Physical activity in type 2 diabetes care

A critical narrative study

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Colophon

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VRIJE UNIVERSITEIT

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Mirjam Suzanne Stuij

geboren te Winterswijk

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Contents

Context **Changing understandings in policy and care**

Experiences **Healthcare dilemmas and daily life narratives**

Openings **Extended talking and walking practices**

Prologue

Exercise as ‘medicine’

‘I have a different outlook on life [now] because diabetes forced me to pay attention to my health more than I did: I do sport very much, and eat as healthy as possible. In all probability, this has prevented my overweight to turn into obesity. Paradoxically, without diabetes I would have been less healthy than I am now with diabetes.’

‘I easily meet the Dutch Standards for Healthy Exercise of 30 minutes: six days a week I cycle or walk briskly for an hour, at least. In addition, I participate in sport three times a week intensively. Still, I always have the feeling I have to exercise more to stay healthy, but I don’t have the energy and time to do so next to my full time job. This regularly gives me the feeling that I don’t do enough to control my diabetes, since my diabetes has worsened instead of improved over the years. The message that blood glucose levels improve by exercise often is presented as an absolute truth. Now that this isn’t the case for me, it gives me the feeling of failure.’

These are experiences a 33-year-old woman wrote down in late 2013 approximately seven years after she was diagnosed with type 2 diabetes. She participated in a survey study in which we asked her to explain the influence of this diagnosis on her life and on the meaning of sport and physical activity (Stuij et al., 2014). These reactions illustrate the starting point of this dissertation, which was a specific interest in the experiences of people with type 2 diabetes with the idea that exercise is a ‘medicine’.

Chapter 1

General introduction

Based on numerous biomedical and epidemiological studies, physical activity (including exercise) is considered a 'corner stone' in type 2 diabetes care alongside diet and medication (Pedersen & Saltin, 2006, p. 6).[1] As such, healthcare professionals are instructed to provide ongoing counselling and treatment on the topic of physical activity—in other words, to provide 'physical activity care'. In medical guidelines, physical activity care is often proposed as providing patients with information and advice or having discussions with the aim to encourage patients to increase physical activity (IDF, 2012; NHG, 2013, 2015). However, type 2 diabetes is a chronic condition characterised by disrupted blood glucose regulation and has become strongly linked to physical inactivity and (extreme) overweight in both its origin and management (O'Donnell, 2015; WHO, 2016a; Zheng et al., 2018). This means that healthcare professionals are instructed to stimulate people who generally are not inclined to be active.

Indeed, although previous studies have indicated that healthcare professionals often see physical activity counselling as an important part of their responsibility and feel confident in their abilities to provide it, they have also highlighted professionals' uncertainties about the effectiveness and uncomfortable feelings in providing detailed advice (Hébert et al., 2012). In addition, limited patient motivation or knowledge and a lack of experienced results of their counselling have frequently been mentioned as important barriers for professionals in physical activity or broader lifestyle counselling, adding to negative emotions and frustrations (Jallinoja et al., 2007; Jansink et al., 2010; Hébert et al., 2012; Huijg et al., 2015; Rushforth et al., 2016).

A negatively experienced relationship has also been also found among people with type 2 diabetes as an important obstacle to adhering to treatment recommendations (Vermeire et al., 2009). Other studies indicate that people with diabetes often attach great importance to professional lifestyle advice and consider it their own responsibility to integrate this in daily life, but they find it very difficult to do so and see support from family and healthcare professionals as a necessity (e.g., Moser et al., 2008; Wermeling et al., 2014). Moreover, in a survey of 5,600 Dutch people with diabetes almost half of the respondents (44%) reported that they hardly ever to never discussed lifestyle with their healthcare professional(s) (Hesselink et al., 2012).

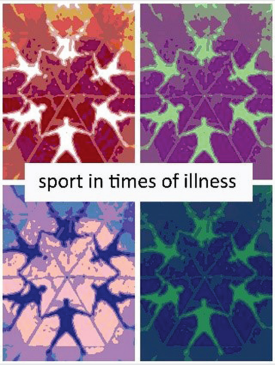
Against this backdrop, the central aim of this dissertation is to provide in-depth insights into experiences with physical activity (as an aspect of care) and openings for physical activity care for people with type 2 diabetes. These insights come from several empirical studies using a qualitative narrative approach, which means an explicit inclusion of the broader socio-political, research and care context, in order to understand how individuals make sense of their experiences. As the subtitle of this dissertation already revealed, this study is critical towards (im)possibilities and understandings offered by the broader context. By connecting the macro-level context with micro-level lived experiences, the purpose of this dissertation is to provoke thought and discussion on the topic of physical activity in type 2 diabetes care to contribute to its further improvement.

Outline of the introduction

The different chapters of this dissertation can be read on their own, because they present the empirical studies in ways that are common to current academic environments; most of them are based on peer-reviewed work, namely journal papers and a book chapter, and written together with other authors (see also Text box 1.1). This general introduction aims to provide information relevant to the overall background and theoretical framework of these studies, and starts with a short introduction to people with type 2 diabetes in the Netherlands. The outline then follows the title of this dissertation. The main title, *Physical activity in type 2 diabetes care*, primarily emphasises the societal aspects and relevance of this study. In the first part of the introduction, a sketch of the broader research, political and societal context is provided, followed by an explanation of the organisation of Dutch type 2 diabetes care. This part ends with the topic of physical activity in type 2 diabetes care. The second part of the introduction explains the subtitle *A critical narrative study*. This refers to the scientific aspects and relevance of this dissertation captured by the three research central questions, the overall theoretical framework, the narrative qualitative approach and the researcher's position. The introduction is concluded with the further outline of this dissertation.

