perspective these two types of control can be seen as complementary and synergistic.

Our concept of 'patient autonomy' is closely related to the more broadly studied topic of patient empowerment, which has been defined as the process through which people gain greater control over decisions and actions affecting their health (Nutbeam, 1998). Our observations about the importance of patient autonomy are in line with this literature, but also seems to reveal in addition that empowerment does not mean simply sharing control with the patient. Rather, the patient can become empowered when control needs are served through provider communication, within a long-term, trustful relationship.

In line with Politi and Street (2011), our findings show that patients prefer decision making that is collaborative rather than shared. Even when patients are highly involved in decision making, they would like their provider to make the decision, and thus take responsibility.

Practice recommendations
Patient-provider communication may benefit when providers become aware that patients communicate strategically to increase or maintain their sense of control

over having HIV, while at the same time warding off responsibility. Patients further exert control 'by proxy' through information exchange within a trustful relationship, and having the provider take responsibility for the treatment.

Providers indicated that they sometimes used risk communication when patients showed resistance towards change. We recommend cautiousness when applying risk communication to increase adherence, first, because it may interfere with patient sense of control, and, second, because general risk communication may not be effective to change individual behavior (Edwards et al., 2000; Peters, Ruiter, & Kok, 2013).

Future research
Future studies should aim to elucidate sense of control in the context of having HIV and other chronic diseases, its effects on patient behavior and wellbeing, and how it can best be supported through health communication. Specifically, it is interesting how patient-centered care and responsibility relate to each other, and how this relationship may hamper or facilitate patient-centered care. From the patient's perspective, research could explore the relationship between sense of control and responsibility, for example, by studying how patients maximize the benefits of feeling in control and simultaneously minimize costs by not taking (full) responsibility, and the consequences of this behavior for patient-provider communication. From the provider's perspective, research could focus on the association between patient-centered care and taking responsibility for treatment and patient outcomes. For instance, studies could explore provider assumptions about taking responsibility for treatment outcomes to such extent that they feel a more paternalistic approach is justified.

Strengths & limitations
Interviewed patients were very satisfied with care and communication, whereas international studies often report dissatisfaction. For example, a large proportion of patients is dissatisfied with information provided about diagnosis, treatment options and related risks and consequences, and prognosis (Kiesler & Auerbach, 2006). The high satisfaction with care may originate from the high quality of HIV care in the Netherlands (de Bruin, Hospers, et al., 2010; Westert et al., 2010). Therefore, our study sample allowed much insight in what patients perceive as matching and the meaning thereof, but we were less able to explore the meaning of a mismatch between patient and provider.

Matching patient preferences could be limited when patients are not in a position to choose their own provider. In Dutch secondary care, new patients are automatically assigned to a provider, without being offered a choice. However, unsatisfied

patients have the right to switch providers; this is, however, quite uncommon, which can be because people are satisfied with their provider or not content but are unaware or dare not request for a change in health care provider.

A strong point of our study is the inclusion of patients from diverse cultural-ethnic backgrounds. However, the HIV patient population from academic hospitals in two large Dutch cities is inevitably different from other hospital populations. This may limit the applicability of findings to other settings.

A final limitation is the inability to draw conclusions from one interview per patient, and that patients retrospectively may give different meanings to their experiences as compared to at the time they were actually experienced.

Conclusion

Patients strategically communicate with their providers to increase their sense of control over having HIV. Differences in the ways patients exchange information, build a trustful relationship with the provider, and share treatment decisions are associated with individual approaches to optimize sense of control. Patient-provider communication may benefit when providers adopt a perspective of optimizing patient sense of control, for instance, by exploring how individual patients aim to do so.

Acknowledgements

Abstract

Many type 2 diabetes mellitus patients have difficulties reaching optimal blood glucose control. With patients treated in primary care by nurses, nurse communication plays pivotal role in supporting patient health. The twofold aim of the present review is to categorize common barriers to nurse-patient communication and to review potentially effective communication methods. Important communication barriers are lack of skills and self-efficacy, possibly because nurses work in a context where they have to perform biomedical examinations, and then perform patient-centered counseling from a biopsychosocial approach. Training in patient-centered counseling does not seem helpful in overcoming this paradox. Rather, patient-centeredness should be regarded as a basic condition for counseling, whereby nurses and patients seek to cooperate, and share responsibility based on trust. Nurses may be more successful when incorporating behavior change counseling based on psychological principles of self-regulation, e.g., goal setting, incremental performance accomplishments, and action planning.

4

Effective nurse communication with type 2 diabetes patients: A review

4.1 Background

Treatment of type 2 diabetes (T2DM) focuses on maintaining a low and stable level of blood glucose (glycemic control). Patients must achieve this by self-management of their diabetes, through a combination of following a healthy diet, engaging in regular physical activity – preferably leading to weight loss – and taking antidiabetic medication (Stone et al., 2010; Toobert, Hampson, & Glasgow, 2000). Unfortunately, less than 20% of T2DM patients reach all three targets for blood glucose (HbA1c), lipids levels, and blood pressure (Casagrande, Fradkin, Saydah, Rust, & Cowie, 2013). Many patients do not achieve the blood glucose goal (Barnett, 2004; Cleveringa, Gorter, van den Donk, & Rutten, 2008; Goudswaard, Stolk, Zuithoff, & Rutten, 2004; Harvey & Lawson, 2009). Changing diet is often experienced as the most difficult part of managing diabetes (Gorter et al., 2010; Rubin & Peyrot, 2001). Adhering to physical activity guidelines can be equally difficult, with at least 60% of diabetic patients being insufficiently active (Plotnikoff et al., 2006). Perhaps even more worrying, systematic reviews show that approximately 40% of people with diabetes take less than 80% of prescribed drugs, with an average adherence of 58% (Cramer, 2004; Cramer, Benedict,

Muszbek, Keskinaslan, & Khan, 2008). All in all, poor health behavior modification following diagnosis places diabetic patients at an increased risk of disease progression, impacting their quality of life, and increasing their risk of premature death (Asche, LaFleur, & Conner, 2011; Roebuck, Liberman, Gemmill-Toyama, & Brennan, 2011; White et al., 2012).

The question of what can be done to improve glycemic control of T2DM patients has been the subject of numerous studies. Intensive multifactorial interventions are effective in reducing cardiovascular risk factors in T2DM patients (Gæde et al., 2003; Hansen, Siersma, Beck-Nielsen, & Fine Olivarius, 2013). However, such interventions have been labeled as biomedical (Jarvis, Skinner, Carey, & Davies, 2010), because they focus on intensifying pharmacological treatment rather than on the psychological and social factors that underlie successful and sustainable behavior change in patients. It is therefore acknowledged that an important part of diabetes care is providing diabetes education to patients, with the aim of improving their self-management (or self-care) activities (Gorter et al., 2010; Thoolen, de Ridder, Bensing, Gorter, & Rutten, 2008). To varying degrees across countries, treatment of T2DM occurs mainly in primary care, with general practitioners' (GPs') practice nurses increasingly providing most of that care (den Engelsen et al., 2009; Edwall et al., 2008; Houweling et al., 2011; Juul et al., 2012). Nurse consultations aim to monitor patients' health and to support patients in self-managing their diabetes through diabetes education (Gorter et al., 2010). In general, this is done by measuring fasting blood glucose, weight (body mass index: BMI), lipids, and blood pressure, and then discussing the results in comparison to previous measurements. Patient health behaviors in the previous period (i.e., diet, physical activity, smoking, alcohol consumption, and medication use) associated with these biomedical outcomes are also discussed (e.g. Edwall, Danielson, Smide, & Öhrn, 2010). Thus, the practice nurse acts both as a medical expert on diabetes, and as a diabetes educator and a lifestyle counselor to support patient diabetes self-management. In their consultations with patients, nurses in primary care are therefore posed with the challenge to communicate with patients in such a way that the clinical risk profile of their patients is maximally improved, through supporting the patient in self-managing the disease. Therefore, nurses need to communicate with patients in such a way that patients actually change their behavior, resulting in improved clinical outcomes. Ideally, nurses apply communication techniques to change behavior based on psychological theories of behavior and behavior change (Abraham & Michie, 2008). Behavior theories commonly define concepts that cause or determine behavior (often referred to as determinants) that can serve as units of change, based on the premise that, if determinants of behavior are changed, behavior changes as a consequence

(Bartholomew, Parcel, Kok, Gottlieb, & Fernandez, 2011). For example, multiple theories such as the theory of planned behavior (Ajzen, 1991) and social cognitive theory (Bandura, 1986) posit that beliefs about the (positive or negative) outcomes of a certain behavior predict that behavior, i.e. are a behavioral determinant. Providing information about the outcome of a certain behavior – such as stating that physical activity lowers blood glucose and increases insulin sensitivity – is an example of a behavior change method.

However, patient-provider communication may even affect patient health directly, beyond its effect on behavioral determinants, and has thus been called by some a powerful placebo (Bensing & Verheul, 2010). For example, the provider may validate the patient's perspective, or express empathy for the patient's emotions. Non-verbal communication, such as eye contact or tone of voice, can provide comfort and cause patients to feel less anxious. This may also increase patient self-efficacy and empowerment, positively affecting self-management activities (Street, Makoul, Arora, & Epstein, 2009). Empowering patients through provider communication from a biopsychosocial perspective is a central tenet of patient-centered medicine (Bensing, 2000).

Despite the potential of communication to improve diabetes patients' health, in practice this is often very difficult. Not only because it is hard to persuade patient to change ingrained lifestyle patterns, but also because nurses (and other providers) are still primarily trained from a biomedical perspective. Hence, they are not accustomed to sharing responsibility for care with patients (e.g.Adolfsson, Smide, Gregeby, Fernström, & Wikblad, 2004). A comparison between barriers to communication and effective methods for communication would provide opportunities for identifying practical recommendations for improving communication with T2DM patients. Therefore, we aim, first, to review factors that may hamper effective nurse-patient communication during diabetes consultations. A second aim is to review empirical evidence for methods aiming to improve communication effectiveness of nurse consultations.

4.2 Methods

Search Method
We conducted a structured literature review to retrieve empirical articles on communication between nurse practitioners in primary care and T2DM patients. We searched the literature through Medline, PsycInfo, and Scopus. Search terms and their derivations used were: diabetes, diabetic, nurse, education, communication,

interaction, intervention, consultation, style, self-management, self-regulation, counseling, and patient-centered. As argued, standard care for T2DM patients often takes place in primary care, with nurses being responsible for diabetes education and lifestyle counseling. An important inclusion criterion, therefore, was nurses as the main healthcare providers, in a primary care setting. Other inclusion criteria were adult patients with T2DM, because communication with children and adolescents requires an altogether different approach. Because these inclusion criteria result in a rather specific area of research, we did not apply criteria to include – or exclude – specific research methodologies. A second reason is that communication between nurses and patients can be studied with diverse methodologies, each with its own pros and cons. That is why we included both qualitative and quantitative studies, in which communication was either observed or manipulated. Other inclusion criteria were:

- published in English
- studies published after 1990, to increase relevancy for current diabetes care practices in primary nursing care.
- Exclusion criteria were as follows:
- non-empirical papers, such as review or opinion articles
- specific patient populations, e.g. pregnant women, or patients suffering from depression
- telecare or telephonic consultations

Search Strategy
Our initial search yielded 548 hits. A review of titles and abstracts leaded to the exclusion of 492 articles, because these concerned adolescent patients, patients suffering from depression (or other psychiatric disorders), no primary care setting (e.g., intramural settings), or not a nurse as the main health care provider. This resulted in 56 papers we selected for full-text review. Scrutiny of full text articles lead to the exclusion of another 26 articles, because they were review papers, opinion articles, examined structural factors (e.g., concerning finances or facilities), had a mixed patient population consisting of both type 1 and type 2 diabetes patients, or provided insufficient information about the role of the nurse. Therefore, our review included 30 studies.

In line with our twofold aim, we categorized and analyzed the included studies according to the focus of their contribution:

1. Communication barriers:
   a. What are common barriers to communication?
   b. What are the consequences of these communication barriers?

2. Effective communication methods for nurses:
   a. What is the effectiveness of behavior change methods?
   b. What is the effectiveness of patient-centered methods?

Given the diversity of methodologies according to the inclusion criteria, effectiveness is reviewed in relation to multiple outcomes: behavioral determinants including patient communication preferences, communication behavior of both nurses and patients, patient health behaviors, clinical outcomes, and health and quality of life. We were interested in effectiveness in terms of (e.g.) statistical significant differences between experimental and control groups, but also in terms of subjective experiences of effects. Both for communication barriers and effective communication methods, data extraction focused on finding common themes across studies.

4.3 Results

From the total of 30 included articles, 13 articles described communication barriers in consultations between nurse practitioners and T2DM patients, and 17 articles described the effectiveness of communication methods in the nurse consultation. One article discussed in the methods effectiveness section is also referred to in the problem analysis (Jansink et al., 2013).

Communication Barriers
Of the included 13 studies, 7 studies employed an observational design using videotaping or audiotaping, four of which coming from a Finnish research group using an observational dataset from one large study (Karhila et al., 2003; Kettunen et al., 2006; Kiuru et al., 2004; Poskiparta et al., 2006). Two studies used interviews or focus groups with nurses (Adolfsson et al., 2004; Jansink, Braspenning, van der Weijden, Elwyn, & Grol, 2010), and another 2 articles used questionnaires (Jallinoja et al., 2007; Woodcock & Kinmonth, 2001). In two articles, combined methodologies were used (Koopman-van den Berg & van der Bijl, 2001; Pill, Rees, Stott, & Rollnick, 1999).

In all 13 studies (see Table 4.1) it is recognized that the root of the problem is having type 2 diabetes poses patients with a lifelong challenge to maintain glycemic control by adhering to health behavior guidelines. It is difficult for patients to change ingrained lifestyle patterns, and thus it is difficult for nurses to guide these patients towards behavior change and deal with their resistance. Specific barriers to effective communication during consultations are the physical examination,

nurses' lack of communication skills, or lack of confidence in these skills (i.e. low self-efficacy); nurses' loss of motivation; and their experiencing role conflict.

Physical examination
The physical examination, when for example blood pressure, weight, and blood glucose are checked, is often a central phase during nurse consultations, but this may itself present communication barriers. According to an observational study (Edwall et al., 2010), the patient's role may shift during physical examination from an active discussion into a passive, silent object undergoing examination. Also, when measurement of weight or waist circumference leads to embarrassment, this may present a communication barrier to both nurses and patients, i.e. avoiding the subject of overweight. Finally, when the physical examination does not indicate problems, this may prevent discussing self-management activities, because it is assumed to be unnecessary (Edwall et al., 2010).

Lack of communication skills and self-efficacy
Nurses' lack of communication skills are identified in self-reported studies, both through interviews (Jansink et al., 2010) and questionnaires (Jallinoja et al., 2007), and in observational studies (Karhila et al., 2003; Kiuru et al., 2004; Koopman-van den Berg & van der Bijl, 2001; Poskiparta et al., 2006; Sibley et al., 2011). Having insufficient knowledge about physical activity and diet recommendations may hamper effective communication. Other concrete skill deficits mentioned by nurses are having problems developing action plans, and not knowing how to tailor their communication to the patient's stage of change (Jansink et al., 2010). The subjective experience of not having sufficient skills may well be interpreted as nurses having low self-efficacy with regard to supporting patient self-management activities.
Loss of motivation Besides feeling powerless, repeatedly giving the same lifestyle advices without noticing any change in patients may lead to loss of motivation. Motivation to talk about health behaviors can also be impeded because nurses want to maintain a good relationship with patients, and feel uneasy about intervening in patients' health behaviors (Jallinoja et al., 2007; Jansink et al., 2010).

Role conflict
A final barrier lies in nurses experiencing a role conflict when applying a patient-centered consulting style, such as motivational interviewing (MI; see the next section for effectiveness). Studies testing the effectiveness of patient-centered communication have interviewed trained nurses to collect their experiences with the method. Interviews reveal that, as a healthcare provider, they want to have a certain authority and to be seen as an expert in order to give health infor-

mation that is perceived as valuable and trustworthy, but the expert role collides with maintaining a patient-centered perspective during the consultation (Adolfsson et al., 2004; Kettunen et al., 2006; Pill et al., 1999). Nurses do not feel confident when they have to switch from being an expert to being a facilitator of the patient's change process. Partly because they feel responsible for the patient's clinical outcomes, nurses want to maintain their control as experts (Adolfsson et al., 2004; Pill et al., 1999). In addition, nurses mention time constraints as a barrier, with patient-centered methods leading to even greater demands on time (Edwall et al., 2010; Jansink et al., 2013; Jansink et al., 2010; Woodcock, Kinmonth, Campbell, Griffin, & Spiegal, 1999).