Text box 1.1: Study context

Most of the empirical studies in this dissertation were conducted as part of a larger research project entitled Sport in Times of Illness (2013–2018). The overall aim of this project was to study meanings people attach to sport and physical activity after diagnosis with a chronic illness. These were people with breast cancer, depression, HIV, or type 2 diabetes. Moreover, the purpose was to provide insight into experiences of relevant healthcare professionals in providing support and advice on physical activity and to study physical activity care practices



This project was a collaboration between Amsterdam UMC (VUmc, department of medical humanities) and Mulier Institute, and the research team consisted of Prof Dr Tineke Abma, Dr Agnes Elling, Mirjam Stuij, MSc. and Ester Wisse, MSc. A public partnership consortium was involved in the contextualisation, translation and dissemination of the results. See www.stzverhalen.nl for more information, results and narratives. The focus of this dissertation is on type 2 diabetes.

In addition, it is important to note that this study was conducted in the Netherlands. This means that the setting in which data collection took place has a specific care framework, sport and physical activity infrastructure and other characteristics. These are further explained below or in the relevant chapters. This is of importance in a study on meanings, because these specifics influence possibilities and impossibilities, attitudes and hence meanings. However, this does not mean that the results and implications are limited to and only relevant for people living in the Netherlands. Indeed, these insights also relate to more general and global issues and developments and therefore placed in the international literature and debates about the topic.

People with type 2 diabetes in the Netherlands

In 2018, almost 1.2 million people in Dutch primary care had diabetes, with slightly more males than females (VZinfo, 2019). This included individuals with type 1 and type 2 diabetes, the most common forms of diabetes, and it was estimated that approximately 9 percent had type 1 (VZinfo, 2019; Vektis, 2019). However, the clinical presentation and progression of diabetes may vary considerably, and not all individuals easily fit into a category at the time of diagnosis (ADA, 2019).[2] The prevalence of diabetes increases with age; about 10 percent of people aged 40 year and older have diabetes (Vektis, 2019). Most people diagnosed at a young age have type 1 diabetes, while most people diagnosed at a later age have type 2 diabetes (VZinfo, 2019).

Although physical inactivity, unhealthy diets and obesity are considered the most important causes for type 2 diabetes, a complex combination of other factors are found to be important, like genetic and early developmental factors (Chen et al., 2012; Zheng et al., 2018). This is further intertwined with intersecting social status categories, like socioeconomic status and ethnicity. Similar to other high-income countries, in the Netherlands, type 2 diabetes is more prevalent among people with a lower socio-economic status and/or a non-western migrant background, especially among people from Turkish, Moroccan or Surinamese descent (Bindraban et al., 2008; Ujcic-Voortman et al., 2009; Agardh et al. 2011; Sacerdotte et al., 2012; Qi et al., 2019; VZinfo, 2019). In general, these groups experience more housing and work problems. These problems are related to health and daily living conditions and might preclude attention to healthy living (Horstman & Houtepen, 2005; CSDH, 2008; Heutink et al., 2010).

Type 2 diabetes is related to a lower quality of life, especially for people who are hindered by fluctuating blood glucose levels, complications of diabetes, overweight, or other illnesses (Wermeling et al., 2012; NHG, 2013). Frequent symptoms of fluctuating blood glucose levels are thirst, increased urination, and neurogenic pains, while long-term complications include blindness, kidney failure, heart attacks, stroke, and lower limb amputation (WHO, 2020).

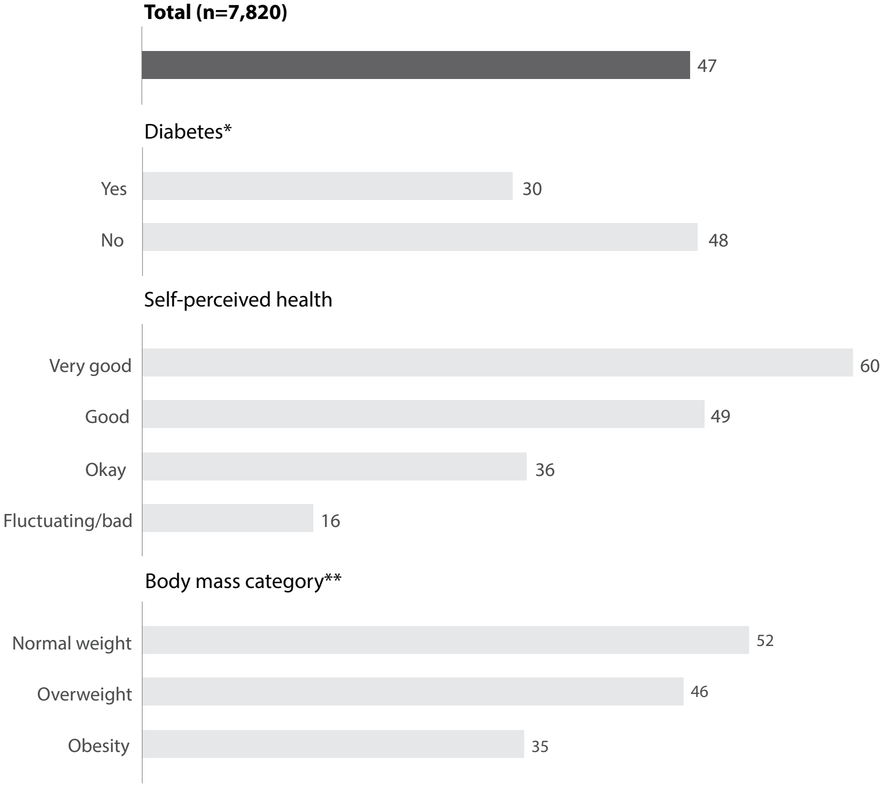
Although estimations diverge, the number of people with a secondary chronic condition besides type 2 diabetes—also called ‘co-morbidity’ in medical terms—is considered high.[3] In a study following 714 people diagnosed with type 2 diabetes over about 17 years, more than 80 percent had at least one other chronic condition at the time of diagnosis and a quarter of those without developed a second condition within the first year (Luijks et al., 2012). Prevalent conditions include cardiovascular diseases, musculoskeletal diseases, and mental disorders (Luijks et al., 2012). Among people aged 40 years and older, the combination of diabetes and cardiovascular disease with either COPD/asthma or cancer is common (Vektis, 2019).