Consequences of communication barriers
Multiple issues can be noted as a result of communication barriers. Nurses may not discuss health behaviors, or apply limited communication skills and styles if they are discussing health behaviors. As a consequence, patients are not persuaded or supported to change their behavior, and patient self-efficacy is not increased. Patients' worries and concerns, that may impede behavior change, are not identified. In fact, patient resistance is often rejected by nurses, going against principles of patient-centeredness.

Limited variation of communication methods
Mostly related to lack of communication skills and self-efficacy, nurses report that sometimes they altogether avoid bringing up the issue of health behavior change during consultations (Jansink et al., 2010). Interviews and observational studies show that, when nurses discuss health behaviors, including medication use, they apply limited communication methods, often providing a recommending style, simple information and advice (Jansink et al., 2010; Kiuru et al., 2004). Such discussions are often instruction-based and instrumental, based on the biomedical model (Karhila et al., 2003; Sibley et al., 2011). Trying to persuade the patient to follow the advice, or supporting the patient to change their diet by actively discussing their past and current change attempts, their concerns, and resources, and giving feedback and praise seem underused styles. Using a supportive style would allow for tailored advice giving and might help to empower patients (Kiuru et al., 2004).

Similarly, nurses are observed to underuse methods to increase patients' self-efficacy. Of Bandura's (Bandura, 1977) four methods to increase self-efficacy, only verbal persuasion is commonly used, whereas self-evaluation, performance accomplishments, and vicarious experience are hardly applied (Koopman-van den Berg & van der Bijl, 2001), although the latter two are considered the most

effective methods (Bandura, 1977). Also, goal setting is almost never applied, in contrast to nurses' self-reports (Koopman-van den Berg & van der Bijl, 2001). Not setting concrete goals is an important common theme across studies, as well as the finding that action plans, i.e. formulating concrete ways to reach behavioral goals, are often not made (Jansink et al., 2010; Karhila et al., 2003; Kiuru et al., 2004; Koopman-van den Berg & van der Bijl, 2001; Poskiparta et al., 2006).

Seldom discussing or identifying patient concerns
Individual patient concerns about the disease or treatment may hamper self-management; however, it is observed that patient concerns are seldom a subject of discussion during consultations (Kiuru et al., 2004; Poskiparta et al., 2006; Sibley et al., 2011). A questionnaire study found that, after one year of counseling, nurses identify the main concerns of individual patients in only 20% of cases (Woodcock & Kinmonth, 2001).

Controlling communication
Moreover, patient resistance (possibly related to their concerns, e.g., about how to deal with recommended behavior change) to advice and recommendations is often met with rejection by nurses (Jansink et al., 2010; Karhila et al., 2003; Kiuru et al., 2004). This may be related to nurses' beliefs that patients are often unwilling to change their behavior because of a lack of motivation, and lack of insight into their own health behaviors (Jallinoja et al., 2007; Jansink et al., 2010). Rejection of patient resistance may have adverse effects, as an early observational study showed a positive relationship between nurses' use of controlling and directive communication, characterized by the nurse issuing recommendations and orders, and interrupting or disagreeing with the patient, and patients' average follow-up blood glucose levels (Street et al., 1993). A patient-centered style can be defined as 'using verbal and nonverbal behaviors that show respect for the patient's feelings and concerns, encourage the patient's participation in the consultation, and indicate an interest in the patient's opinions' (Street et al., 1993, p. 715). When nurses use a patient-centered style, patients express more feelings and showing more decision-making behavior. However, from this study it remains unclear whether nurses' controlling communication was a response to patients' problems with adhering to the prescribed regimens and resulting poor clinical outcomes, or actually contributed to poor glycemic control.

Effectiveness of Communication Methods
Of the 17 articles examining communication methods, 12 concerned methods based on patient-centeredness, while another five studies examined behavior change methods.

Effectiveness of Behavior Change Methods
Although very little studies have examined the effectiveness of theory-based behavior change methods in the diabetes nursing practice, results seem promising in terms of changing behavior, or determinants thereof. However, improvements in clinical outcomes have not yet been reported. Of the five included studies, two are RCTs (Farmer et al., 2012; Sturt et al., 2008), with Sturt et al. (2008) having done an earlier pilot study using a quasi-experimental design (Sturt, Whitlock, & Hearnshaw, 2006). Additional evidence comes from two observational studies (Bundesmann & Kaplowitz, 2011; Schlenk & Boehm, 1998).

Farmer et al. (2012) tested the effects of a nurse-led, single-session intervention on patients' adherence to taking their oral antidiabetic medication. The intervention was based on the theory of planned behavior (Ajzen, 1991), and aimed to increase motivation by targeting attitudes, social norms, and perceived behavioral control. The results showed an increase in medication adherence, with no adverse effects on satisfaction with treatment or communication. However, the intervention had no effect on average blood glucose, according to the authors because the purpose was to measure short-term efficacy in terms of behavior change (Farmer et al., 2012).

The RCT from Sturt et al. (2008) targeted health behavior determinants from Bandura's (1977) self-efficacy theory. Methods of goal achievement and goal evaluation were employed to show lower diabetes-related distress and increased diabetes self-efficacy among intervention patients. However, after six weeks, blood glucose and other cardiovascular risk factors did not differ between intervention and control group (Sturt et al., 2008), in contrast to the uncontrolled Phase I trial where the eight T2DM patients did show a modest decrease in average blood glucose (Sturt et al., 2006).

Results from the observational studies provide some additional evidence for strategies based on social cognitive theory (SCT) (Bandura, 1986). In the intervention group of an RCT testing the effectiveness of contingency contracting, nurses rated what strategies patient deployed to successfully perform contracted health behaviors. Breaking the behavior into steps and self-monitoring the behavior were the strategies most frequently deployed to subsequent successful performance of diet behaviors. Breaking the behavior into steps was the most frequently used strategy to successfully perform exercise, and self-monitoring was the most frequently used strategy to successfully perform blood glucose monitoring (Schlenk & Boehm, 1998).

Table 4.1 | Summary of studies analyzing problems in health behavior communication between primary care practice nurses and T2DM patients

Study	Sample/Design	Variable(s) measured	Results/Conclusions
Adolfsson et al. (2004)	Swedish primary care physicians (n=5) and nurses (n=11) participated in focus group interviews.	Physicians' and nurses' views on implementing empowerment group education in diabetes; opportunities and barriers.	A central theme was conflicting roles, especially between the traditional role as a physician/nurse and the empowering role. Traditional meant giving advice and recommendations; empowering meant listening, using open questions, and stimulating patients to find their own solutions to self-care problems. This shift caused feelings of insecurity. It was especially difficult to set goals and make a concrete action plan. Empowerment method was felt to be more exhausting and time-consuming.
Edwall et al. (2010)	Swedish patients (n=20) from two nurse-led diabetes clinics. Observational study: annual check-ups were recorded on videotapes.	Initiation and performance of the interaction during the physical examination in annual diabetes check-ups.	Patients are active participants during annual check-ups, initiating discussion about their thought and concerns. The check-up is characterized by cooperation between nurse and patient. Discussion of self-management behaviors could be improved, e.g., by discussing self-management even when no problems are identified.
Jallinoja et al. (2007)	Finnish primary care physicians and nurses (n=220). Questionnaire study.	Practices of, and attitudes to, lifestyle counseling.	Information provision, motivating, and supporting patients are considered tasks. Slightly more than half of providers estimated they have sufficient lifestyle counseling skills for these tasks. Other barriers: time constraints and feeling uneasy with intervening in patients' health behaviors. When patients have difficulties changing their behavior, this is seen by providers as unwillingness.
Jansink et al. (2010)	Dutch primary care nurses (n=12). Semi-structured, in-depth interviews.	Barriers in counseling patients about diet, physical activity, and smoking cessation.	Barriers at nurse level: Lack of communication skills and skills to make concrete action plans. Lack of specific knowledge about diet and physical activity. Lack of motivation due to repeating the same message and lack of effectiveness thereof. Time constraints. Barriers at patient level (as perceived by the nurse): Lack of knowledge of guidelines for healthy lifestyle, and lack of insight into discrepancy between guidelines and actual behavior. Unwillingness to change, sometimes stemming from negative experiences with dietician. Lack of skills to change due to low income and/or physical disabilities. Compliance-related barriers: lack of immediate results, self-discipline. Stress situations and social pressure leads to relapse.
Karhila et al. (2003)	Finnish T2DM patients (n=18) and their nurses (n=5). Observational study employing videotaped counseling sessions (n=73).	Negotiation of lifestyle behavior change.	The process of negotiation was mainly controlled by the nurses. Goal setting was not used by nurses, nor were concrete action plans made. Patients' resistance did not lead to alternative seeking, but resulted in nurses trying to persuade patients, or accepting patients' decision not to conform.
Kettunen et al. (2006)	Finnish case study, with eight videotaped recordings from consultations from one nurse with a single patient, over the course of two years.	The processes of how the nurse initiated change talk, how the patient responded to this, and how communication produced change talk.	Three types of change talk were identified: rejected, restrictive, and expansive. When the nurse produced a medical agenda, this led to rejected change talk, with missed opportunities for talking about lifestyle change. Restricted and expansive change talk occurred within orientation towards the patient's agenda. Restrictive change talk was observed when the patient was taciturn and generally not motivated to talk about change. Expansive change talk was observed when the nurse stayed within the patient's frame of reference, combined with using reflective questions, encouragements, and creating space in the conversation.
Kiuru et al. (2004)	Finnish T2DM patients (n=18) and their nurses (n=5). Observational study employing videotaped counseling sessions (n=55).	Communication styles and the elements of dietary advice giving by nurses. The way this advice is received by patients.	Dietary advice-giving by the nurses can be categorized into four different styles: recommending, persuasive, supportive, and permitting. The recommending style is the dominant style (51.7% of speech episodes) and consists of suggestions and recommendations concerning patients' diet. The recommending style can be seen as neutral and not raising (much) resistance. However, this may also lead to patients underestimating the importance of following the advice, and lacks the development of concrete and detailed action plans, tailored to the patient's personal situation. Nurses were not eager to clarify the problems and concerns surrounding patient's defensive reactions, and resistance was often rejected by nurses. The supportive style seems underused (13.3% of speech episodes), because it is characterized by exploring patients' concerns, and asking questions about their resources to follow the advice, as well as positive feedback and encouragement. This allows for tailored advice-giving, and may have the potential to empower patients.

Table 4.1 | Continued

Study	Sample/Design	Variable(s) measured	Results/Conclusions
Koopman-van den Berg & van der Bijl (2001)	Dutch nurse diabetes educators (n=261) filled out a questionnaire. Of four of these nurses, their educational programs were observed using a semi-structured observation list. Self-reported answers from the questionnaire were compared with findings from the observations.	Frequency of the use of self-efficacy-enhancing methods by nurse diabetes educators.	Categorization of methods was based on Bandura's four sources of self-efficacy (enhancing) information: performance accomplishments, modeling, verbal persuasion, and self-evaluation. According to self-report, performance accomplishments were used most frequently and modeling strategies the least. However, results from the observations diverged from self-report: practicing skills and setting goals (part of performance accomplishments method) were self-reported but not observed. Most frequently observed technique was verbal persuasion.
Pill et al. (1999)	British nurses (n=18). Combined data gathering: audiotaped recordings of consultation and interviews with the nurses.	Reasons for self-reported inability to change consulting style, after nurses had received intervention.	Main reason was that nurses felt responsible for their patients' health, especially when clinical results were suboptimal. This prevented nurses granting autonomy to their patients, thus going against one of the premises of patient-centered care and communication.
Poskiparta et al. (2006)	Finnish T2DM patients (n=17) and their physicians (n=7)/nurses (n=5). Observational study employing videotaped counseling sessions (n=129).	Frequency and duration of dietary fat and physical activity speech. Content of dietary fat and physical activity counseling was analyzed, as well as initiations of counseling and provision of feedback.	Dietary fat and physical activity counseling was present in 2/3 of nurses' consultations. Hindering or facilitating factors for lifestyle behaviors as brought up by patients were often not followed up by professionals. Discussions were often characterized by minimal feedback from one party on the comments of the other party. Nurses' communication skills were limited, particularly their ability to develop concrete, detailed plans to implement lifestyle advice.
Sibley et al. (2011)	British nurse prescribers (n=20) audio-recorded 59 consultations with both type 1 and type 2 DM patients.	The facilitation of effective medicine-taking in diabetes.	Consultations are primarily instruction-based, with limited variation in the discussed themes. Nurses were focused on instrumental, task-oriented discussion, and neglected patients' concerns or beliefs about medicine taking. Affective discussions of making sense of medication use, and self-assessed medication-taking deserve much more attention.
Street et al. (1993)	US non-insulin dependent diabetes mellitus patients (n=47). Nurse-patient interactions were audiotaped; coded communication behaviors were scored as frequencies and associated with blood glucose at follow-up.	The association between nurses' communication style and patients' metabolic control.	Controlling and directive nurse communication was associated with poorer metabolic control at follow-up (9-12 weeks later). Causality is not determined: nurses' controlling communication may be a response to patients' problems. The other explanation is that controlling communication hinders participative decision making and stops patients from taking an active self-management role.
Woodcock et al. (2001)	British patients (n=250) and their practice nurses (n=64). Questionnaire study: open question (main concern), followed by checklist.	The differences between patients' and practice nurses' perceptions of patients' main concerns.	Nurses' perceptions of what patients worry about are quite different from what patients report. Common concerns of patients are fear of getting worse and damage caused by diabetes, but practice nurses rank these concerns lower. Many concerns remain unidentified by nurses.

A second observational study showed that if patients recalled getting information on how to perform one of the self-care behaviors, this significantly increased the odds of patients reporting performing that behavior. Modeling, such as when the healthcare provider examined the patient's feet, also greatly enhanced the odds of patients examining their feet. When patients recalled both having received information and the healthcare provider modeling the behavior, odds ratios were multiplied for feet self-examination The authors suggest that modeling teaches patients how to perform the behavior, thus increasing their skills and/or self-efficacy (Bundesmann & Kaplowitz, 2011). However, this study is based on cross-sectional data, thus causality could be inversed.

Effectiveness of Patient-Centered Methods
Of the 12 articles concerning patient-centered methods, eight reported the effects of introducing patient-centered counseling. Six articles reported the effects of four studies training nurses in motivational interviewing (MI) (Britt & Blampied, 2010; Heinrich, Candel, Schaper, & de Vries, 2010; Jansink et al., 2013; Jansink et al., 2013; Pill et al., 1998; Stott et al., 1996) (see Table 4.2). MI is a directive patient-centered method, based on exploring and resolving the patient's ambivalence about behavior change in order to increase intrinsic motivation (Rollnick, Miller, & Butler, 2008). Another study, reported in two articles, used a different patient-centered strategy (Kinmonth, Woodcock, Griffin, Spiegal, & Campbell, 1998; Woodcock et al., 1999). Of the five studies aiming to test the introduction of patient-centered counseling, four were randomized controlled trials (RCTs) (Heinrich et al., 2010; Jansink et al., 2013; Kinmonth et al., 1998; Pill et al., 1998), whereas one study employed a quasi-experimental design (Britt & Blampied, 2010). Finally, we included four articles that examined effective counseling methods from the patient's perspective using interviews (Edwall et al., 2008; Moser, Houtepen, Spreeuwenberg, & Widdershoven, 2010; Moser, van der Bruggen, Widdershoven, & Spreeuwenberg, 2008) or focus groups (Nagelkerk et al., 2006).

Results of the patient-centered counseling trials are less than positive. First, nurses report declining enthusiasm for applying MI during trials, despite their initial positive expectations (Pill et al., 1998; Stott et al., 1996; Woodcock et al., 1999). Pill et al. (1998)[2] even report the effectiveness evaluation of their trial failed, because two years after the start of the intervention, only 19% of clinicians in the experimental group still actively put the method into practice. Other studies also show that it is difficult – though not impossible – to increase nurses' MI skills through training (Britt & Blampied, 2010; Jansink et al., 2013).

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2 The intervention was not labeled as MI; however, the pilot study reported by Stott et al. (1996) does explicitly mention that motivational interviewing is the technique applied.

When MI training does improve nurses' communication behaviors, this may lead patients to report or show more active communication with their nurse, and greater wellbeing and treatment satisfaction after one year follow-up (Britt & Blampied, 2010; Kinmonth et al., 1998; Pill et al., 1998; Woodcock et al., 1999). Even improvements in knowledge and chance locus of control are reported (Heinrich et al., 2010), although Kinmonth et al. (1998) report lower patient knowledge scores in the intervention group compared to the control group. However, patient clinical outcomes, such as blood glucose, blood pressure, blood lipids do not improve (Heinrich et al., 2010; Jansink et al., 2013; Pill et al., 1998) – or even deteriorate (Kinmonth et al., 1998) – in the intervention groups receiving MI-based diabetes care compared to the control groups in all included studies. This also goes for behavioral outcomes such as fat intake, vegetable and fruit intake, smoking, and physical activity (Heinrich et al., 2010; Jansink et al., 2013; Kinmonth et al., 1998; Pill et al., 1998).

Another set of patient-centered studies focus on patient autonomy support (Edwall et al., 2008; Moser et al., 2010; Moser et al., 2008). The rationale is that, in a shared-care setting, both patients and healthcare providers are responsible for the patient's health. To become active participants in their own care, patients need autonomy to be able to actively make choices (Moser, van der Bruggen, & Widdershoven, 2006), an assumption that lies at the root of patient-centered medicine (Bensing, 2000; Street et al., 1993).

All the studies used in-depth interviews with patients and thus do not provide outcomes of the effects of autonomy (support) on health behaviors or clinical outcomes. Instead, studies examined how patients perform self-management activities, and how nurse communication can augment patient strategies (Moser et al., 2008); how patient autonomy can be supported by nurses through their relationship with patients (Moser et al., 2010); and how patient self-management is supported by regular check-ups by the nurse (Edwall et al., 2008).

A core process of autonomy is self-management, defined as patients' activities relating to taking care of their health and diabetes, including skills and decision making (Moser et al., 2008). Patients' self-management activities included keeping to a diet and exercising. Because of the complex and ever-changing nature of diabetes and associated self-management, nurse communication is very important in supporting patients with their self-management activities. Specifically, nurse care helps patients by confirming, monitoring, and modifying self-management strategies, thus helping patients to develop individualized self-management skills (Moser et al., 2008).

Table 4.2 | Summary of studies testing effectiveness of communication methods and/or behavior change interventions

Study	Sample/Design	Variable(s) measured	Results/Conclusions
Britt & Blampied (2010)	New Zealand patients (n=18). Quasi-experimental intervention study; 9 patients in motivational enhancement therapy (MET) group (4 sessions), and 9 in patient education (PE) group. All session (MET and PE) were audiotaped.	Differences between MET and PE group regarding practitioner communication behaviors and patient communication behaviors.	MET is a four-session form of MI. After training, nurses used more open questions, reflections, and MI-adherent responses compared to baseline. It was relatively hard for nurses to reach beginner proficiency in MI skills. The amount of patients' change talk increased during sessions, in line with MI theory.
Bundesmann & Kaplowitz (2011)	US patients (n=1438) were interviewed through telephone (computer assisted telephone interview; CATI).	The association between nurses' communication about self-care (as reported by patients) and patients' self-reported self-care behaviors.	Self-care information and modeling by nurses is positively associated with patients' self-care behaviors, notably performing blood glucose monitoring, foot examinations, and amount of exercise.
Edwall et al. (2008)	Swedish patients (n=20) at two nurse-led diabetes clinics. Interview study using broad, open questions.	Patients' experiences with regular check-ups by the diabetes nurse specialist.	Patients expressed the importance of regular check-ups in helping them self-managing their disease. Four interlinked themes were identified through patient responses: being confirmed, meaning being seen as a unique person, being listened to and believed. This is necessary for openness and collaboration with the nurse. Second, being guided, being regularly reminded and updated with knowledge about the disease and its treatment. Third, nurses helped patients to become confident and independent. Finally, being relieved from feelings of anxiety and loneliness in dealing with diabetes.
Farmer et al. (2012)	British patients (n=211). Randomized controlled intervention study of behavior change methods.	The effects of a theory-based behavior change intervention on patients' medication adherence.	Medication adherence improved significantly; treatment satisfaction was unaffected. Clinical outcomes are awaited from follow-up trial.
Heinrich et al. (2010)	Dutch patients (n=584) from 36 general practices. Randomized controlled intervention study of MI.	Patient outcome measures: quality of life, self-efficacy, knowledge, chance locus of control, blood glucose, lipid concentrations, BMI, blood pressure, fruit/ vegetable intake, physical activity.	Follow-up measurements after 12 and 24 months indicated adverse intervention effects on blood glucose and fat intake. Positive intervention effects were found for knowledge and chance locus of control. For other outcomes, no intervention effects were found.
Jansink et al. (2013)	Dutch practice nurses (n=65). Randomized controlled intervention study of MI.	Increase in MI skills after training, compared to control group.	MI training had minimal impact on lifestyle counseling at one-year follow-up. Of a total of 24 MI skills, only two skills showed significant improvement. In addition, when nurses did show MI skills, this was associated with increased consultation time.
Jansink et al. (2013)	Dutch patients (n=521) from 53 general practices. Randomized controlled intervention study of MI.	Patient outcome measures: blood glucose, lipid concentrations, BMI, blood pressure, fat/fruit/ vegetable intake, physical activity, quality of life, readiness to change.	A comprehensive diabetes program, including MI, did not have significant effects on any of the behavioral, clinical, or quality of life outcome measures. The authors question the applicability of MI to improve the effectiveness of diabetes care.
Kinmonth et al. (1998)	British patients (n=250), from 41 practices, in RCT of patient-centered care.	Patient outcome measures: quality of life, wellbeing, blood glucose, lipid concentrations, BMI, and blood pressure.	After one-year follow-up, patients in the patient-centered intervention group reported better communication with care providers, great wellbeing, and treatment satisfaction. Blood glucose did not differ between groups, and knowledge scores were lower, and weight and blood triglyceride levels were higher, in the intervention group.

Table 4.2 | Continued

Study	Sample/Design	Variable(s) measured	Results/Conclusions
Moser et al. (2008)	Dutch patients (n=15). Interview study using broad, open questions.	Patients' understanding and experiences of self-management in a nurse-led care program.	Patients want to maintain a sense of autonomy while self-managing their diabetes on a day-to-day basis. Commonly, patients develop several self-management strategies, called daily, off-course, and preventive self-management. Nurse support is very helpful, especially when it helps patients develop the skills to autonomously manage their diabetes.
Moser et al. (2010)	Dutch patients (n=15). Interview study using broad, open questions.	Processes that support autonomy in the relationship with their nurse and family, as perceived by patients.	When relationships are perceived as being supportive, this helps maintain patients' autonomy. Three processes are part of this: preserving patterns of concern and interactions, nurturing collaborative responsibilities, and being engaged in trustful and helpful family relations.
Nagelkerk et al. (2006)	US patients (n=24) participated in three audio-taped focus groups.	Barriers and effective strategies for self-management, as perceived by patients.	Most important barrier was lack of knowledge of specific diet plan. Effective strategies named by patients were collaborative relationship with nurse, which also promotes fostering a positive attitude and proactive learning. This is also stimulated by discussing feelings and fears.
Pill et al. (1998)	British practices (n=29), and their patients (n=190). RCT of patient-centered care.	Effects of motivational interviewing-based consultation training on clinical outcomes (blood glucose) of patients.	Two year after the start of the intervention, only 19% of clinicians were still applying the method systematically. There were (thus) no effects on patients' clinical outcomes.
Schlenk & Boehm (1998)	Data from a larger trial were used, with US patients (n=117).	The strategies patients use to complete self-care behaviors as described in contingency contracts.	Frequent behavioral strategies used by patients to perform dietary and exercise behaviors were breaking the behavior into steps and self-monitoring the behavior.
Stott et al. (1996)	British family physicians (n=30), practice nurses (n=33), and patients (n=200). Questionnaires and two focus groups.	Testing the uptake and acceptability of visual aids based on motivational interviewing.	Changing consulting behavior is not easy for physicians or for nurses. All the clinicians accepted two or more training sessions. Nurses in particular expressed high engagement with the method. Visual aids were used frequently by the majority of clinicians.
Sturt et al. (2006)	British patients (n=8) in a small, Phase I trial with pre-post measurements.	Effects on patients' self-efficacy and blood glucose.	Self-efficacy improved, and blood glucose decreased. Some patients reported a decrease in treatment satisfaction, and nurses found intervention time-consuming.
Sturt et al. (2008)	British patient (n=245) from 48 practices in RCT of nurse-led behavior change intervention based on social cognitive theory.	Patient outcome measures: blood glucose, blood pressure, blood lipids, diabetes related distress, diabetes self-efficacy.	After 6 month follow-up, no effects on blood glucose or other clinical outcomes. Patients in the intervention group reported lower diabetes-related distress and increased diabetes self-efficacy.
Woodcock et al. (1999)	Same study as reported by Kinmonth et al. (1998): 41 British practices, in RCT of patient-centered care.	Effects on caregivers' attitudes towards patient-centered care and patient-centered behaviors. Behaviors were self-reported and rated by patients.	Patients were more satisfied with care from trained than comparison nurses. However, compared to the control group, trained nurses lost motivation for the patient-centered approach over time; perceived time constraints; and their self-efficacy to deliver patient-centered care declined. Important aspects of standard care were rated lower by trained nurses.

These authors later examined how autonomy can best be supported within the patient-nurse relationship. Autonomy is fostered by supportive communication patterns, characterized by empathic interaction with the patient, and authentic concern for the patient's wellbeing and personal situation. Second, patients feel supported when they can share responsibility for their care with members of their healthcare team, and when the various healthcare providers collaborate, e.g., through coordination by the nurse (Moser et al., 2010).

These results are mirrored by an interview study about patients' experiences with the regular check-ups by the diabetes nurse (Edwall et al., 2008). For patients to continuously self-manage their diabetes in daily life, it is important that they regularly receive practical and emotional support from a nurse whom they trust. Patients feel they can trust nurses when these approach the patient as a unique individual, by listening to and believing the patient. This helps patients to be open to the nurse about problems and concerns, so that they can take responsibility for their own health. Regular check-ups also ensure maintaining and increasing knowledge of diabetes and its treatment, with the help of feedback from the nurse. Nurses' support provides patients with the resources to independently (or autonomously) manage the disease (Edwall et al., 2008).

Finally, a study employing focus groups with T2DM patients also highlights the importance of a positive, collaborative relationship with the healthcare provider for encouraging confidence and taking responsibility for self-management (Nagelkerk et al., 2006).

4.4 Discussion

The inability of patients to perform sufficient self-management behaviors and attain glycemic control poses primary care nurses with the challenge of effectively supporting T2DM patients' self-management activities. The aim of this review was, first, to identify barriers that have been found to hinder communication. A second aim was to identify methods that can be effective in improving effective communication between nurses and T2DM patients.

Based on our findings, we were able to categorize common communication barriers as the context of the physical examination, a lack of nurses' communication skills and self-efficacy, loss of their motivation, and nurses experiencing a role conflict when adopting a patient-centered perspective. As a result of these barriers, nurses may abandon discussion of patient self-management altogether,

or simply communicate by providing general advice. Specifically, nurses often do not set behavioral goals with their patients. Perhaps more worryingly, nurses may resort to rejecting patient resistance, controlling communication, and (thus) not identifying or addressing patients' worries and concerns.

As a response to these problems, many authors have called for patient-centered counseling. However, our results indicate that the application of patient-centered counseling (such as MI) by nurses in diabetes care has been found to be ineffective, in addition to being time consuming, incompatible with nurses' perceptions of professional responsibilities, and difficult to properly apply. This is in line with a systematic review on the effectiveness of modifying patient-provider interaction, in which the authors conclude that changing provider behavior is difficult to sustain and mostly ineffective (van Dam, van der Horst, van den Borne, Ryckman, & Crebolder, 2003). It is much more effective to focus on enhancing the interaction by increasing patient participation and empowerment (van Dam et al., 2003).

Although there have been provocative calls for a new era in which diabetes self-management focuses more on medication adherence than on diabetes education and patient-centered care (Rutten, 2005), the biomedical approach remains subject to debate, for instance because of concerns about increasing polypharmacy (Hunt, Kreiner, & Brody, 2012). This also relates to two seemingly paradoxical trends in medicine, namely, that medicine is striving to become both more evidence-based and more patient-centered (Bensing, 2000). These two approaches may be difficult to combine, because evidence-based medicine generally leads to standardized treatment guidelines and protocols that are often not compatible with the shared decision-making principles of patient-centered care, as promoted by the American Diabetes Association and European Association for the Study of Diabetes (Inzucchi et al., 2012). This paradox provides the context in which many of the communication barriers we have identified occur. Nurses feel responsible for patient clinical outcomes, but they are dependent on the self-management activities of the patient. Through the physical examination, nurses have to confront the patient with biomedical information, but then they have to take a patient-centered approach from the biopsychosocial model to educate patients to self-manage themselves. With such an inherent contradiction to start with, also noted in other studies (Rhodes, Langdon, Rowley, Wright, & Small, 2006), it is small wonder that nurses experience a role conflict and lack confidence in their communication skills, and over time loose motivation to thoroughly discuss self-management activities. Loss of motivation and feelings of powerlessness even leaves nurses at an increased risk for burnout (Allen & Mellor, 2002).

Lack of skills and low self-efficacy are not overcome by courses in patient-centered counseling skills. These courses are often short and without the needed continuous guidance to acquire these complex skills. Instead, such courses may even result in nurses being confronted with their lack of communication skills, and with the difficulty of acquiring these skills on a professional level, leading to even lower self-efficacy. Instead of introducing special counseling skills, the second half of our review about effective communication methods provides suggestions for practical applications and future research.

We found some evidence that, during standard consultations, nurses can effectively apply behavior change methods that are based on behavioral theories, such as the theory of planned behavior (Farmer et al., 2012) or social cognitive theory (Bundesmann & Kaplowitz, 2011; Schlenk & Boehm, 1998; Sturt et al., 2006; Sturt et al., 2008). Although these studies did not report effects on clinical outcomes, self-management and determinants thereof improved. More studies are required to test the efficacy of behavior change methods applied by nurses during standard consultations. Preferably, the selection and application of behavior change methods should not be based on a single theory, as currently seems to be the case, but on an analysis of the determinants of self-management behaviors using multiple behavioral theories (Bartholomew et al., 2011). Recent studies suggest that a framework of self-regulation, which is a broad term for all (sequences of) goal-directed actions, and the underlying psychological processes of goal pursuit (Carver & Scheier, 1982, 1998), are important for diabetes self-management. A meta-analysis (Huisman, De Gucht, Dusseldorp, & Maes, 2009) has shown the importance for weight loss and/or blood glucose control of using self-regulation principles such as adjusting goals when patients set unrealistic weight loss goals. Another study (Huisman et al., 2009) found that a summary score for patients' self-regulation skills predicted lower blood glucose levels. Thus, in line with a recent review (Mann, de Ridder, & Fujita, 2013), we propose that nurse communication may benefit from nurses having knowledge about self-regulation processes, and the strategies that can help patients boost self-regulation or overcome known barriers to self-regulation.

Conditions for effectively implementing interventions include helping patients find a balance between adhering to the treatment and maintaining their own individual lifestyle by continuously providing practical and emotional support, and helping them maintain positive self-evaluations (Edwall et al., 2008; Moser et al., 2010; Moser et al., 2008). In general, patients want to live an autonomous life as diabetics by sharing responsibility for their diabetes and its treatment, in collaboration with their nurse and their family, whom they trust, and to whom they can fully

disclose their problems, struggles, and failures relating to their self-management, all of which is essential for successful self-management.

Conclusion and Implications for Practice and Research

Although nurses' lack of communication skills and lack of self-efficacy in communicating with resistant T2DM patients have been established both objectively and subjectively, training in patient-centered counseling techniques does not seem to be the answer. Rather, we propose a combination of actions to tackle this serious issue.

First, there should be general awareness that nurses work in a context where they have to be both focused on biomedical outcomes, and taking a patient-centered perspective. This paradox challenges nurse resources such as self-efficacy and motivation. We propose that the focus should be less on changing nurse counseling behaviors, but on methods that actively and concretely support patients to change their behavior. Preliminary evidence suggests that nurses can effectively apply theory-based behavior change methods that involve concrete and incremental goal setting, self-efficacy enhancement, and planning the execution of behaviors, while providing feedback and opportunities for positive self-evaluations. Future research should focus on testing the effectiveness of various theory-based behavior change methods as implemented by nurses, paying special attention to examining the necessary conditions under which these methods are effective. Specifically, we propose testing the hypothesis that theory-based behavior change methods can be effectively applied by nurses in routine consultations. Behavior change methods should cover the stages of the self-regulation of human behavior (Carver & Scheier, 1982, 1998). A second hypothesis is that a basic condition for the effectiveness of these methods is trust, so that patients will disclose the worries and failures that hinder their self-management, thus being able to share the responsibility for their disease with their healthcare providers and family.

5

Quality assessment of practice nurse communication with type 2 diabetes patients

Abstract

Objective

Nurse self-management support for type 2 diabetes patients may benefit from applying theory-based behavior change counseling. The 5As Model was used to assess if, and how, nurses applied the five key elements of self-management support in standard care.

Methods

Seven practice nurses audio recorded a consultation with 66 patients. An existing instrument for assessing counseling quality was used to determine if the 5As were applied. Applied As were compared with quality criteria, to provide an in-depth assessment.

Results

In almost every consultation, nurses assessed health behaviors, and arranged a follow-up meeting. However, nurses advised behavior change in less than half of the consultations, while setting goals and assisting patients to overcome barriers were used even less. Comparing applied As with quality criteria revealed several issues that could be improved.