It is estimated that the number of people with type 2 diabetes will increase in the future, and that it will be the third most prevalent chronic condition in 2040, besides arthritis and neck/back problems, as it was in 2015 (VTV, 2018). In 2015, diabetes was ranked third in the ‘burden of disease’ in the Netherlands, a measure to indicate health loss in a population as a result of disease. This measure is determined by the number of ‘lost years’, which are years lost due to premature death and years living with a decreased quality of life (so-called Disability Adjusted Life Years; VZinfo, 2015).

Physical activity behaviour

People with diabetes in the Netherlands meet the physical activity guidelines advised for health less often than people without diabetes (see Figure 1.1). Similar differences are found for weekly sport participation (resp. 29 and 52% in 2018; CBS i.s.m. RIVM, 2020a). The sports most popular among people with diabetes are fitness, walking and swimming (CBS i.s.m. RIVM, 2020a). Participation rates, regarding both physical activity and sport, are also related to other aspects of health and illness, like self-perceived health and body weight (see Figure 1.1). In addition, participation is related to socio-economic and cultural aspects; people with a higher level of education, higher income, and without a migration background, more often meet the physical activity guidelines and practice sport weekly, than those with a lower level of education, lower income, or with a non-western migrant background (CBS i.s.m. RIVM, 2020b, 2020c).

Figure 1.1 Percentage Dutch adults (18+) meeting the physical activity guidelines in 2018



Source: Gezondheidsenquête/Leefstijlmonitor, CBS i.s.m. RIVM, 2020a; * not further specified; ** normal weight is defined as BMI < 25kg/m^2, overweight as 25-30 kg/m^2 and obesity as > 30 kg/m^2

Physical activity in healthcare: the broader research, political and social context

In August 2017, the Health Council of the Netherlands, an independent scientific advisory body for the government, published its ‘physical activity guidelines’ (Health Council of The Netherlands, 2017). These guidelines prescribe the amount of physical activity recommended for health benefits, which for adults is 150 minutes of activity of moderate intensity per week plus muscle and bone-strengthening activities twice per week. This means, for instance, cycling or walking combined with climbing stairs or using dumbbells. These guidelines were formulated at the request of the minister of health, welfare and sport, because she wanted one measurable and clear guideline to replace the three former guidelines, plus an update of the scientific evidence on the relation between health and physical activity (VWS, 2016).

This request for an update implies that the knowledge underlying physical activity guidelines is not something static, nor is it something agreed or similarly acted upon worldwide, as illustrated by the considerable variability found in physical activity recommendations worldwide (Parrish et al., 2020). This example also introduces two powerful ‘fields’ that have an impact on the field of physical activity care, namely research and governmental policy. For instance, these fields have an impact on the content of care protocols, the organisation of care in terms of legal and financial frames and dominant understandings related to the topic of physical activity and health. Another ‘field’ that is of importance and intricately interwoven in this context is that of broader societal perceptions. These fields are briefly introduced.

Physical activity in health research

Although attention to the relation between physical activity and health is far from new, systematic research began in the mid-20th century. In 1949, Jeremy Morris, ‘the man who invented exercise’ according to the *Financial Times* (Sept 2009), observed health differences in men working on the London double-decker buses: although both drivers and conductors had similar social backgrounds and status, the ones sitting behind the wheel more frequently had heart disease than those climbing the stairs all day. Four years later, his study ‘Coronary heart disease and physical activity of work’ was published in *The Lancet* (Morris et al., 1953).

Exercise epidemiology became a new field of research, and many studies followed. Today, not only coronary heart disease but the cause and solution of all kinds of diseases and chronic conditions are linked to physical (in)activity, including type 2 diabetes as well as cancer, depression, pulmonary diseases, musculo-skeletal disorders and overall premature mortality (U.S. Department of Health and Human Services, 1996; Warburton et al., 2006; Lee et al., 2012;

Pedersen & Saltin, 2006, 2015). In 2012, *The Lancet* published a special series on physical inactivity, stating that it is 'the fourth leading cause of death worldwide' (Kohl et al., 2012, p. 294). As such, the overall message is that physical activity is good for health and inactivity is unhealthy and even deadly.

More or less simultaneously with the beginning of exercise epidemiology, 'health behaviour' became a new focus of medical scientists and psychologists, who shifted their attention from human behaviour as a simple product of biological characteristics like instincts, habits and neurological mechanisms towards the agency of individuals who could autonomously choose to act to maintain or regain their health (Armstrong, 2009). From the 1970 onwards, high-impact medical journals like *JAMA* and *The New England Journal of Medicine* increasingly included articles on different aspects of physical activity related to health and the need for exercise advice in the clinical setting (Berryman, 2010).

This increasing focus on physical activity behaviour in relation to health fits with a process of medicalisation—a process in which everyday activities are problematised over time or certain behaviours are framed as deviant and become a legitimate target for healthcare interventions (Armstrong, 2009; see also Lupton, 1995; Wheatley, 2005; Cheek, 2008). In addition, human agency was explicitly added as an ingredient, implying a change towards an emphasis on individual choice for behaviour. Overall, exercise epidemiology and medical research became important referees of health problems, providing ever 'better' and more 'objective' evidence and resulting in prescriptions to people on how to live (cf. Horstman & Houtepen, 2005)—literally illustrated by so-called Exercise on Prescription programmes (e.g., Sørensen et al., 2006).