Conclusion

Nurses consistently discussed health behaviors with patients, but important elements of self-management support were not applied.

Practice implications

Self-management support may benefit from training nurses in performing assessments that form the base for specific advice, setting goals, and addressing barriers to behavior change. Nurses also have to learn how to combine being medical expert and a behavioral counselor. Clarifying both roles to patients may facilitate communication and relationship establishment.

5.1 Introduction

Patients with type 2 diabetes mellitus (T2DM) need to control their blood glucose level, blood pressure and lipid levels in order to minimize their increased risk for heart disease and other complications (Inzucchi et al., 2012). However, less than 20% of T2DM patients reaches all three clinical targets (Casagrande et al., 2013), and more than one third of patients does not reach glycemic control (Barnett, 2004; Goudswaard et al, 2004). Besides adhering to medical prescriptions, self-managing clinical risk factors requires patients to (simultaneously) change to a healthier diet and be more physically active, ideally leading to weight loss (Stone et al., 2010; Toobert et al., 2000). Diabetes self-management through changing health behaviors is often challenging for patients, because it is their habitual unhealthy lifestyle that has contributed to the development of T2DM (Gorter et al., 2010; Plotnikoff et al., 2006; Rubin & Peyrot, 2001).

With T2DM mainly being treated in primary care, the practice nurse or diabetes specialist nurse is the main caregiver providing self-management support and health behavior change counseling to T2DM patients (Boström, Isaksson, Lundman, Graneheim, & Hörnsten, 2014; Carey & Courtenay, 2007; den Engelsen et al., 2009). Even though diabetes care is equally effective when it is transferred from physicians to nurses (Houweling et al., 2011), nurses often struggle with health behavior change counseling because of several communication barriers, and a lack of effective communication skills training (Mulder, Lokhorst, Rutten & van Woerkum, 2014).

In general, nurse consultations consist of a physical examination, followed by a discussion of health behaviors. During the physical examination, blood glucose, blood pressure, lipid levels, and/or weight (BMI) are measured, providing clinical outcomes that are taken into account when discussing past and future health behaviors (Edwall et al., 2010). The physical examination may set the stage for a biomedical approach, where central communications methods are advise giving and communicating risks of non-adherence to recommendations (Jansink et al., 2010; Kiuru et al., 2004). Self-management support, however, requires a patient-centered approach from a biopsychosocial perspective, which entails being responsive to patient preferences, needs, and values (Hudon et al., 2012; Institute of Medicine, 2001). Unfortunately, nurses may feel unconfident and experience conflict between their roles as a medical expert, and their role as a patient-centered counselor (Adolfsson et al., 2004). Training nurses in patient-centered communication does not yet seem effective in overcoming these issues (Mulder et al., 2014).

Besides taking a patient-centered approach, effectiveness of behavior change counseling may benefit when based on behavioral theory and evidence (Mulder et al., 2014). Originally developed for smoking cessation counseling (Fiore et al., 2000), the 5As Model is an example of a theory-based counseling model, suitable for application in busy health service environments, and not requiring sophisticated skills or experience (Lawn & Schoo, 2010). The 5As refer to Assess current risk behaviors, Advise behavior change, Agree upon clear goals for behavior, Assist in addressing barriers and securing social support, and Arrange follow-up contact (Glasgow et al., 2003). Across diverse populations and health behaviors, use of the 5As is associated with change in health behaviors and determinants thereof (Glasgow, Goldstein, Ockene & Pronk, 2004; Goldstein, Whitlock & DePue, 2004; Jay, Gillespie, Schlair, Sherman & Kalet, 2010). Because the 5As Model covers the key elements of self-management support, it presents a unifying conceptual framework for evaluating and implementing behavioral change counseling interventions in primary care (Whitlock, Orleans, Pender & Allan, 2002).

Aim
Often, nurses have received training in behavior change counseling, and therefore it is expected that standard counseling practices reflect, to varying extent, the 5As. However, to our knowledge, no studies have assessed nurses' use of the 5As in counseling T2DM patients, which is therefore the focus of the current study. It not only matters *if* the 5As are applied, but also *how* they are applied. Specifically, it is recommended that the 5As are used as an integrated sequence, and in collaboration with the patient. A second aim is, therefore, to analyze *how* the 5As are used, based on criteria that have been formulated for the application of each A (Glasgow et al., 2003, 2004).

5.2 Methods

Design and setting
An observational study was performed to assess the content and quality of communication during standard, quarterly consultations. Six primary care centers in four communities in the center of the Netherlands participated. The data was collected at the primary care centers, in the private consultation room of the practice nurse.

Participants
Seven practice nurses (one male) participated who provided diabetes care to the T2DM patient population in their practice. They were all registered nurses. The male participant was a diabetes specialist nurse. The six female participants were practice nurses with post-graduate training that included behavioral change counseling. Across 64 recorded consultations, a total of 66 patients participated (38 males), between 35 and 86 years of age (missing data for five patients). Of the 66 patients, 21 patients managed their blood glucose level through a combination of diet and physical activity; 39 patients used oral antidiabetic medication, and 3 patients used insulin (missing data for three patients).

Data collection
The practice nurses were given a digital voice recorder, with oral and written instructions how to use it provided by the first author (BM) during a visit to the practice that marked the start of the study. The nurses were informed that the study aim was to monitor patient-provider communication, without further explaining any details. They were requested to ask patients permission to tape-record the conversation, after giving each patient a short explanation about the study. Each nurse recorded between 1 and 15 consultations (median = 9), on average lasting 17 minutes (range between 7 and 37 minutes).

Analysis

All tape-recorded consultations were transcribed verbatim. During the first round of analysis, use of the 5As was measured with 19 items, as described by Jay et al. (2010), and translated into Dutch by Van Dillen, Noordman, van Dulmen & Hiddink (2014). This instrument was originally developed for assessing quality of weight counseling. However, weight counseling is an important part of health behavior change counseling for diabetes patients, and addresses diet and physical activity similarly to counseling overweight patients (ADA, 2010; Inzucchi et al., 2012). We anticipated the discussion of other health behaviors relevant for diabetes patients, currently not part of the assessment instrument, particularly medication use and smoking.

During the second step, the analysis focused on how the 5As were applied. Based on the literature, we summarized criteria for the application of each A, and for the model as a whole (Table 5.1) (Glasgow et al., 2003, 2004; Goldstein et al., 2004; Whitlock et al., 2002). Application of each A was compared to its criteria, and consistencies and discrepancies were labeled. Also, we focused on whether the 5As were applied sequentially and integrated, such that the application of a certain A builds upon the information elicited or conveyed during the previous A. Our aim was to identify themes by labeling instances of how the 5As were applied. During the analysis, we continuously developed labels, merged them into higher order themes, and compared themes across consultations; a process referred to as 'constant comparison' (Strauss & Corbin, 1988).

Both analyses were separately performed by BM and MB, after which outcomes were compared. For the quantitative analysis, and based on the original instrument to assess weight counseling, interrater concordance was 90%. Discrepancies were solved through discussion.

Ethical considerations

All patients signed an informed consent after the nurse told them about the study and their right to decline participation. Anonymity and confidentiality was assured to both patients and nurses. The medical ethical committee of Wageningen University approved the study (project nr. 12/03).

5.3 Results

A quantitative assessment of the use of the 5As

The quantitative assessment showed large variation in the use of each A (see Table 5.2). Assess and Arrange were applied in all but one consultations (98%), based on

the original instrument that focuses on weight counseling through discussing diet and physical activity. This one consultation mainly dealt with assisting the patient with self-monitoring of blood glucose. Advise was the next most frequently used A, in 25 consultations (39%), followed by Agree in 9 consultations (14%) and Assist in 6 consultations (9%).

We identified additional applications of the 5As that are typical for diabetes care, but currently not present in the assessment instrument. For Assess, this involved assessment of biomedical outcomes or clinical risk factors, and this occurred in all consultations. Biomedical assessment typically included measuring (fasting) blood glucose, blood pressure, and weight. Sometimes, blood glucose, blood pressure or weight was self-monitored by patients at home, and these self-monitored results were discussed during the consultation.

We considered some instances of discussing self-monitoring of blood glucose (SMBG) to be a specific application of Assist. By supporting patients to self-monitor blood glucose (e.g., by lending out a device for SMBG), nurses intended to increase patient control over barriers to their blood glucose level, for example, by helping patients gain insight in how their dietary and physical activity patterns influence their blood glucose level. This occurred in four consultations (6%) of three nurses.

Besides diet and physical activity, two additional health behaviors were addressed in the consultations. First, in three consultations (5%) of two practice nurses, they used Assess to identify smoking behavior, and intention and self-efficacy to quit. The nurses also Advised these patients to quit smoking. Other As were not applied to smoking cessation in these consultations.

Second, behavior change counseling concerned medication intake in 51 consultations (80%). Various types of medication were discussed, such as blood glucose lowering medication (e.g., metformin), but also medication to control blood pressure, cholesterol, or other comorbidities. Counseling medication intake included Assess in 51 consultations (80%), specifically assessment of patient beliefs about medication, effects and side-effects, adherence, current prescriptions and renewal of prescriptions, and current medication supply at home. Advise to either start or stop medication, or to continue current medication intake occurred in 13 consultations (20%). In 8 consultations (13%), this led to explicit instances of Agree. Assist with medication intake was applied in 2 consultations (3%). Finally, we identified four consultations (6%) in which Arrange was applied to measure the effects of medication that was changed as a result of biomedical assessment in that consultation.

Table 5.2 | Percentage of consultations in which each A was applied

The 5 As	Diet & physical activity	Medication intake	Smoking
Assess	98 %	80 %	5 %
Advise	39 %	20 %	5 %
Agree	14 %	13 %	-
Assist	9 %	3 %	-
Arrange	98 %	6 %	-

A qualitative assessment of the use of the 5As

Assess
Nurses discussed the current diet and physical activity pattern with patients, but generally ignored underlying knowledge, beliefs and emotions. Compared to the criteria, the behavioral assessments appeared to be standardized as to being a regular part of counseling, and through being related to outcomes of the standard biomedical assessment. However, the formulation of questions showed no clear structure, and generally lacked specificity. Nurses often asked closed-ended questions:

NURSE: *'And otherwise, do you otherwise eat healthily?'*

Closed-ended questions often stimulated patients to endorse the question, instead of providing more information:

NURSE: *'Yes, so normally you are moving all the time?'*
PATIENT: *'I'm moving all the time, yes.'*

Patient answers were often not followed by questions to quantify how much the patient typically eats or exercises:

PATIENT: *'I get sufficient exercise, in my opinion, yes.'*
NURSE: *'Yes, more like in daily life, or also intentionally walking or biking?'*
PATIENT: *'Well, in daily life. I never sit. I never read a book. I'm always busy.'*
NURSE: *'Yes, exactly.'*

Table 5.1 | The 5As Model: definitions and criteria (Glasgow et al., 2003, 2004; Goldstein et al., 2004; Whitlock et al., 2002).

A	Definition	Criteria
Assess	Assessment of patient knowledge, beliefs and behaviors.	Assessment should be standardized and specific.
Advise	Advising behavior change.	Advice should be clear, specific and personalized.
Agree	Setting goals.	Goal-setting should be informed, collaborative; goals should be mutually negotiated, achievable, and specific (the what, when, where, and how of agreed actions).
Assist	Anticipating barriers to behavior change and identifying strategies to overcome barriers, including securing social and environmental support.	Assistance in problem solving should generate multiple solutions, produced or selected by patients based on their personal history, skills, social environment, and willingness.
Arrange	Arranging follow-up contact.	Follow-up support and assistance is aimed at augmenting Assist. Ideally, it includes connecting with community resources.
The 5 As	A model describing the key steps in chronic illness self-management support; it is a recommended method to train clinicians, and implement or evaluate behavior change counseling in primary care.	The 5As should form an integrated sequence; the As should be interrelated, and iterative within and across consultations.

Assessments hardly ever resulted in specific, quantified information about current diet or physical activity pattern.

When nurses weighed patients as part of the biomedical assessment, they seemed careful not to confront patients with their weight or weight gain:

NURSE: *'You've gained about one and a half kilo. But well, blood pressure [is] good.'*

When assessing patient beliefs about losing weight, assessment generally remained superficial by using closed-ended questions:

NURSE: *'Let's see. Well, indeed a little weight gain, two kilos gained.'*

PATIENT: *'Oh, that has to come off again.'*
NURSE: *'You think you can do that?'*
PATIENT: *'I try.'*
NURSE: *'You know what you have to do to get that [weight] off.'* [silence]

Advise
Most Advise was unspecific and not personalized, often because it was based on the biomedical assessment, and not on a behavioral assessment. Instead of Advise, nurses provided a lot of general information to patients. Often, it remained unclear what the nurse actually wanted to patient to do:

NURSE: *'Yes and I think that walking is very important for you. Because like you said so yourself, well, if you don't walk, you immediately gain weight.'*

Dietary advice was also typically not quantified, and stated in general terms:

NURSE: *'So it is healthier to eat that [take-out meal] only once in a while.'*

Agree
Setting goals usually meant the nurse proposed a goal and persuaded the patient to agree.

NURSE: *'You also put sugar in that [tea]. Put in half the sugar you normally use, try...'*
PATIENT: *'Shall I...'*
NURSE: *'Yes, try that, start with that.'*

We didn't identify instances of negotiation, or involving patients to collaboratively set goals. Goal-setting did not specify the what, when, where, and how of performing the behavior.

NURSE: *'Yes, or pick up walking again.'*
PATIENT: *'Yes, I will pick that up too.'*
NURSE: *'Yes, yes.'*

Assist
Barriers to performing health behaviors were often discussed without addressing how these could be overcome. When patients mentioned barriers, these were often confirmed by nurses as being problematic, but strategies to deal with barriers were not developed:

NURSE: *'Yes, yes so actually the moment you come home [from work], that's the moment with the highest chance for you to go [walking]. Is that right?'*
PATIENT: *'It's... yes.'*
NURSE: *'But you don't go, because then dinner is served.'*
PATIENT: *'Exactly.'*
NURSE: *'Okay'.*
PATIENT: *'Yes I always come home at seven, and the children are waiting for me. Then immediately, we all eat together, that's why. Yes, no time, immediately have to [eat].'*
NURSE: *'Yes, it's difficult.'*
PATIENT: *'Yes yes, difficult.'*
NURSE: *'Ehm, well, you know the importance of exercise.'*

If strategies to overcome barriers were discussed, single solutions were presented to the patient, without the patient having a role in producing or selecting solutions:

NURSE: *'You do a lot by bike? Everything by bike?'*
PATIENT: *'If it's possible, I'll do it by bike, yes. If it's attainable. But during the winter I'm bothered by my hands, you know. I have arthrosis of the hands.'*
NURSE: *'And during the wintertime that is bothering you more of course, with that cold, yes.'*
PATIENT: *'It hurts very much.'*
NURSE: *'Yes, put on gloves.'*
PATIENT: *'Yes, put on gloves, but I cannot always... well I can, but.'*
NURSE: *'Well, I'm going to measure your blood pressure, right?'*

Securing social support was not used as a strategy to deal with barriers.

Arrange
Arrange was a standard feature of the consultation because patients typically, and without deliberation, get a new appointment after three months. However, Arrange was seldom a consequence of Assist to follow-up how strategies to overcome barriers to agreed behavioral goals. When an earlier follow-up consultation was arranged, this was in response to bad biomedical outcomes that warranted a change in medication:

NURSE: *'(...) but all right, instead of tablets of 500 [milligram] you are going to take a tablet of 850 [milligram] and then I just want to measure your blood glucose again in four weeks.'*

Applying the 5As as an integrated sequence

Issues within each A impeded using the 5As as in integrated sequence. Particularly, when Assess was unspecific, this prevented identifying areas for behavioral change. Also, Advise could not be specific and personalized when the Assessment had not resulted in detailed information about the discussed health behaviors. Instead, when Advise was actually a form of providing general information, this hindered goal setting (Agree), and anticipating barriers to behavior change (Assist).

The physical examination and computer interaction also affected application of the 5As as an integrated sequence. On the positive side, the biomedical outcomes from the physical examination could provide an opportunity to discuss health behaviors:

NURSE: *'Well, you have a nice fasting sugar of 6.3. Very well.'*
PATIENT: *'Oh, so that's good then?'*
NURSE: *'Yes, that is very good, yes.' (...) 'And besides taking your pills, are there any other things you do to keep the sugar low?'*

Also, nurses could look up information in the computer about what was discussed last time. This facilitated follow-up of behavior change counseling and the integrated, sequential application of the 5As

NURSE: *'And the last time you talked about picking up swimming again. Did you manage to do that?'*

On the downside, the physical examination and/or computer interaction could lead to an interruption in the flow of the conversation. This could result in a change in discussion topic, even when the discussion was focused on health behavior:

NURSE: *'How is your weight?'*
PATIENT: *'It stays about the same.'*
NURSE: *'Yes. No weight gain or loss?'*
PATIENT: *'No. I try, but it's hard.'*
NURSE: *'No, it's hard. Because how do you try? By snacking less or eh...?'*
PATIENT: *'Well, I don't do that all that much.'*
NURSE: *'No, no than it's all a bit harder.' [silence, sound of pumping tonometer, silence].*
NURSE: *'142, 76. I'll measure it again in a moment. [silence, nurse types]*

5.4 Discussion and conclusion

Discussion

Many T2DM patients do not reach clinical goals, because they have self-management problems such as changing diet and physical activity level. Practice nurses provide regular self-management support, but research indicates that nurses may lack communication skills and self-efficacy. Thus far, interventions aimed to increase communication skills have shown limited efficacy. The aim of the present study was to assess standard behavior change counseling of practice nurses with T2DM patients, in order to identify specific opportunities for improving current practices. The assessment was based on the 5As model, which presents a conceptual framework that covers all the key elements of self-management support (Glasgow et al., 2003).

The quantitative assessment showed that nurses typically Assess current health behaviors, and Arrange personal follow-up consultations. On the positive side, discussing health behaviors was part of standard care provided to patients. However, in less than half of the consultations, the nurses gave specific Advise to change dietary or physical activity behaviors. In less than one in five consultations, Assist was applied to support patients with identifying and overcoming barriers, and in about one in twelve consultations, nurses and patients Agreed upon clear, specific and personalized behavioral goals. This is in line with an earlier assessment of physician counseling, using the same instrument, which showed low use of Agree and Assist (Jay et al., 2010).

The qualitative assessment indicated multiple issues that may hinder effective self-management support as described by the 5As Model. First, Assess did not result in specific, quantified information about current patient health behaviors. It also did not involve assessing patient beliefs. As a consequence, areas for behavioral change were not identified, nor were the underlying beliefs that could have presented topics for discussion. Because Assess is the foundation of self-management support (Glasgow et al., 2004), these issues hamper Advise and other subsequent As. Particularly, Advise was not specific or tailored, Agree, when applied, did not reflect collaboratively setting goals, and Assist did not involve discussing strategies to overcome barriers to behavioral change. Finally, Arrange was not intended to follow up on agreed goals and strategies for behavioral change, but reflected scheduling the next standard consultation, as is routine in the Netherlands.

These results align with previous findings. Although using other models or perspectives, these issues are mirrored in the literature. For example, Jansink et

al. (2010) found that nurses often do not know how to make action plans that explicitly state behavioral goals, barriers and strategies, which is a central feature of effective self-management support (Glasgow et al., 2004). Instead, and similar to our findings, nurses usually provide general information and non-personalized advice, using communication styles that are not supportive or likely to empower patients (Kiuru et al., 2004). Nurses rarely look for collaboration or sharing control, thus showing a tendency to control communication (Jansink et al., 2010; Kiuru et al., 2004; Karhila et al., 2003). Nurses try to be helpful, but often do so from their perspective as a medical expert. This may indicate that they experience a role conflict when they combine being an expert with being a counselor (Adolfsson et al., 2004; Kettunen et al., 2006). Finally, our findings underscore previous work reporting that the physical examination may present both barriers and opportunities to discussing health behavior change (Edwall et al., 2010).

Future research should aim to further validate the use of the 5As as an overall framework for self-management support for patients with T2DM. To assess the use of the 5As within this patient group, the assessment instrument should be expanded to include smoking and medication intake. Self-monitoring of blood glucose could be added as an additional item for Assist, and we also suggest an additional item for securing social support.

Conversation analysis, with a focus on the interaction at the micro-level, could be used to examine how the 5As can or should be applied, including specific opportunities and limitations, based on how nurses and patients together shape their interaction. Experimental research could examine the effectiveness of nurses explaining their various roles on reducing role conflict, and increasing patient-centeredness of self-management support through benefiting equality, trust, and disclosure of concerns.

Conclusion

Our assessment indicates structural gaps in self-management support. Nurse communication would greatly benefit from using brief, standardized assessments of health behaviors and underlying beliefs, which can subsequently form the base for advice and support. Whether based on the 5As or similar models of behavioral change counseling, it is important that all steps are taken in a patient-centered manner, meaning in close collaboration with the patient, by sharing control with the patient, and being responsive to the patient's needs, values and preferences (Bensing, 2000). However, nurses may experience a role conflict when combining their role as a medical expert with their role as counselor.

Practice implications

Nurses attempt to guide and support patients towards self-management of diabetes. Although health behavior change is consistently discussed with patients, nurses need training and guidance to systematically apply the key elements of self-management support. This also means that they have to learn to combine being a medical expert with being a counselor that delegates control to patients. Perhaps making their different roles explicit to patients could help nurses to share control and responsibility, and establish a sense of equality. This could help patients to avoid feeling judged or criticized, thus increasing trust in the nurse. For example, nurses could clarify that as a medical advisor, they would advise a patient to lose weight, and as a counselor, they would like to discuss how the patient thinks about that advice.

Methodological issues

The data were gathered within the Dutch health care system, providing a specific context that has to be taken into account when interpreting findings. For example, nurses are typically required, among other things, to assess biomedical outcomes, record them into the computer, and schedule the next appointment with the patient. These and other structural factors shape communication between nurses and patient, including behavior change counseling.

6

General discussion

The overall aim of this thesis was to explore how provider communication during consultations can support patient self-management. Three empirical studies and a literature review have provided insights from different, and complementary, theoretical and methodological angles.

6.1 Summary of conclusions

The first study confirmed the hypothesis that psychosocial resources, such as social support and sense of control, and stressors, such as financial stress and psychological distress, mediate the association between socioeconomic position and four different health behaviors (Chapter 2). The absence of stressors and presence of resources could be represented by a single underlying factor, indicating similar effects of stressors and absence of resources on health behaviors. Furthermore, the association between socioeconomic position and health behaviors was modest, while the direct associations between stressors and resources with health behaviors were substantial. Therefore, it was concluded that addressing potentially modifiable resources and stressors through health communication may benefit people from all kinds of backgrounds, particularly those with low socioeconomic status as they have to deal with a higher level of stressors and less resources.

Because worse perceived health status had considerable negative associations with health behaviors (even when controlling for chronic disease status), it was concluded that patients coping with a chronic disease present a target group that particularly warrants attention.

The analysis of patient interviews showed that HIV patients strategically communicated with their health care providers to increase their sense of control (Chapter 3). Patients increased their sense of control by exchanging information that fulfilled cognitive and emotional needs for assurance and relief, and by establishing a trustful relationship with a competent provider who is respectful, non-judgmental and genuinely involved. Through this relationship, patients felt that their sense of control over the disease was further increased 'by proxy'. Patients strived for a level of decisional involvement that matched their preferences for being in control, yet at the same time wanted to share (or even diffuse) responsibility for the treatment.

Providers may not be aware of patient control needs, even though they were generally successful in matching patient preferences. Providers beliefs about what patients preferred regarding relationship establishment and decisional involvement were very much in line with actual patient preferences. However, providers felt that if informing patients about possible adverse outcomes of non-adherence yielded no effects, a more paternalistic approach was warranted, using risk communication about negative consequences of non-adherence to raise awareness. This was in contrast with provider's basic idea of empowering patients. Apparently, providers felt responsible for patient treatment outcomes, and looked for more persuasive methods when patients did not adhere to treatment recommendations.

Type 2 diabetes mellitus (T2DM) was chosen as another chronic disease to study how resources and stressors can be addressed in health communication. A review of the literature on practice nurse communication with T2DM patients showed that nurses encounter several communication barriers, for which no clear solutions yet exist (Chapter 4). Lack of communication skills and low self-efficacy were common barriers that could result in not discussing health behaviors, or merely giving advice. Patient-centered counseling methods that have gained popularity during the last two decades, such as motivational interviewing, did not seem effective – or even counterproductive – in improving patient health behaviors or clinical outcomes. Moreover, nurses experience these methods as complex and difficult to apply, thus possibly undermining nurses' self-efficacy even more. Also, nurses may experience a role conflict when they have to shift from being a medi-

cal expert who gives advice to a counselor who adopts a patient-centered perspective. Instead, limited evidence indicated the effectiveness and feasibility of nurses applying theory-based behavior change methods that directly focus on changing patient health behaviors.

Assessing the quality of nurse communication during standard consultations showed that important elements of behavior change counseling were not applied (Chapter 5). A comparison with the key elements of behavior change counseling as described by the 5As Model (referring to Assess, Advise, Agree, Assist and Arrange) revealed that nurses did not effectively assess health behaviors and underlying beliefs, even though health behaviors were discussed in virtually all consultations. Presumably due to this lack of a proper assessment, nurses did not provide specific and tailored advice in the majority of consultations. Nurses seldom agreed with patients over behavioral goals, or provided assistance in overcoming barriers to behavior change. Instead of counseling patients towards behavior change, nurses often gave general information intended to be advice, often as a result of the biomedical assessment, and thus from a biomedical perspective.

Overall, the research presented in this thesis showed:
a. which general factors related to control explain variation in health behaviors;
b. what and why patients prefer in provider communication and how providers can meet these preferences;
c. what hinders or helps providers to provide effective self-management support.

Starting from these conclusions I will try to formulate overarching ideas about how provider communication can support self-management of chronically ill patients. It is important to address stressors and psychosocial resources in health communication, especially with chronically ill patients, because of their associations with health behaviors. Social support is an important resource, affecting multiple behaviors, as is sense of control. Particularly for patients from lower socioeconomic groups, financial worries can be a stressor that is negatively associated with health behaviors. Second, because stressors and resources can be represented by a single factor, discussing and alleviating stressors, such as concerns or distress, may translate into increasing resources such as sense of control. Vice versa, increasing resources, such as a patient's social support network, can result in alleviating stressors (Chapter 2). Patients generally look to increase their sense of control over their illness and the physical and social consequences thereof, and discussing their concerns may be their first strategy to do so. However, patients may differ as to the strategies they chose to increase their control and reduce worries in order to strive for wellbeing. Patient strategies may offer a good starting

point for provider communication. Whatever the strategy, a good relationship between patient and provider can be a source of support by itself, resulting in perceptions of control. In addition, a good relationship opens the way for disclosure and discussion of patient concerns, thus providing further opportunities for patients to increase their control (Chapter 3). This suggests that social support can increase control perceptions in several ways. Providers may have trouble addressing control and support, because this asks for communication skills other than those necessary for providing medical information, and providers may feel they lack these counseling skills. Second, it means sharing control over communication and this may further increase provider feelings of being uncomfortable in the role of counselor, especially when patients resist to medical recommendations. Paradoxically, training providers in patient-centered counseling techniques may not be the answer. Rather, providers should be trained to work from a behavioral theory-based perspective, whereby they apply specific methods such as goal-setting and addressing barriers to change from a patient-centered perspective, and within a supportive relationship (Chapter 4). Current application of behavioral theory-based methods is very low, although providers regularly address health behaviors and seem to be in need of clear communication tools to discuss behavior and behavior change (Chapter 5).

Overall, effectively supporting self-management in health care occurs through two major pathways: building supportive relationships, and – based on the supportive relationship – using theory-based behavior change methods to help patients change self-management behaviors. Merely establishing a supportive relationship may contribute to patient wellbeing, but may in itself not lead to behavior change. In turn, applying behavior change methods but neglecting the relationship is also unlikely to be effective.

6.2 Comparing HIV care with diabetes care

Although different methods were used for each study, this thesis enables a comparison between communication in HIV care and communication in diabetes care, providing relevant insights for communication with chronically ill patients. Both HIV care providers and diabetes care providers started from a patient-centered orientation, but seemed to fall back on a more disease-centered orientation when a patient-centered approach apparently yielded no success in terms of behavior change. A disease-oriented approach meant providers focused on curing the disease instead of caring for the patient, for example, by stressing the negative consequences of non-adherence to recommendations or treatment. A

disease-centered orientation is inevitably associated with a more paternalistic, provider-centered approach, because the provider acts as an expert who knows what is best for the patient (Bensing, 2000). As shown in this thesis, this is strongly associated with the provider feeling responsible for the patient's clinical outcomes and health.

An important difference was that HIV providers were much more oriented towards discussing patient problems and concerns than diabetes care providers. HIV care providers explicitly aimed for disclosure with the aim of assisting patients to overcome barriers. For HIV patients, this seemed related to their treatment satisfaction, trust in the provider, and indeed disclosing personal issues they were currently dealing with. Although diabetes patients were not interviewed, audio recorded consultations showed very few instances of discussing patient concerns, or assisting patients to deal with their concerns. This can be an area for improvement in diabetes care, because addressing patient concerns supports their self-management (Woodcock & Kinmonth, 2001). The difference in discussing patient concerns may result from the fact that HIV patients are treated in secondary care by highly specialized providers, because it used to be an acute and lethal disease. Additionally, for HIV patients, treatment adherence means taking their medication properly, whereas for diabetes patients adherence to treatment means taking their medication as well as adjusting ingrained health behaviors such as diet and physical activity. All in all, diabetes care providers are less specialized, while at the same time they have more health behaviors to discuss. Therefore, there are opportunities for improving diabetes care both through patient-provider relationship establishment, and through the application of theory-based behavior change methods that result in individual action plans for patients.

Both for HIV care and diabetes care providers, taking and sharing responsibility seems to be an unresolved issue with implications for communication. When providers feel responsible for treatment or clinical outcomes, they may resort to risk communication to try to persuade the patient. However, this may cause patients to feel less supported, threaten the patient-provider relationship and prevent further disclosure. Although providers taking responsibility is probably an expression of their commitment to patient health, providers cannot take responsibility for patient wellbeing and behaviors (Anderson & Funnell, 2010). Self-management support may benefit if providers recognize that providing support – in all its forms – is the essence, and that patients are the ones in control. It is possible, however, that responsibility taking is partly an automatic, unconscious mindset that is not easy to change.

6.3 Contributions to the literature

A central concept in this thesis is self-management, which is viewed as the patient's day-to-day tasks to cope with, and adapt to, the medical, functional and emotional consequences of chronic illness (Corbin & Strauss, 1988). This concept was studied in an explorative manner, for two diseases, and from both the patient's and the provider's perspective. When comparing the findings with the current literature, it is important to relate to concepts from existing theory, as this enables accumulation of evidence, and generalization of evidence across settings (Michie, Johnston, Francis, Hardeman & Eccles, 2008). However, this comparison is shaped by the fact that no single theoretical framework was used as the starting point for this thesis, and by the non-experimental methods that were applied. As a result, no evidence for or against a specific theory or change method will be discussed, nor will a certain theory be singled out for discussion. Rather, supporting self-management has been studied using a wide range of theories and concepts. Therefore, a 'meta-view' on the field was taken to discuss our findings against current trends in this rather fragmented literature. This allows for a comparison with various constructs, as well as addressing trends in the field of self-management support as a whole.

There appear to be (at least) three interrelated – but not integrated – bodies of literature that address self-management support. Closely related are patient empowerment, from the field of health promotion, (Anderson & Funnell, 2010), and patient-centered care (Bensing, 2000) in health communication. In health psychology, multiple concepts about control and support relate to self-management issues that are discussed in this thesis (e.g., Bandura, 2006; Ryan & Deci, 2000; Skinner, 1996).

Patient empowerment and patient-centered care
With the start of the Health Promotion Movement (WHO, 1986), empowerment was introduced as one of its central concepts, defined as the process through which people gain greater control over decisions and actions affecting their health (Nutbeam, 1998). Although empowering patients is often presented as the way forward in caring for chronically ill patients (Kreps, 2011), the concept itself remains rather elusive. First, no uniform definition or operationalization exists (Koelen & Lindström, 2005), and this hinders the advancement of theory and research. A second and perhaps related point is that health care providers have difficulties understanding patient empowerment, and how they are supposed to empower patients. According to Anderson and Funnell (2010), this is because providers are trained and socialized in the traditional approach to care as the treatment of acute illness. As a result, providers take responsibility for care and

treatment outcomes, which conflicts with the fact that patients have to self-manage their own illness. Providers who truly want to adopt empowerment must have an 'Aha Erlebnis' to realize that patients themselves are responsible for care, and that providers are responsible for enabling patients to make informed decisions. Thus, providers have to stop their frustrating attempts to persuade patients to behave themselves according to recommendations (Anderson & Funnel, 2010). In line with these tenets from patient empowerment, responsibility taking and sharing has been identified in this thesis (Chapters 3 and 4) as a paradoxical tug-of-war. To put it strongly: providers should not take responsibility for patient self-management, but do, and patients should take it, but do not always want to. However, the question is whether it is feasible and acceptable to ask providers to undergo such a paradigm shift in the service of sharing responsibility, and thus empowering patients. Noteworthy in this respect are the similarities between the concepts of patient empowerment and patient-centered care, as 'empowerment is fundamentally based on meeting patient's needs. i.e., patient-centered.' (Anderson & Funnell, 2010, p. 279).