Physical activity as part of governmental health policy

Physical activity is an important topic in current Dutch health policy. This topic was introduced by the 2006 governmental public health policy document *Opting for a healthy life*, which features a picture of people running along the beach on its front cover to illustrate this healthy lifestyle (Ministry of Health, Welfare and Sport, 2006). In this document, the government emphasised that 'diseases of affluence' such as type 2 diabetes and complications thereof could largely be prevented when people 'opt for healthy lifestyles' with 'plenty of exercise and enjoying healthy food' (pp. 8-12). The health policies *Being healthy, staying healthy* and *Health close to people* further elaborated on and emphasised the importance of lifestyle (Ministry of Health, Welfare and Sport, 2008a, 2012). In the latter document, the government explicitly introduced physical activity and exercise as a new spearhead of their health policy, because it 'promotes both physical health and mental wellbeing' (p. 14).

Although the 2006 document clearly illustrates the rise of 'lifestyle politics' in the Netherlands (Dehue, 2014), lifestyle was not a new topic. Worries about the stagnating life expectancy of Dutch men in the 1970s, mainly due to heart and vascular disease and traffic accidents, informed upcoming governmental ideas about the importance of lifestyle and behaviour and the individual's possibilities and responsibility for health and behaviour change (SCP, 1975; Boer & Kooiker, 2012). Internationally, the medical and public health 'problem' of exercise and broader lifestyle behaviour became a topic in several distinct governmental publications in Canada, the United Kingdom and the United States and in reports of the World Health Organisation (Lalonde, 1974; Department of Health, 1976; U.S. Department of Health, Education, and Welfare, 1979; WHO, 1986).

These publications were considered a turning point in policy because of the introduction of the term 'health promotion'—aimed at the whole population instead of people who are ill—and a new focus on prevention of non-communicable diseases and lifestyle behaviour, including a strong emphasis on the responsibility of the individual for maintaining health (Lupton, 1995). In addition, the governmental publications of Lalonde (1974) and the British Department of Health (1976) impacted healthcare policies and organisation because they put a clear emphasis on the importance of both individual responsibility and lifestyle behaviour as topics in healthcare, also prompted by needs to reduce healthcare costs (Foth & Holmes, 2018; Thompson et al., 2018).

Behavioural health promotion strategies that followed—often focussing on health education, with the underlying idea that providing knowledge on health risks and healthy behaviour would urge people to change their behaviour—were found to be most effective among people with higher educational and income levels, which are those who generally live more 'healthy' (Nutbaum, 2000; see also Busch & Schrijvers, 2010; Ball, 2015). Nonetheless, the idea of chronic disease as a result of individual lifestyle choices has remained dominant in governmental policies from the 1970s onwards, and health promotion programmes that target lifestyle behaviour to prevent chronic diseases have been normalised and gain public acceptance easily (Baum & Fisher, 2014).

Societal perception about physical activity and health

These perceptions also resound in individual motivations for and ideas about physical activity. Indeed, health-related arguments are important—if not the most important—reasons for participation in sport and physical activity in the Netherlands (van den Dool, 2019). In addition, ideas on the importance of physical activity for health have also increasingly appeared in the media, as these first paragraphs from an opinion piece published in a Dutch national newspaper illustrate:

> *General practitioner has to prescribe peppers, not pills*
> The Netherlands are ill and heavy. The numbers speak for themselves. Nearly half of all adults are overweight and over five million Dutch people suffer from one or more chronic conditions. We all know why this is. It has even been neatly scientifically proven. We eat the wrong things, we exercise too little, and we have too much stress. And because of this we get ill, or fat first and then ill.
>
> This is why 900,000 Dutch people suffer from diabetes type 2 at the moment. And every year an Amsterdam Arena [the largest football stadium in the Netherlands] full of new patients is added to this list. In total, 55,000 men and women per year, 150 a day. People, like you and us, who will lose out on their quality of life and are expected to die ten years earlier as a result of this disease.
>
> So, the burden of disease is big. So are the costs. According to the Statistics Netherlands, the Netherlands spent almost 95 billion euros on healthcare in 2015. According to the Netherlands Bureau for Economic Policy Analysis, an average family spends almost a quarter of its income on healthcare. Calculated, this could increase up to between 30 and 40 percent in 2040. A substantial sum of money we can do a lot of different nice and useful things with.
>
> But there is good news too. Illness and its associated costs could be avoided if we made different choices. As an individual, as a society and as a healthcare system.
>
> Suffering and costs as a consequence of lifestyle-related diseases, such as type 2 diabetes, obesity, rheumatism, and gastrointestinal disorders, could be limited if we started on working on lifestyle as medicine. (*NRC Handelsblad*, April 2017, translation by the author)

The authors, a general practitioner and two other professionals, emphasised their concerns about the prevalence of overweight and chronic conditions by using ‘we’: this is something that concerns all of ‘us’ (i.e., the Dutch). The authors therefore emphasised the societal importance. Moreover, they referred to a sort of common sense, stating, ‘We all know how this happened.’ It is something obvious based on general knowledge. However, these authors did not mention that the ‘we’ in relation to eating the wrong things, exercising too little or having too much stress is not evenly spread among individuals in the Netherlands, nor is the prevalence of type 2 diabetes—as introduced in the beginning of this chapter. The implications of these differences for healthcare practices are a topic throughout this dissertation.

Care for people with type 2 diabetes

Since type 2 diabetes is a chronic condition, the main aim of care is to prevent and treat symptoms and complications by maintaining blood glucose levels within ‘normal’ ranges (glycaemic control; NHG, 2013). Type 2 diabetes care in the Netherlands is of a very high quality, especially because of the multidisciplinary team approach, access to care and treatment for all patients, the structural integration of diabetes education as a topic of care and the national Care Standard for type 2 diabetes, which is strictly followed by general practitioners (Garrofé et al., 2014). This Care Standard was developed by the Dutch Diabetes Federation (NDF), approved by all national patient and healthcare professional associations and describes the standard for treatment activities that are necessary for ‘good diabetes care’ based on evidence-based guidelines and law (NDF, 2018; Struijs & Baan, 2011).