Just as empowerment, patient-centered care can also be considered a 'fuzzy' concept (Bensing, 2000), among other reasons because it is a multifaceted construct that essentially presents a philosophy of care, which is hard to accurately describe or measure (Epstein et al., 2005). Moreover, as the literature review in this thesis shows (Chapter 4), it is difficult to train providers in patient-centered counseling, and it is unclear how providers should be taught to adopt such a philosophy. Specifically, it remains questionable whether relatively few training sessions can teach providers *how* to communicate in an empowering and patient-centered manner. Such limited training may even backfire and further undermine providers' self-efficacy (Chapter 4). Moreover, it is unclear whether empowering patients actually leads to better patient outcomes, as patient-centered counseling may even lead to worse clinical outcomes (Chapter 4).

Other barriers to implementing patient empowerment or patient-centered care may relate to structural factors and trends within the health care system. As Bensing (2000) notes, health care is becoming more and more evidence-based, protocolled, and standardized, with the aim of making it more (cost-)effective. This conflicts with the empowerment and patient-centered movements, because this leaves physicians with less options to tailor treatment decisions to individual patients. Physicians may even point to professional association guidelines to (intentionally) prevent discussion with patients (Bensing, 2000). Finally, medicine still relentlessly focuses on curing diseases, including chronic illnesses such as HIV (Allers et al., 2011) and type 2 diabetes mellitus (Milne et al., 2007).

Patient empowerment and patient-centered care also share the idea that effective self-management support requires a specific patient-provider relationship. In order to support self-management, this relationship should be a partnership, based on equality rather than hierarchy, in which the provider is a collaborator and a supporter (Anderson & Funnell, 2010). Control over communication should be shared with patients, for instance, over what is discussed and how, and over decision making, to promote patient control and responsibility taking (Bensing, 2000). Interestingly, the importance of the relationship for counseling has since long been recognized in clinical psychology, although this seems seldom recognized in health communication. At least in name reminiscent of patient-centered care, person-centered therapy (PCT), developed by Carl Rogers, proposes that the relationship between the client and the therapist holds important conditions that are necessary and, when all present, sufficient for change. Rogers (1957) described the conditions that he claims over time lead to 'constructive personality change'. Importantly, the therapist has to create an environment where the client can freely express feelings and concerns, which enables the client to find the most effective answers for him or herself. Three central processes to create this environment are congruence (also called genuineness), unconditional positive regard and empathy, meaning that the therapist is transparent and does not hide behind a professional façade, accepts the client without judgment and (thus) listens attentively, and conveys appreciation and understanding of the client's perspective (Rogers, 1957). Decades of research based on Rogers' work has shown that especially empathy and unconditional positive regard are important conditions for a good relationship and together have substantial therapeutic effect (Kirschenbaum & Jordan, 2005). Moreover, it appeared that these 'common factors' in the relationship account for therapeutic change, regardless of the specific method that is applied. indeed, the quality of the relationship is the single most important factor affecting positive client outcomes (Sexton & Whiston, 1994).

Although therapeutic change can be seen as quite different from behavior change, important similarities can be noted. Just as the client in therapy, the patient, too, has to be motivated and able to find the best ways to change his or her own behavior. Therefore, if interpersonal health communication is directed at supporting patients to change their own behaviors, through a long-term relationship with regular interaction, Rogers' insights are highly relevant. These insights are reflected in the findings of Chapter 3, which has shown that patients prefer to build a long-term relationship with a provider who is genuinely involved, is non-judgmental and conveys a sense of equality. As Rogers (1957) stated, this is indeed associated with trust in the provider, and with disclosing personal issues, worries and concerns. Future research should further examine the importance of the relation-

ship for outcomes for patient with chronic diseases, and if and how relationship establishment can and should be taught to providers.

All in all, comparing this thesis with patient empowerment and patient-centered care allows for several observations. Research under both these headers has provided valuable insights into factors that are important for effective self-management support. Paradoxically, it seems that these concepts are easily endorsed in health care, yet hard to apply. This may also go for the findings of this thesis. However, application of important findings may be facilitated if recommendations can be stated in clear and concrete terms of what patients need, and how providers can match those needs. As argued, effective self-management support requires on the one hand a supportive relationship, based on trust, and aiming for disclosure of patient concerns. On the other hand, if self-management support is aimed at behavior change, this requires a systematic and theory-based approach, taking the supportive relationship as the starting point. Conditions for relationship establishment as identified in this thesis are in line with theory and research on therapeutic relationships in clinical psychology, most notably Rogers (1957).

Control and support in psychology
Psychology in general presents us with an abundance of theories that may help to provide better understanding of the findings in this thesis. Using theory has specific advantages, namely increased effectiveness of behavior change interventions, while also allowing empirical evidence to accumulate across settings (i.e. generalized knowledge development), and advancing theory itself (Michie et al., 2008). This is also in line with Koelen and Lindström (2005), who suggest that the concept of empowerment can be better understood and operationalized using theoretical concepts from psychology such as health locus of control, self-efficacy and other control concepts. As noted, the empowerment and patient-centered movement suggest that patient control is strongly tied to provider support. along similar lines, psychological theories describe how the individual exercise of control is determined by social relationships and interaction.

According to self-determination theory (SDT), autonomy, competence and relatedness are basic human needs that are important for health and well-being (Ryan & Deci, 2000). Meeting those needs is essential for humans to be active self-regulators, or, once they are patients, active self-managers. Health care provides a social environment, and health communication a way, through which patient autonomy and competence (which are control constructs according to Skinner, 1996), and relatedness can be supported or broken down, or anything in between. For example, SDT predicts that controlling communication may lower patient

self-motivation and ability, thus lowering the overall effectiveness of communication (Ryan & Deci, 2000). Indeed, empirical research has shown that autonomy support predicts weight loss at follow-up, while directive support may hinder weight loss (Gorin, Powers, Koestner, Wing & Raynor, 2014).

Similar to the core assumptions of SDT, social cognitive theory (SCT) poses that humans are by nature proactive self-organizing and self-regulating beings (Bandura, 2006). As such, humans are described as agents, characterized by certain properties such as that they form intentions to perform future behaviors, including action plans for executing them. In addition, SCT states that humans not only exercise control through their own agency, they also exercise proxy agency, by influencing others who can help them reach their goals (Bandura, 2006). Furthermore, self-efficacy is an important control belief that can be influenced socially when others are seen as models for behavior, or when persuasion is used to convince people of their abilities (Bandura, 1998). As predicted by SCT, effects of social support on behavior are mediated by self-efficacy (e.g., Williams & Bond, 2002).

The findings of Chapter 2 showed the importance of social support and sense of control for health behaviors, also, but not limited to, for people with lower socio-economic status. This is in line with SDT and SCT, which also goes for the findings of Chapter 3, where it was shown that patients actively strive to increase their (sense of) control over their disease through strategic communication and supportive relationship establishment with their providers, although mostly in an implicit manner. In Chapter 4 it was found that providers themselves struggle with issues of control, for example, low communication self-efficacy, and experiencing frustration about lack of control over patient outcomes. Chapter 4 also indicated that provider lack of control may result in providers undermining patient control, through their attempts to gain control over patient outcomes through directive communication. Finally, in Chapter 5 a theory-based model was used to evaluate provider communication. Using such a model (in this case: the 5As Model) helps providers to gain a sense of control over communication, because they are provided with a tool to develop an action plan in collaboration with patients.

Implications for self-management support
Viewing the results of this thesis in light of SDT and SCT that both describe and predict under what conditions humans are active self-regulators, this provides insights as to how patients may become active self-managers. Patients, just as healthy people, strive for wellbeing through experiencing autonomy and feeling competent in dealing with the demands of their daily life, including, but not

limited to, their disease. Furthermore, competency, self-efficacy, or other control perceptions, are supported by social relations and interactions, including those with their health care providers.

What exactly self-management support should look like depends on how self-management is viewed in terms of its core functions of medical self-management, self-managing functional limitations, or self-managing worries and negative emotions. In many studies, self-management is not defined or operationalized to the extent that it is clear what exactly support is aimed at. This limits how the study results should be interpreted. For example, recently published results of a large trial to support self-management of over 5500 patients with diabetes, chronic obstructive pulmonary disease or irritable bowel syndrome showed no effectiveness of the intervention (Kennedy et al., 2013). Even though this appears to be a well-designed and large-scale intervention, self-management is not defined. Self-management support is defined as 'increasing the capacity, confidence, and efficacy of the individual for self management' (Kennedy et al., 2013, p. 2), and even though patient outcomes included shared decision making, self-efficacy and health related quality of life, medical self-management seemed to be the main target. Above all, understanding the study and its outcomes would benefit from a clear conception of what self-management is, what it is directed at, and thus, how it should be supported.

Therefore, it is important to clearly define self-management in studies testing the effectiveness of self-management support, particularly as to what is its function. In addition, it is important to acknowledge that effective self-management may have direct effects on wellbeing and quality of life, and that patients often see self-management as serving wellbeing, over and above as self-management serving their health. It is therefore recommendable that self-management is defined and addressed as having (at least) three core functions.

Furthermore, self-management support that is more narrowly defined as medical management behaviors requires the integrated application of a set of key elements, that result in an individual action plan (Schwarzer, 2008). An action plan describes these key elements for each patient, by specifying behavioral goals, and barriers to these goals as well as the strategies to overcome barriers. The action plan also describes a follow-up plan to monitor progression and enable adjustment of goals and strategies. Finally, the action plan is shared with the patient's providers and social support network (Glasgow et al., 2004). Therefore, such an action plan supports self-management by giving patients control over what is needed to change their behavior, and by explicitly addressing barriers, such as stressors, that may hinder behavioral change. This is further strengthened through

and with the provider and social network of the patient, thus linking personal resources with social resources.

However, many trials find that implementation of communication methods is difficult, which lead Kennedy et al. (2013) to state that 'A common problem in health services research is that effective interventions are often not feasible and feasible interventions are often not effective' (p.4). Even though the relationship itself has, as argued, healing properties (Street & Epstein, 2008), applying the relationship itself as a tool for self-management support is not something that can be easily learned in the commonly short training sessions. This is especially the case because effective communication involves multiple sub skills, and ultimately factors that are perhaps hard to learn, such as genuine involvement and empathy, and non-judgmental attitude. Future research has to test the effectiveness and applicability of self-management support as founded in supportive relationships, and using theory-based methods were behavior change is needed.

6.4 Future research

Resulting from the discussion of this thesis' findings, at least three avenues for future research can be formulated. To start with a theoretical point, the first recommendation is to use control concepts to further unify the various functions of interpersonal health communication, thus advancing theory and research. Interpersonal health communication serves functions such as exchanging information, managing emotions and uncertainty, and supporting self-management (Street & Epstein, 2008). Exactly how these functions build important control perceptions and expectancies, such as autonomy, competence and self-efficacy, could be further clarified and related to existing theories that have these concepts at its core, such as self-determination theory and social cognitive theory. The meaning of control for patients and providers can be also be further explored empirically. For example, studies could explicitly focus on what control means for various patient groups suffering from chronic illnesses; to what extent control over illness-related issues is indeed an implicit or explicit goal for patients; and what strategies patients employ to increase or maintain their sense of control. Likewise, future research could shed light how providers view the concept of patient control, and how they believe patient control can best be supported. Also, it would be interesting to examine to what extent providers believe they are or need to be in control of the conversation, and over the patient or patient outcomes.

A second avenue for research, and related to control, is the matter of taking responsibility. Future research could shed more light on the extent to which patients take responsibility for their disease and self-management activities such as health behaviors. How does responsibility taking help or hinder control perceptions and expectancies, and how does this translate into actual behaviors? Patients that are happy to diffuse responsibility to their provider are more likely to see their provider as an expert, to whom they can transfer control. To what extent are providers prone to let this happen, and what are effects on communication? From the provider perspective, it would be interesting to study the extent to which providers feel responsible for patient outcomes, and how this affects communication behaviors.

A third research avenue is to study the effectiveness of training providers to communicate in line with the conclusions of this thesis. As such, future research could address the effectiveness of training providers in three main competencies. The first competency is to support patients' sense of control over their disease, primarily by addressing patient concerns and worries, and discussing the strategies patients use for coping with those concerns. Research could focus on the effectiveness of training providers in identifying and addressing patient concerns and coping strategies in terms of control perceptions, behaviors and wellbeing. Concerning the second competency, research could provide evidence for the effectiveness of supportive relationships, as well as clarify how to train providers to build supportive relationships with patients. Further advancement can be made as to how a good relationship supports behavior change, for example, through disclosure of worries and concerns, and then realizing current or potential strategies for dealing with problems. Also, it would be interesting to study whether the conditions as formulated by Rogers (1957) are effective for building relationships and supporting self-management in health care. In addition, the role conflict that is experienced by providers between being a medical expert and a behavioral or psychosocial counselor relates to Rogers' (1957) process of congruence. Providers may express difficulties being a counselor, because they have to let go of their expert role, in favor of a role in which they are less in control and feel less confident. However, when providers are not congruent, i.e. not being transparent about their roles, and even hiding behind their professional role, this may hinder relationship building and patient disclosure. Future research could address to what extent relationship establishment and patient disclosure is indeed hindered by incongruence, or supported by congruence. In contrast to 'regular' counselors or psychotherapists, health care providers indeed have multiple roles. It would be interesting to study the effectiveness of clarifying the provider's multiple roles to the patient on reducing role conflict and (thus) improving patient disclosure and relationship establishment.

The third competency is using theory-based behavior change techniques in current health care settings. The effectiveness and feasibility could be examined of implementing these techniques to formulate individual action plans with the aim of supporting self-management. It is also interesting to study whether the effectiveness of behavior change techniques depends on the relationship between patient and provider.

It matters to all three competencies to examine how much training and support providers need to enable effective application thereof. Too short and ineffective training may backfire, leading providers to lose motivation and self-efficacy. Because implementation is such an important and often underestimated issue, it is recommendable to first explore provider perceptions of outcomes and (self-) efficacy of training. Ideally, providers are involved in the development of training programs.

6.5 Implications for practice

The conclusions from this thesis lead to several recommendations for health care provider communication with chronically ill patients. First, providers should be aware that effective self-management support primarily consists of supporting control perceptions and expectancies, because these matter to patient health, wellbeing and behavior. In general, patients look for control over their disease, but they may use vary different strategies to do so, that have to be taken into account during communication. For example, some patients look for control by downplaying the seriousness of the disease, or not accepting, or not wanting to face the emotional side. Other patients have fully come to terms with having the disease, feel responsible, want to be fully involved in treatment, and look for as much information as possible, both in and outside of the consultation. Whatever the patient's strategy, the patient's perspective on how to control the disease has to be the foundation for communication, at least in the beginning of the treatment, when the relationship between patient en provider still needs to develop.

According to patients, providers are indeed important for augmenting control perceptions and expectancies of patients. Building control can be accomplished through two major and related pathways: building supportive relationships, and communication that is focused on issues, worries, and concerns that matter to or occupy the patient at that moment, thus threatening control perceptions.

When behavior change is a consultation goal of the provider, theory-based behavior change methods should be used, within a good relationship, and building upon that relationship, and from the perspective of patient issues and concerns. In order to build a good relationship, and effectively use behavior change methods, providers may benefit from being aware that having control over patient outcomes, and feeling responsible, are issues that may affect their communication with patients. Taken together, self-management support in health care can potentially be improved if providers are extensively trained in three areas. The first area is building control perceptions of patients, by being able to identify patient concerns and patient strategies to deal with concerns. Second, training could help providers establish trustful relationships by showing providers how to be accepting, non-judgmental and genuinely involved. Finally, providers can learn to support behavior change by applying theory-based behavior change techniques that result in an individualized action plan.

6.6 Conclusion

For patients, perceptions of control over the disease present a central issue in their daily self-management. Control perceptions are closely related to perceptions of support from their provider. Self-management support in health care can thus occur through two pathways.

First, the patient-provider relationship provides patients with emotional and practical support. This increases patient control perceptions and therefore may impact wellbeing directly, as well as have a positive impact on health behavior. A good relationship is built through regular interactions over time with a competent and genuinely involved provider, thus allowing trust to build. Importantly, a trustful relationship is a condition for patients to disclose their issues and worries, providing opportunities for practical and emotional support.

A second path for effective self-management support is directed at behavior change. Commonly, this is an important part of the provider's agenda. Effective behavior change support needs to build on a good and trustful relationship. Moreover, behavior change support requires the integrated application of several theory-based elements, ideally leading to an individual action plan stating concrete and feasible behavioral goals, based on an assessment of current behaviors and underlying beliefs. The action plan also states multiple strategies to tackle barriers to change, as brought forward by the patient.

Control perceptions are central constructs in psychology, and these could serve to unify various approaches to self-management support. Future work could further explore and model how health care providers may support patient self-management through building social support and augmenting control perceptions by establishing relationships and theory-based guidance towards behavior change.