These treatment options are paid for by health insurers as part of the basic insurance every Dutch citizen is obliged to have. More specifically, these payments are part of a bundled payment system, which implies that health insurers pay a single fee to care groups—legal entities often representing healthcare professionals—for all the primary care a patient with type 2 diabetes needs (Bakker et al., 2012). This is regardless of the number of consultations a patient needs and is part of the type 2 diabetes integrated care programme, which is called *Ketenzorg* in Dutch. This system was introduced in 2010, and first evaluations indicated that the organisation and coordination of care and collaboration among different healthcare professionals improved as did protocol adherence, although the administrative burden of professionals increased and the quality assurance measures seemed to be a point of attention (Bakker et al., 2012; Struijs & Baan, 2011, Struijs et al., 2012).

Over 85 per cent of Dutch people with type 2 diabetes are treated in primary care (Vektis 2015), where the general practitioner has the final responsibility. When patients are in need of complex care—for instance, when treatment does not result in glycaemic control or when people have certain risk factors or consequences of complications—referral to or consultation with an internist in secondary care is advised (Sluiter et al., 2012). In primary care, most care is handed over to ‘practice nurses’ (*praktijkondersteuners* in Dutch), and in secondary care nurses specialised in diabetes can be reassigned tasks by the internist (NDF, 2018; Struijs et al., 2012). These nurses are considered to have an important role in patient education and encouraging of adherence, such as to lifestyle prescriptions (Raaijmakers et al., 2013).

Physical activity in type 2 diabetes care

According to the Dutch type 2 diabetes guideline for general practitioners, the instructions on physical activity are to

> encourage the patient to be sufficiently physically active (half an hour a day and an hour a day when they are overweight), and to work on improving their fitness. The aim is to be active with moderate intensity for at least 2.5 hours a week. Even without weight loss, this has a beneficial effect on glycaemic regulation and on (death from) cardiovascular disease. A small increase in physical activity is already beneficial. Advise a lifestyle that matches the capabilities, motivation, and daily routine of the patient. For most overweight patients and for many elderly people, brisk walking, cycling, or swimming are easiest to accomplish. (NHG, 2013, p. 6-7; translation by the author)

According to the earlier mentioned survey study among Dutch people with diabetes (Hesselink et al., 2012), respondents most often reported that they discussed lifestyle with their diabetes nurse (60%), internist or general practitioner (both 33%). The practice nurse was mentioned by only a quarter (27%) of respondents. In addition, 30 per cent of the respondents highlighted specific information needs; almost half of them mentioned the need for more information about ‘diabetes in daily life’ and 35 per cent about ‘sufficient physical activity’.

Frequently mentioned barriers for physical activity counselling among healthcare professionals were lack of time in general, short consultation time and lack of training or knowledge on how to provide counselling (Jansink et al., 2010; Hébert et al., 2012; Huijg et al., 2015). Active professionals were found to be more likely to address the topic (Hébert et al., 2012), although professionals might also consciously leave their own daily life practices outside their care practices (Laws et al., 2008), possibly with the intention to adhere to ‘objectivity’ in medical practice. Moreover, Dutch healthcare professionals indicated that the role of physiotherapists in type 2 diabetes care seemed unclear and, according to physiotherapists themselves, too limited (Raaijmakers et al., 2013).[4]

Overall, there is a large body of knowledge about people with type 2 diabetes and self-management skills, compliance with healthcare advice or barriers and facilitators of physical activity (e.g., Korkiakangas et al., 2009; Vermeire et al., 2007; Barton et al., 2016). While useful, such studies tend to focus on how changes in physical activity behaviour occur from a healthcare and patient perspective. They have less to say about how people negotiate their relation to physical activity *and* sport outside the medical domain, or from an ill person’s perspective (Frank, 2000). In addition, a meta-synthesis of studies on barriers to medication adherence illustrates key discrepancies in understandings of what patients require to improve their adherence; while professionals focus on providing more information about the physiological and biomedical effects, patients emphasise their difficulties in integrating medication regimens into their daily lives (Brundisini et al., 2015). These findings illustrate a divide between professionals' and patients' perspectives on care needs and the importance of the contexts in which people live.

A critical narrative study

Many studies on similar or closely related topics follow the epidemiological evidence on relations between physical activity behaviour and type 2 diabetes. This is often illustrated by the first sentences of the articles. For instance, Hébert and colleagues (2012, p. 625) began their systematic review on primary care providers' perceptions of physical activity counselling by stating, 'Insufficient physical activity is a serious public health concern, with multiple studies demonstrating an association between higher levels of physical activity and reduced morbidity and mortality.' Similarly, the systematic review of Korkiakangas and colleagues (2009, p. 416) begins, 'An increase in the number of sedentary adults is one reason behind today's continuously rising prevalence of type 2 diabetes.' These sentences are often followed by numbers to show the scale of 'the problem'—for instance, the number of inactive people.

These introductions are used to illustrate the urgency of the study presented and reveal the stance of the researchers. They follow the epidemiological studies that stress the importance of physical activity for people with diabetes. The current study takes a different perspective: one that is critical of the 'top-down' presentation of epidemiological evidence and instead aims to elicit what this evidence means to people and how it affects them in their daily lives or working practices. As such, this study combines a critical approach with a narrative one. With this, the aim is to offer a new perspective on physical activity as an aspect of care for people with type 2 diabetes, and contribute to thought and discussion on its further improvement. Therefore, the three main research questions of this dissertation are as follows:

1) What can we learn about physical activity (care) experiences from people with type 2 diabetes and healthcare professionals?
2) What can openings created by extended talking and walking practices add to an improvement of physical activity care?
3) How can the broader socio-political, research and healthcare context further support an improvement of physical activity care practices for people with type 2 diabetes?

These questions are answered in Chapter 9, which comprises the general discussion of this dissertation. First, an explanation of the overall study approach follows.

A theoretical framework with four main lenses

As illustrated in the previous sections, this study is strongly embedded in a social, political and normative context—a context that defines 'good' and 'bad' physical activity behaviour in relation to health, and especially to type 2 diabetes. Since I, the author and main executing researcher, also work and live in this context, it is important to explain how I relate to the topic of study, and introduce myself, my supervisors (and co-authors of most of the chapters) and the overall theoretical framework of this study (Collins & Stockton, 2018). This framework was not fixed from the beginning but is rather something I further developed over time, such as while listening to stories or observing in practice, in discussions about these field work experiences or writings with my supervisors, in conversations with our consortium partners and by a further reading of the literature. As such, this framework is embedded in the empirical research and based on a selection I considered fitting and relevant for the context studied.

Overall, I departed from a social constructivist epistemology, which means that I approach reality as socially constructed through lived experiences and interactions (Creswell & Poth, 2018).[5] To gain an understanding of this reality, I used four main theoretical lenses 'to think with' (Jackson & Mazzei, 2013). In these four lenses, the voices of my two supervisors can also be heard (see Chapter 7 for a further introduction to their voices). I did not use these lenses in a strict or systematic way, but they guided the questions I asked during different phases of fieldwork, analysis and writing. In other words, I used them to develop an understanding of the topic of study: physical activity care for people with type 2 diabetes. More specifically, they are interwoven in the empirical chapters in different ways and with different emphases (see Table 1.1) and serve as guides to answer the main research questions of this dissertation (Chapter 9).

Although these lenses have some overlap, they focus on different levels. The first two—healthism and system versus lifeworld—are more abstract lenses to focus on the (macro-level) societal and political context and the care context, respectively. These represent the critical part of this study. The other two—logic of care and narrative habitus—fit with the narrative approach and stem from and are embedded in the empirical research. These two put the focus on (micro-level) specificities of 'good' care practices and on how daily life and work experiences are shaped by the exchange of stories, respectively. These lenses are briefly introduced.

Societal and political level: healthism

Healthism (Crawford, 1980)[6] is a critical concept I use to question a dominant frame that is often taken for granted in our society and hence might not necessarily be noticed. This critical frame centres on the idea of rational and autonomous choices of individuals and their responsibility to work to achieve good health, maintain it and prevent illness (from getting worse). Crawford argued that from the 1970s onwards, personal responsibility for health became ‘the sine qua non of individual autonomy and good citizenship’ (Crawford, 2006, p. 112). As such, healthy living has become the equivalent of good living instead of part of it (Crawford, 1980).

This emphasis on individual responsibility clearly resonates with currently dominant neoliberalist perceptions, both societal and political (e.g., Wheatley, 2005; Cheek, 2008; Baum & Fisher, 2014). These perceptions are not only related to health and health behaviour but represent broader societal ideas about the relation between the role of (smaller) governmental and (larger) individual responsibilities. However, the Netherlands Scientific Council for Government Policy cautioned that ‘society today makes heavy demands on people’s self-reliance’ resulting in expectations and demands not everyone is capable of, and this not only includes a small group of ‘vulnerable’ individuals (WRR, 2019, p. 3; see also WRR, 2017).

In governmental health policy, this frame is illustrated by the previously described rise and dominance of ‘lifestyle politics’ from 2006 onwards, in which health is primarily considered ‘a matter of choice and merchandise’ (Dehue, 2014, p. 236; see also Mol, 2011). Indeed, motivated by concerns about an increasing number of people diagnosed with chronic illnesses with explicit reference to type 2 diabetes, the central message of the 2012 health policy was that ‘health must once again become a personal responsibility’, with lifestyle behaviour as a means to take this responsibility (Ministry of Health, Welfare and Sport, 2012, p. 18).

Related to type 2 diabetes, this self-responsibility frame is very dominant. Self-discipline regarding diet and exercise became central in diabetes management at the beginning of the 20th century, resulting in more general ideas that good health with diabetes was a consequence of adherence to advice and poor health of being careless (Feudtner, 2003; O’Donnell, 2015).[7] Indeed, the emphasis on physical activity behaviour in care protocols fits within a larger framework of self-management—a key aspect of type 2 diabetes care in which the individual’s control over diabetes is a central aim (IDF, 2012; see also Gomersall et al., 2011; Elissen et al., 2013).

Moreover, in research on behavioural interventions for people with type 2 diabetes, the responsibility for illness control and thus health is often placed at the locus of the individual patient (Gomersall et al., 2011), illustrating the importance of the broader (research) context in which dominant ideas are created and/or further confirmed. In addition, both medical research and policy often frame (extreme) overweight as a personal responsibility, resulting in a dominant societal blame frame at the level of individual behaviour and choice (Saguy, 2013; see also Pieterman, 2017).[8]

Organisation of type 2 diabetes care: system and lifeworld

I used Habermas' ideas on system and lifeworld (1984) as a lens to focus on different rationalities, or 'worlds', present in type 2 diabetes care. While the system world refers to a scientifically, technically, bureaucratically and impersonally driven rationality, the lifeworld is proposed to illustrate a value- and communication-based face-to-face rationality (Habermas, 1984). These worlds are considered structurally present in modern societies and hence in care contexts, resulting in an ongoing tension between them (van den Ende & Kunneman, 2008; Kunneman, 2015).