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Summary

Globally, chronic diseases present a huge economic and humanitarian burden. On the individual level, patients have to cope with the consequences of having a chronic illness, a process called self-management, and they can do so in various ways, thus effecting their own health and wellbeing. Because chronically ill patients are regular health care users, supporting patients to self-manage may have beneficial effects in terms of patient health and wellbeing as well as reduce health care costs. How interpersonal communication between patients and health care providers may effectively support self-management is an area that is still in need of further examination.

In **Chapter 1**, the research in this thesis is introduced by showing the relationships between chronic illnesses, health behaviors and health communication. The global rise in chronic diseases such as cardiovascular diseases, diabetes and STD's can largely be attributed to health behaviors such as smoking, physical inactivity, unhealthy diets and unsafe sexual intercourse. Despite large investments in interventions to promote healthy behaviors, the impact of these interventions is often limited and these are not expected to turn the tide on the population level. Therefore, more and more people will become patients who are treated in the health care system, which has implications for how to communicate with them about their disease.

Patients with a chronic illness have to take care of themselves, because their disease cannot be cured, and because their daily decisions affect the progression of their disease; they have to self-manage. Patients' regular visits to their health care provider present an opportunity for self-management support, because health behaviors are a common topic in the consultation room. Moreover, research indicates that provider advice and face-to-face communication can be more effective than mass media communication and mediated personal communication (e.g., email or telephone).

However, self-management can be defined in different ways, and accordingly, self-management support can take many different forms. Importantly, some definitions describe self-management from a patient perspective, whereas other definitions are more normative by stating what patients are required to do to prevent disease progression, from a medical point of view. In this thesis, self-management is seen as fundamentally being a patient matter, aimed at maintaining

wellbeing by managing the medical side, dealing with the functional limitations due to the disease, and coping with the emotional consequences. An overall aim of this thesis is to provide a better understanding of how, from a patient perspective, to provide effective self-management support during interpersonal health communication.

Early studies on self-management indicate that control is a central construct explaining the effectiveness of support. For example, a sense of control over the disease, or high self-efficacy regarding specific self-management behaviors, can predict health and wellbeing directly as well as positively influence health behaviors. Therefore, the starting point of this thesis is to view self-management support as supporting patients' actual and perceived control over their disease. Studying patient-provider communication can provide further conceptual and practical insights into how communication may support self-management. The specific objectives of this thesis are

a. to explore control factors that may help to explain variation in health behaviors;
b. to examine patient preferences for provider communication that ultimately aims to support self-management, and how providers can meet these preferences; and
c. to examine what hinders or helps providers to provide effective self-management support.

Self-management support through communication is studied for two diseases for which patient self-management is important: HIV and type 2 diabetes mellitus (T2DM). Self-management behaviors affect the progression of both diseases, and in addition, patients self-manage in order to maintain their wellbeing, which may be threatened by the physical and social implications of having either HIV or T2DM. Also, provider communication affects outcomes for both patient groups, but more insight is needed into how providers should communicate during consultations to effectively support self-management. Studying self-management support for two diseases provides a broader empirical base, which also enables better conceptual understanding.

Besides addressing two chronic diseases, the four empirical studies in this thesis all employ different methods and include a cross-sectional survey study (Chapter 2), a thematic analysis of interviews with HIV patients and their health care providers (Chapter 3), a literature review on communication in diabetes care (Chapter 4), and an analysis of audiotaped conversations between practice nurses and T2DM patients (Chapter 5). Chapter 6 discusses the findings of the individual chapters in light of the research aims and presents overall conclusions.

Chapter 2 serves as an entry point for a central idea in this thesis that perceptions of control have an effect on health, both directly, and through their effect on health behaviors. As argued, control constructs seem to have an important place in patient self-management, theoretically being both a cause and outcome thereof. Similarly, control perceptions are one element of a reserve capacity that may help to explain socioeconomic health disparities. Specifically, people from lower socioeconomic strata may have less resources such as sense of control and social support, and at the same time have to deal with more stressors that deplete these resources. Having less resources while coping with more stressors places these groups at disadvantage, which may help to explain their worse objective and self-reported health, as well as their worse health behaviors. That is why in this chapter it was examined whether stressors and resources mediated the relation between education and health behaviors. Additional aims were to examine whether the presence of stressors and the absence of resources can be represented by a single underlying factor, and whether an aggregate measure of stressors and resources has an added effect over the use of individual measures.

Cross-sectional questionnaire data were collected on sociodemographic variables, stressors, resources, and health behaviors among 3050 inhabitants of the city of Utrecht. Results showed that higher levels of stressors and lower levels of resources could indeed be represented by a single factor. Also, lower resources and higher stressors co-occurred among those with lower educational levels. Stressors and resources partially mediated the relationship between education and exercise, breakfast frequency, vegetable consumption and smoking. Important mediating stressors were financial stress and poor perceived health status, whereas sense of control and social support were significant mediating resources. However, the association between socioeconomic position and health behaviors was modest, while the direct associations between stressors and resources with health behaviors were substantial. It was therefore concluded that the presence of stressors and absence of resources helps to explain socioeconomic differences in health behaviors, but that addressing changeable resources and stressors through health communication may benefit the population as a whole. The considerable impact of worse perceived health status on behaviors indicated that patients indeed need support with coping with a chronic disease. Building their sense of control and providing social support are possible ways to do so.

Focusing more directly on self-management support, **Chapter 3** examined the communication preferences of HIV patients. This chapter further built on studies showing that communication with health care providers is important for supporting patients with adaptation to HIV and adhering to their treatment, in order

to maintain health and quality of life. Previous studies also indicated that communication is optimal when patient preferences are matched. Patient-provider communication serves three general goals of information exchange, relationship establishment and involvement in treatment decisions. The aim of the present study was to explore HIV patient communication preferences within each of these three goals, and to explore how patients experienced matching – or not matching – their preferences during communication with their providers. A second aim was to explore provider beliefs about patient preferences, and their views on optimal communication. Data was collected through interviews with 28 patients and 11 providers from two academic hospitals.

Results indicated that that HIV patients strategically communicated with their health care providers to increase their sense of control. Patient preferences reflected their cognitive, emotional and practical needs, and patients aimed to increase their sense of control over their HIV through communication that served those needs. Through a trustful relationship with a competent and genuinely involved provider, patients aimed to further increase their sense of control by proxy. This relationship thus provided patients with emotional support, but also enabled patients to disclose their issues and concerns, which provided further opportunities for them to get support. This study thus further showed the importance, and also the interrelationship, between control and support.

Providers were well aware of patient communication preferences, and their beliefs were generally well in line with patient preferences. Providers seemed to take responsibility for patient treatment outcomes – at least to some extent. This also seemed to match preferences of patients who were eager to share that responsibility with their providers, for example by not becoming too involved in medical decision making. However, this also resulted in providers looking for persuasive methods, such as communicating risks, when patients did not adhere to treatment recommendations. Furthermore, provider interviews did not indicate that they were aware of the control needs that underlie patient communication.

Chapter 4 concerns communication between T2DM patients and their main health care providers that support their self-management. In the Netherlands, those health care providers are the practice nurse in primary care. Previous research reveals that T2DM patients have self-management issues, resulting in problems with controlling blood glucose levels and other cardiovascular risk factors. One of the explicit aims of nurse consultations is improving patient health through supporting self-management. Optimal communication may have direct and indirect beneficial effects on T2DM patients' health and wellbeing. However,

research indicates that patient-nurse communication can be difficult in practice. Nurses are primarily trained from a biomedical perspective, and therefore may find it difficult to share responsibility for treatment and treatment outcomes with patients. As a result, nurses may use communication strategies that are not actually supportive. Furthermore, supporting self-management of T2DM patients can be problematic because an overall aim is to change health behaviors such as diet and physical activity. These health behaviors are often part of an ingrained lifestyle that has contributed to the development of T2DM. The aim of this Chapter was to provide practical recommendations to improve nurse-patient communication. This was done through a structured literature review that focused, first, on factors that may hinder effective nurse-T2DM patient communication during consultations. A second focus was on empirical evidence for methods that aim to increase effectiveness of nurse communication.

For nurses barriers to communication were the physical examination, lack of communication skills and communication self-efficacy, and conflict between their roles of medical advisor and behavioral change counselor. These barriers are probably related to the context in which nurses have to work. Nurses often start with biomedical examinations, and then counsel patients towards behavior change. However, lack of skills and self-efficacy contributes to using less effective strategies such as giving advice, and not using more effective strategies such as identifying and addressing barriers to change or patient concerns. Nurses find it generally difficult to deal with patient resistance, and may resort to controlling communication, such as interrupting and disagreeing with patients.

The review of effective communication methods showed that training nurses in patient-centered counseling does not seem helpful in overcoming these barriers, and may even have adverse effects on patients' clinical outcomes. Rather, limited evidence suggested that nurse communication may be effective when counseling is based on psychological principles of self-regulation, notably goal setting, incremental performance accomplishments, and action planning. All communication should support patient autonomy through a relationship that is built on mutual trust, leading nurses and patients seek to cooperation and share responsibility.

In **Chapter 5**, the 5As Model was used to assess if, and how, nurses applied the five key elements of self-management support, because the previous chapter indicated that communication effectiveness may benefit from applying theory-based behavior change counseling. The 5As Model is an evidence- and theory-based counseling model that can be used for both applying and evaluating communication. The 5As refer to Assess current risk behaviors, Advise behavior change,

Agree upon clear goals for behavior, Assist in addressing barriers and securing social support, and Arrange follow-up contact. When applied integrated and consecutively, the 5As result in an individualized action plan, describing behavioral goals and strategies to reach these goals. In this Chapter, an existing instrument was used to evaluate recordings of seven practice nurses with 66 patients. Besides evaluating whether As were applied, applied As were compared with quality criteria to provide an in-depth assessment.

Results showed that nurses assessed health behaviors in practically every consultation. Individual follow-up meetings were arranged as part of standard care. However, in less than half of the consultations nurses advised behavior change. Goals setting and assisting patients to overcome barriers to behavior change were used even less. Comparing applied As with quality criteria revealed that nurses mostly ignored existing beliefs and emotions related to health behaviors. Furthermore, behavioral assessment was unspecific, thus hampering concrete advice giving and subsequent goal setting. When barriers to health behaviors were discussed, the hindering effects of barriers were often confirmed without brainstorming strategies to overcome them. Overall, important elements of self-management support were not applied or not applied properly. It was therefore recommended that nurses be trained in performing assessments that form the base for specific advice, goals setting and addressing barriers. Communication may also benefit when nurses learn how to combine being medical expert and a behavioral counselor, for example, by clarifying both roles to patients.

Chapter 6 offers a summary of the conclusions of the three empirical papers and the literature review, which allows to relate the most important insights to each other and draw conclusions that exceed the findings of the single papers. The cases of HIV and type 2 diabetes mellitus are compared, and key study findings are compared to existing literature, ending with avenues for future research and practical recommendations for health communication.

Drawing on the papers, the importance of resources such as sense of control and social support is discussed, both outside and inside health care settings. It is described how control perceptions and social support are related, and how interpersonal health communication may augment these resources in order to support self-management. The comparison of HIV care and diabetes care points to similarities and differences in current communication practices that are relevant for self-management support.

The findings of this thesis are compared to the literature under three broad themes that dominate the literature surrounding self-management support: patient empowerment and patient-centered care, control and support in psychology, and implications for self-management support. Contributions to the literature are followed by suggestions for future research, focusing on the potential of control constructs to clarify and unify theories and studies in the field of self-management; on matters of responsibility taking and sharing in health communication; and on testing the effectiveness of training providers to communicate using three main competencies: to support patient control perceptions, to build supportive relationships, and to use theory-based behavior change techniques. Finally, recommendations for practice offer concrete suggestions to improve or maintain communication effectiveness, for individual providers as well for the health care system. These suggestions include being aware of – and trying to elicit – patients' underlying control perceptions and needs, as well as the strategies patients use to increase their sense of control. Supporting self-management through supporting control perceptions can be accomplished through building a supportive relationship, and by addressing issues and concerns that may threaten perceptions of control. Finally, when the provider has a behavioral change agenda, systematic use of theoretically-based communication methods is likely to be most effective.

Samenvatting

Wereldwijd vormen chronische ziekten een enorme humanitaire en economische last. Op individueel niveau moet patiënten zelf leren omgaan met de gevolgen van hun chronische ziekte, een proces dat zelfmanagement wordt genoemd. Patiënten kunnen op veel verschillende manieren aan zelfmanagement doen, waarmee ze hun eigen gezondheid en welzijn beïnvloeden. Omdat chronisch zieke patiënten regelmatige zorggebruikers zijn, kan zelfmanagementondersteuning daarnaast helpen om kosten voor de gezondheidszorg te verminderen. Hoe interpersoonlijke communicatie tussen patiënten en zorgverleners daadwerkelijk zelfmanagement kan ondersteunen is een gebied dat nader onderzoek behoeft.

In **Hoofdstuk 1** wordt het onderzoek in dit proefschrift geïntroduceerd door de relaties tussen chronische ziekten, gezondheidsgedrag en gezondheidscommunicatie te bespreken. De wereldwijde stijging van chronische ziekten zoals hart- en vaatziekten, diabetes en SOA's kan grotendeels worden toegeschreven aan gezondheidsgedrag zoals roken, lichamelijke inactiviteit, ongezonde voeding en onveilige geslachtsgemeenschap. Ondanks grote investeringen in interventies om gezond gedrag te bevorderen is het effect van deze interventies vaak beperkt en kunnen dit soort interventies naar verwachting niet het tij keren op populatieniveau. Daarom zullen steeds meer mensen een chronische ziekte krijgen, waarvoor zij behandeld zullen worden in de gezondheidszorg. Deze ontwikkeling heeft gevolgen voor de manier waarop met patiënten het beste gecommuniceerd kan worden over hun ziekte.

Patiënten met een chronische ziekte moeten voor zichzelf zorgen, omdat hun ziekte niet kan worden genezen en omdat hun dagelijkse beslissingen de progressie van hun ziekte beïnvloeden. Patiënten moeten hun ziekte zelf managen. De regelmatige bezoeken van patiënten aan hun zorgverleners bieden een kans voor ondersteuning van deze zelfmanagement, omdat gezondheidsgedrag vaak al een regelmatig onderwerp van bespreking is. Daarnaast wijst onderzoek uit dat advies van zorgverleners en interpersoonlijke communicatie effectiever zijn dan massamediale communicatie en gemedieerde persoonlijke communicatie (bijv. via e-mail of telefoon).

Echter, zelfmanagement kan op verschillende manieren worden gedefinieerd en overeenkomstig de verschillende definities kan ondersteuning van zelfmanagement diverse vormen aannemen. Een belangrijk verschil is dat sommige definities

zelfmanagement beschrijven vanuit het perspectief van de patiënt, terwijl andere definities meer normatief zijn door te stellen wat patiënten moeten doen vanuit medisch oogpunt om progressie van de ziekte te voorkomen. In dit proefschrift wordt zelfmanagement fundamenteel gezien als een zaak van de patiënt en gericht op het behoud van welzijn. Patiënten doen dit door het managen van de medische kant, het omgaan met de functionele beperkingen als gevolg van de ziekte en tot slot het omgaan met de emotionele gevolgen ervan. Een algemeen doel van dit proefschrift is om een beter begrip te krijgen van hoe zelfmanagement effectief te ondersteunen is tijdens interpersoonlijke gezondheidscommunicatie, vanuit het perspectief van de patiënt.

Vroege studies over zelfmanagement geven aan dat controle een centraal construct is in het verklaren van de effectiviteit van zelfmanagementondersteuning. Een gevoel van controle over de ziekte, of hoge eigen-effectiviteit met betrekking tot specifiek zelfmanagementgedrag, kunnen bijvoorbeeld gezondheid en welzijn van patiënten voorspellen, maar ook gezondheidsgedrag positief beïnvloeden. Daarom is het uitgangspunt van dit proefschrift om zelfmanagementondersteuning te zien als het ondersteunen van de daadwerkelijke en waargenomen controle van patiënten over hun ziekte. Het onderzoeken van patiënt-zorgverlenercommunicatie kan verdere conceptuele en praktische inzichten bieden omtrent hoe communicatie zelfmanagement kan ondersteunen. De specifieke doelstellingen van dit proefschrift zijn: a) om de controlefactoren te verkennen die kunnen bijdragen aan variatie in gezondheidsgedrag; b) om voorkeuren van patiënten te onderzoeken voor zorgverlenercommunicatie die uiteindelijk gericht is op ondersteuning van zelfmanagement, en hoe zorgverleners kunnen voldoen aan deze voorkeuren; en c) te onderzoeken wat zorgverleners verhindert of juist helpt om zelfmanagement effectief te ondersteunen.