The rationality of the system world in (Dutch) type 2 diabetes care can be found in the organisation of the integrated care programme, and efficiency and effectiveness as dominant care frames (e.g., NDF, 2018). Guidelines for healthcare professionals are evidence based, have a focus on (strict) control of measurable results (e.g., blood glucose level, body weight, blood pressure) and are strictly followed (NHG, 2013; Garrofé et al., 2014; WHO, 2016b). This means that working according to rules and protocols, including a limitation in time and finances, is the standard.

In this healthcare (system) setting, recognition of the patient's lifeworld and its problems might not always be acceptable or easy to discuss (Mishler, 2005). This lifeworld represents the daily experiences of living with type 2 diabetes. As such, the topic of physical activity might be especially difficult, because it is a daily life practice entering care or being 'colonised' by the system world. Moreover, professionals also have daily life experiences with physical activity, either positive or negative and recent or long ago, and probably have (personal) opinions about it, such as in relation to their own health. Therefore, their lifeworlds might also enter physical activity care practices consciously or unconsciously, silently or aloud and helpfully or unhelpfully.

Physical activity care practices: logic of care

While the former two lenses are aimed at the (impact of the) broader context in which physical activity care is provided, the next two bring the focus to micro-level care practices and experiences. The logic of care, as proposed by Mol (2006), focuses on elements or specificities that fit with 'good' physical activity care practices. Importantly, 'good' is in quotation marks, because what is 'good' care is not something general or to be defined beforehand. Instead, it is very much dependent on the situation, the people involved, what they can and want to do and an acknowledgement that total control is impossible because of the whims of bodies.

As such, what 'good' care implies is not easily grasped. Mol (2006) has defined a logic as a meaningful connected cluster of ways of thinking and doing, and the main aim of a logic of care is the improvement of people's lives. Based on a case study on secondary care for people with diabetes in the Netherlands, Mol positioned this logic against another that is quite dominant in the current care context: a logic of choice in which (individual) informed and autonomous choice and action is the ideal.

Thinking and acting from a logic of choice begins with individuals who are equal to each other and thus have equal rights to choose for themselves and can make healthy choices in equal ways if they are provided with enough information (Mol, 2006). Related to the topic of physical activity, this is illustrated by the emphasis on diabetes education in care protocols and the governmental policies in which people can 'opt' for healthy lifestyles (e.g., IDF, 2012; Ministry of Health, Welfare and Sports, 2012; NGH, 2013). However, reasoning from a logic of care starts from the perspective that people are inherently interdependent but have different and varying needs that need to be specified again each time during consultations. This means that a 'local calibration' of scientific evidence and guidelines is needed to specify what a 'good' life entails to an individual at a specific moment, which is something all involved need to do together by 'tinkering'—trying what works and what does not (Mol, 2006)—such as in relation to types and amounts of physical activities, and where and with whom to participate in such activities.

An important requisite for good care is communication, meaning talking and listening to each other. Indeed, it *is* good care as well (Mol, 2006, p. 101). Exchanging experiences inside the consultation room helps to adjust different care activities to each other and to appropriate these for someone's daily life. This implies that exchanging stories is a moral activity; it is a part of 'good' care. Therefore, this lens brings an explicit focus to narrative aspects of ('good') physical activity care practices.

Storytelling: narrative habitus

The fourth lens I use is that of a 'narrative habitus' we all have (Frank, 2010). Following Bourdieu, Frank defined this narrative habitus as a shared repertoire of stories we easily recognise, as part of an 'inner library' that provides us with a sense of what stories or storylines are appropriate in a certain setting and which are not. This library helps us, on an embodied and mostly tacit level, to conform to common norms of storytelling. Conformation provides us with capital (power); deviation from these norms does not. In this sense, stories can connect or disconnect people (Frank, 2010).

People make sense of events and experiences by telling stories to each other, because this offers them the opportunity to reflect on and connect certain events and to give experience meaning (Riessman, 2008; Gubrium & Holstein, 2009). Experiences with illness are an important source for storytelling. Based on reading, listening to and thinking with many illness stories, Frank proposed three frequent underlying types of illness narratives: restitution, quest and chaos (Frank, 1995/2013). Each one has a certain plotline, or a recognisable narrative thread that shows how different story elements—like acts, events and choices—are understood and connected to each other (Polkinghorne, 1995; Murray & Sools, 2015).

The basic plot of this story is ‘yesterday I was healthy, today I’m sick, but tomorrow I’ll be healthy again’ (Frank, 1995, p. 77). In a quest plotline, the illness is presented as a journey or a challenge with both losses and gains, and the chaos narrative displays chaos, despair and life ‘never getting better’ (Frank, 1995, p. 97). Overall, these three common narrative types are differently appreciated and reacted to in our society. Although this appreciation is not something fixed and depends on the context and public, the restitution narrative—which often includes an important role of the medical world in this restitution—is generally considered the most legitimate, while chaos narratives seem more difficult to listen and react to and might therefore be less tellable (Frank, 1995/2013; see also de Swaan, 2004; Smith & Sparkes, 2008, 2011).

The story a person tells is not only dependent on the available plotlines but also on embodied experiences of the teller and vice versa. For instance, physical activity can be experienced as a means to control diabetes and hence reinforce the appeal of the (dominant) storyline about physical activity and health. However, embodied experiences with diabetes may also challenge physical abilities that were formerly taken for granted (Corbin, 2003) or the sense of self (Charmaz, 2006) and affect the affinities for some stories over others in the available narrative menu (Frank, 2006; see also Sparkes et al., 2012). This also means someone’s narrative habitus is not deterministic or comprehensive but can change over time (Frank, 2010; Bourdieu, 1984).

In the current study, I use the lens of a narrative habitus to pay attention to stories and underlying storylines about the experienced relation between physical activity and type 2 diabetes. It brings a focus to storylines and how they are told—which ones are often told, easily told or told with confidence or in defence? How do individuals relate to dominant ideas on individual responsibility and options for diabetes control? This brings a detailed focus to what individuals say about their lived experiences with type 2 diabetes and physical activity and how they discuss these.