Zelfmanagementondersteuning door middel van communicatie is onderzocht voor twee chronische ziekten waarvoor zelfmanagement belangrijk is: HIV en diabetes mellitus type 2. Bij beide ziekten beïnvloedt zelfmanagement de progressie ervan, en bovendien doen patiënten aan zelfmanagement met het oog op hun welzijn, die kan worden aangetast door zowel de fysieke als sociale gevolgen van het hebben van HIV of diabetes type 2. Daarnaast geldt dat communicatie door zorgverleners effecten heeft op uitkomsten voor beide groepen patiënten, maar is er meer inzicht nodig in hoe zorgverleners kunnen communiceren om zelfmanagement effectief te ondersteunen. Het onderzoeken van zelfmanagementondersteuning voor twee verschillende ziekten biedt ook een bredere empirische basis en een beter begrip van de gebruikte concepten.

Niet alleen wordt zelfmanagementondersteuning voor twee chronische ziekten bekeken, ook worden in de vier empirische studies van dit proefschrift verschillende methodes gebruikt, waaronder een cross-sectioneel surveyonderzoek (Hoofdstuk 2), een thematische analyse van interviews met HIV-patiënten en hun zorgverleners (Hoofdstuk 3), een literatuurstudie naar communicatie in de diabeteszorg (Hoofdstuk 4), en een analyse van opgenomen gesprekken tussen praktijkondersteuners en diabetespatiënten (Hoofdstuk 5). In Hoofdstuk 6 worden de bevindingen van de afzonderlijke hoofdstukken besproken en algemene conclusies gepresenteerd in het licht van de onderzoeksdoelstellingen.

Hoofdstuk 2 dient als startpunt voor een centraal idee in dit proefschrift, namelijk dat de perceptie van controle een effect heeft op de gezondheid, hetzij direct, hetzij indirect door het effect ervan op gezondheidsgedrag. Zoals betoogd hebben controleconstructen een belangrijke rol in zelfmanagement en kunnen ze theoretisch gezien zowel oorzaak als resultaat daarvan zijn. Percepties van controle kunnen ook een onderdeel zijn van een psychosociale reservecapaciteit die sociaaleconomische gezondheidsverschillen helpt verklaren. Mensen uit de lagere sociaaleconomische strata hebben over het algemeen minder psychosociale hulpbronnen, zoals waargenomen controle over het leven en ervaren sociale steun, terwijl ze tegelijkertijd te maken hebben met meer stressoren die deze hulpbronnen belasten. Met minder hulpbronnen en meer stressoren hebben lagere sociaaleconomische groepen een psychosociale achterstandspositie, die slechtere objectieve en zelf-gerapporteerde gezondheid helpt verklaren, evenals hun suboptimale gezondheidsgedrag. Daarom werd in dit hoofdstuk onderzocht of hulpbronnen en stressoren de relatie tussen opleidingsniveau en gezondheidsgedrag mediëren. Bijkomende doelstellingen waren om te onderzoeken of het ontbreken van hulpbronnen en de aanwezigheid van stressoren kunnen worden weergegeven met een enkele onderliggende factor (d.w.z. de afwezigheid van een hulpbron heeft eenzelfde effect als de aanwezigheid van een stressor), en of een cumulatieve maat van stressoren en hulpbronnen een sterker effect heeft op gedrag dan de afzonderlijke maten.

Cross-sectionele data werd verzameld onder 3050 inwoners van de stad Utrecht met betrekking tot sociaaldemografische variabelen, psychosociale hulpbronnen, stressoren en gezondheidsgedrag. De resultaten toonden aan dat hogere niveaus van stressoren en lagere niveaus van hulpbronnen inderdaad kunnen worden vertegenwoordigd door een enkele factor. Daarnaast hadden mensen met lagere opleidingsniveaus over het algemeen minder psychosociale hulpbronnen en rapporteren ze hogere stressoren. Stressoren en hulpbronnen medieerden gedeeltelijk de relatie tussen opleidingsniveau en lichaamsbeweging, ontbijtfre-

quentie, groenteconsumptie en roken. Financiële stress en een slechtere ervaren gezondheid waren sterke mediërende stressoren, terwijl waargenomen controle over het leven en sociale steun sterke mediërende hulpbronnen waren. Echter, de relatie tussen sociaaleconomische positie en gezondheidsgedrag was bescheiden, terwijl de directe associaties tussen stressoren en hulpbronnen met gezondheidsgedrag aanzienlijk waren. Daarom werd geconcludeerd dat de aanwezigheid van stressoren en afwezigheid van hulpbronnen sociaaleconomische verschillen in gezondheidsgedrag helpt verklaren, maar dat het aanpakken van hulpbronnen en stressoren door middel van gezondheidscommunicatie de bevolking als geheel ten goede kan komen. De aanzienlijke impact van slechtere ervaren gezondheidsstatus op gedrag geeft aan dat patiënten inderdaad ondersteuning nodig hebben met het omgaan met een chronische ziekte. Hun gevoel van controle versterken en het bieden van sociale steun zijn mogelijke manieren om dit te doen.

Hoofdstuk 3 richt zich directer op ondersteuning van zelfmanagement door de communicatievoorkeuren van HIV-patiënten te onderzoeken. In dit hoofdstuk wordt verder gebouwd op studies waaruit blijkt dat de communicatie met zorgverleners belangrijk is voor de ondersteuning van patiënten om zich aan te passen aan hun HIV status en om therapietrouw te zijn, met het oog op het handhaven van hun gezondheid en kwaliteit van leven. Eerdere studies gaven ook aan dat de communicatie optimaal is wanneer die is afgestemd op de voorkeuren van patiënten. Patiënt-zorgverlenercommunicatie dient drie algemene doelstellingen, te weten uitwisseling van informatie, het opbouwen van een relatie tussen zorgverlener en patiënt, en de patiënt betrekken bij behandelingsbesluiten. Het doel van deze studie was om communicatievoorkeuren van HIV-patiënten te verkennen binnen elk van deze drie doelstellingen, en om te onderzoeken hoe patiënten afgestemde - of niet afgestemde - zorgverlenercommunicatie ervaren. Een tweede doel was het verkennen van de overtuigingen van zorgverleners over de voorkeuren van patiënten, alsmede hun perspectief op optimale communicatie. De gegevens werden verzameld door middel van interviews met 28 patiënten en 11 zorgverleners van twee academische ziekenhuizen.

De resultaten gaven aan dat HIV-patiënten strategisch communiceren met hun zorgverleners om hun gevoel van controle te verhogen. Voorkeuren van patiënten weerspiegelden hun cognitieve, emotionele en praktische behoeften, en patiënten hadden als impliciet doel om hun gevoel van controle over hun HIV status te verhogen door communicatie die deze behoeften dient. Door middel van een vertrouwensvolle relatie met een competente en oprecht betrokken zorgverlener beoogden patiënten hun gevoel van controle te verhogen via 'volmacht'. De relatie met de zorgverlener verschafte patiënten emotionele steun, maar stelde

patiënten ook in staat om hun problemen en zorgen te onthullen, waardoor er verdere mogelijkheden voor het verkrijgen van ondersteuning ontstonden. Deze studie toont dus verder het belang en ook het onderlinge verband tussen controle en sociale steun aan.

Zorgverleners waren zich terdege bewust van communicatievoorkeuren van patiënten en hun overtuigingen stemden over het algemeen overeen met deze voorkeuren. Echter, zorgverleners leken – tot op zekere hoogte – verantwoordelijkheid te nemen voor de behandeling en patiëntuitkomsten. Dit leek goed te passen bij de voorkeuren van patiënten die graag de verantwoordelijkheid met hun zorgverleners deelden, bijvoorbeeld door niet steeds of volledig betrokken te worden bij de medische besluitvorming. Het kon zorgverleners echter ook aanzetten tot het gebruik van overtuigende communicatie, zoals risicocommunicatie, wanneer patiënten niet therapietrouw waren. Bovendien bleek uit de interviews dat zorgverleners zich niet bewust waren van de controlebehoeften die ten grondslag liggen aan patiëntcommunicatie.

Hoofdstuk 4 betreft de communicatie tussen type 2 diabetespatiënten en hun belangrijkste zorgverleners die hun zelfmanagement ondersteunen. In Nederland is dat doorgaans de praktijkondersteuner van de huisarts (poh). Eén van de expliciete doelstellingen van de consulten van de poh is het verbeteren van gezondheid van de patiënt door zelfmanagement- ondersteuning. Uit eerder onderzoek blijkt dat patiënten problemen hebben met zelfmanagement, wat resulteert in onvoldoende beheersing van de bloedsuikerspiegel en andere cardiovasculaire risicofactoren. Optimale communicatie kan directe en indirecte gunstige effecten op de gezondheid en het welzijn diabetespatiënten hebben. Echter, uit onderzoek blijkt ook dat poh's in de praktijk moeite hebben met de communicatie met patiënten. Poh's worden opgeleid vanuit een voornamelijk biomedisch perspectief en kunnen het daarom moeilijk vinden om de verantwoordelijkheid voor de behandeling en behandelingsresultaten met patiënten te delen. Hierdoor gebruiken poh's mogelijk communicatiestrategieën die niet daadwerkelijk ondersteunend zijn. Bovendien kan het ondersteunen van zelfmanagement van patiënten problematisch zijn in termen van het veranderen van gezondheidsgedrag zoals voeding en lichamelijke activiteit. Deze gezondheidsgedragingen zijn vaak onderdeel van een jarenlange levensstijl die heeft bijgedragen aan de ontwikkeling van type 2 diabetes. Het doel van dit hoofdstuk is om praktische aanbevelingen te doen om de communicatie tussen poh en patiënt te verbeteren. Dit wordt gedaan door middel van een gestructureerde literatuurstudie gericht op, ten eerste, factoren die effectieve communicatie met diabetespatiënten kunnen belemmeren. Een tweede focus ligt op het bespreken van empirisch bewijs voor methoden die tot

doel hebben de communicatie effectiviteit van verpleegkundige communicatie te verhogen.

Veel voorkomende communicatiebarrières zijn het lichamelijk onderzoek, gebrek aan communicatieve vaardigheden en eigen effectiviteit, en het ervaren van conflicten tussen de rol van medisch expert en de rol van ondersteuner van gedragsverandering. Deze barrières zijn mogelijk gerelateerd aan de context waarin verpleegkundigen werken. Poh's beginnen namelijk vaak met biomedisch onderzoek en bespreken vervolgens gedragsverandering met patiënten. Echter, gebrek aan vaardigheden en eigen effectiviteit draagt bij aan het gebruik van minder effectieve strategieën zoals alleen advies geven. Effectievere strategieën, zoals het identificeren en aanpakken van belemmeringen om te veranderen, worden minder vaak gebruikt. Poh's vinden het moeilijk om om te gaan met weerstand van patiënten, en kunnen hun toevlucht nemen tot directieve communicatie, zoals onderbreken van en discussiëren met patiënten.

Uit de bespreking van effectieve communicatiemethoden blijkt dat het trainen van poh's in patiëntgerichte counseling niet effectief is in het overwinnen van deze barrières, en mogelijks zelfs nadelige gevolgen heeft voor klinische uitkomsten van patiënten. Daarentegen suggereert beperkt bewijs dat communicatie effectief kan zijn als het is gebaseerd op psychologische principes van zelfregulering, met name het stellen van doelen, het opdelen van doelen in kleine stapjes en actieplanning. De autonomie van patiënten kan worden ondersteund door middel van een relatie met de zorgverlener die is gebaseerd op wederzijds vertrouwen, waarbij poh's en patiënten samen werken en verantwoordelijkheid delen.

In **Hoofdstuk 5** wordt het 5A's Model gebruikt om te beoordelen of, en hoe, verpleegkundigen de vijf kernelementen van zelfmanagementondersteuning toepassen. In het vorige hoofdstuk is namelijk besproken dat communicatie effectief kan zijn door de toepassing theorie-gebaseerde counseling voor gedragsverandering. Het 5As Model is gebaseerd op theorie en empirisch bewijs en kan worden gebruikt voor zowel het toepassen als het evalueren van communicatie. De 5As verwijzen naar huidig gedrag beoordelen ('Assess'), adviseren van gedragsverandering ('Advise'), afspreken welke duidelijke doelen voor het gedrag ('Agree'), helpen bij het wegwerken van belemmeringen en het verkrijgen van sociale steun ('Assist'), en vervolgafspraken maken ('Arrange'). De geïntegreerde en achtereenvolgende toepassing van de 5A's resulteren in een individueel actieplan, waarin gedragsdoelen en strategieën om deze doelen te bereiken worden beschreven.

Er is een bestaand instrument gebruikt om opnames van zeven praktijkondersteuners met 66 patiënten te evalueren. Naast de beoordeling óf de 5A's worden toegepast, worden toegepaste A's vergeleken met kwaliteitscriteria om te evalueren hoe ze door poh's worden gebruikt.

Resultaten lieten zien dat de poh's gezondheidsgedrag in vrijwel ieder consult met de patiënt beoordeelden. Ook werden individuele vervolgafspraken gemaakt als onderdeel van de standaardzorg. Echter, in minder dan de helft van de consulten adviseerden poh's gedragsverandering. Het stellen van doelen en het bijstaan van patiënten om belemmeringen voor gedragsverandering te overwinnen werden nog minder gebruikt. De vergelijking met de kwaliteitscriteria liet zien dat verpleegkundigen vrijwel nooit bestaande overtuigingen en emoties met betrekking tot gezondheidsgedrag beoordeelden. Bovendien was de gedragsbeoordeling niet specifiek, waardoor het geven van concrete adviezen en het stellen van doelen werden belemmerd. Als belemmeringen voor gedragsverandering wel werden besproken, dan werden barrières vaak bevestigd maar zonder te brainstormen over strategieën om ze te overwinnen. Alles tezamen werden belangrijke elementen van zelfmanagementondersteuning niet of niet goed toegepast. Daarom wordt aanbevolen dat poh's worden getraind in het uitvoeren van assessments die de basis vormen voor specifiek advies, doelen stellen en het aanpakken van belemmeringen. Communicatie kan ook verbeteren wanneer poh's leren hoe de rollen van medisch expert en gedragscounselor te combineren, bijvoorbeeld door beide rollen te verduidelijken aan patiënten.

Hoofdstuk 6 biedt een samenvatting van de conclusies van de drie empirische hoofdstukken en de literatuurstudie, waardoor de belangrijkste bevindingen aan elkaar gerelateerd kunnen worden en conclusies kunnen worden gepresenteerd die de losse hoofdstukken overstijgen. HIV en type 2 diabetes worden vergeleken, en de belangrijkste bevindingen van het proefschrift worden vergeleken met bestaande literatuur. Hoofdstuk 6 eindigt met mogelijkheden voor toekomstig onderzoek en praktische aanbevelingen voor gezondheidscommunicatie.

Op basis van de voorgaande hoofdstukken wordt het belang van hulpbronnen zoals gevoel van controle en sociale steun besproken, zowel binnen als buiten de gezondheidszorg. De relaties tussen controlepercepties en sociale steun worden beschreven, en hoe interpersoonlijke gezondheidscommunicatie deze hulpbronnen kan helpen verhogen teneinde zelfmanagement te ondersteunen. De vergelijking van de zorg voor HIV-patiënten en diabetespatiënten wijst op overeenkomsten en verschillen in bestaande communicatie die relevant zijn voor zelfmanagementondersteuning.

De bevindingen van dit proefschrift worden vergeleken met drie terreinen binnen de wetenschappelijke literatuur die relevant zijn voor zelfmanagementondersteuning: empowerment van patiënten en patiëntgerichte zorg, controle en steun in de

psychologie, en implicaties voor zelfmanagementondersteuning. Bijdragen aan de literatuur worden gevolgd door suggesties voor toekomstig onderzoek, gericht op de potentie van controleconstructen om theorieën en studies op het gebied van zelfmanagement te verduidelijken en te verenigen; op het gebied van verantwoordelijkheid nemen en delen in gezondheidscommunicatie; en op het testen van de effectiviteit om zorgverleners te trainen gebaseerd op drie algemene competenties: controlepercepties van patiënten versterken, steunende relaties opbouwen, en theorie-gebaseerde gedragsveranderingstechnieken toepassen. Ten slotte bieden de aanbevelingen voor de praktijk concrete suggesties om communicatie te verbeteren aan zowel individuele zorgverleners als aan de gezondheidszorg als geheel. Zorgverleners kunnen bewust zijn van de onderliggende controlepercepties en -behoeften van patiënten, en proberen deze te identificeren. Dit geldt ook voor de strategieën die patiënten gebruiken om hun gevoel van controle te versterken. Het ondersteunen van zelfmanagement door het ondersteunen van controlepercepties kan worden bereikt door middel van het opbouwen van een steunende relatie en door het bespreken van problemen en zorgen die controlepercepties bedreigen. Tot slot wordt gesteld dat wanneer zorgverleners patiënten willen begeleiden naar gedragsverandering, het systematisch gebruik van theoretisch-gebaseerde communicatiemethoden waarschijnlijk het meest effectief is.

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