A narrative methodological approach

To offer in-depth insights into individual complexities and care practices within the broader context in which these are shaped, I primarily used a narrative methodological approach to collect and analyse data (see Table 1.1) and write about these. I find myself primarily within the social sciences, which means that I try to connect individual and societal stories (Riessman, 2008), although I am also inspired by other disciplines like anthropology and care ethics.[9] With this narrative approach, I aim to offer concrete and context-dependent knowledge to learn from (Flyvbjerg, 2001).

The main body of this dissertation is based on in-depth interviews and (participant) observations. I collected these in a 'narrative' way, which means that I provided the respondents with much room for their own input and invited them to offer feedback on the storied interview account I sent back to them afterwards. Moreover, I made field notes of (participant) observations displaying narratives on actions, which are short descriptions of (conversational) practices primarily collected over a longer period of time. I (or we) considered these interview transcripts, accounts and field notes stories because of sequence and consequence, as in these texts, 'events [were] selected, organised, connected, and evaluated as meaningful for a particular audience' (Riessman, 2005, p. 1).[10]

This means that we considered ordering, the meaning-making function and the production of these stories in a certain social context as central elements (Riessman, 2008). By selecting what seemed relevant in the context of this study, storytellers retrospectively ordered events while creating sequence and coherence among these. They did so in relation to me as the interviewer, unknown to them and asking specific questions, but possibly also in relation to an invisible broader public of this study present through the audio recorder and interview formalities. Moreover, the storytellers did this in relation to other stories, such as by integrating well-known plotlines about physical activity and type 2 diabetes in their own stories.

During the analysis, we studied these meaningful patterns by beginning with each individual story. We paid much attention to the story as a whole, including its coherence, complexities, incongruencies and interactions (Riessman, 2008). We focussed both on the content ('what') and form ('how') of the story. Gradually, by alternating between the levels of the individual stories and all stories together, we moved to a more general narrative thread running through the data. The empirical chapters provide further specifics on data collection and analysis.

Researcher position

In this study, I was not an objective outsider researcher, but, following Bourdieu (1990), I became part of the field I studied—not as someone with type 2 diabetes or another chronic condition, someone overweight or a healthcare professional, but as a qualitative researcher with an explicit interest in micro-level experiences with physical activity care practices. This means that I offered respondents and others interested a somewhat 'outsider' perspective on (their) stories and practices influenced by the theoretical framework I applied. I offered this perspective, for example, by asking (certain) questions during field work, providing respondents with written accounts or reflections afterwards, engaging in conversations with interested others or presenting my work in different settings.

In this dissertation, I bring these interpretations of stories, practices and relevant documents together. This is why reflexivity is important: who am I in this process of knowledge production? In its essence, this is about the question 'how did the author come to write this text?' (Richardson, 2000, p. 254) and requires a further introduction of me as a researcher (and beyond). Part of who I am is described above by introducing the literature in which this study is embedded, the theoretical framework and narrative approach I applied and by my professional biography at the end of this dissertation. However, another part is less tangible. This has to do with power relations and my own normative position in this field of study, including my own possible 'blind spots'.

For instance, being the researcher and author, I held much power in formulating the research questions, the analytical frame and decisions on what stories to tell further in terms of what ended up on paper and what did not. However, as a qualitative researcher in the field of type 2 diabetes care and physical activity research, I often had and have to relate myself to more powerful evidence-based research frameworks. This also accounts for my critical perspective on the emphasis on individual responsibility in and seeming universality of general ideas related to physical activity and health. At times, my not-so-dominant position probably offered me an advantage, such as when participants told me stories that challenged mainstream thinking. However, at other times, I needed to better explain and defend my research position. I reflect on this in the general discussion of this dissertation (Chapter 9).

Maintaining these power relations involved responsibilities and ethical implications, especially in relation to the people who told me their stories or let me participate and observe in practice. The difficulties in conducting such a study in an ethical and responsible way was something I was often confronted with and reflected on but find difficult to put into words precisely. I tried to be open about the 'what' and 'why' of the study with participants and the broader public, although the aims were not completely clear to me from the beginning and changed slightly when I got to know the field of study better. This was also because of counterarguments I heard, such as those offered by our public partnership consortium. As a result, I gradually shifted from a very critical study approach especially centring on the experiences of people with type 2 diabetes towards a strong inclusion of healthcare professionals' difficulties in providing physical activity care in the context in which they work.

Regarding my own social location, it is important to note that I do not stand apart from sport and physical activity practices or from other lifestyle practices, and neither does my social environment. I do have (personal) experiences with and ideas about these, although these are far from clear and straightforward. They are based on so many elements, and I am probably not aware of them all. Overall and strongly related to the topic of study, my background as a

White, highly educated woman born and raised in a middle-class family in the Netherlands offers me certain privileges related to aspects of health, sport and physical activity.

For instance, part of my social environment, and especially part of my professional environment, is (very) ‘sport minded’ and ‘health minded’. In addition, although my research perspective is somewhat critical, I am very familiar with the medical and epidemiological literature about the physical and mental benefits of physical activity and the contents of the Dutch physical activity guidelines for health. It seems impossible not to translate these into my own life, either consciously or unconsciously, complete or partly, for myself and my two children.

Finally, my own upbringing and experiences with sport and physical activity from childhood onwards are of importance. From the ages of 4 to approximately 23, I always practiced at least one sport in an organised context, and this was something I took for granted for most of those years. However, I quit playing badminton at 23 because of the strain on my hypermobile joints, and I did not find a satisfactory substitute. From then on, my practices were more scattered and shifted more towards physical activity. Overall, the meanings of sport and physical activity have varied over the course of my life. My sport and physical activity biography is included at the end of this dissertation, and other reflective threads are woven into several chapters.

Outline of this dissertation

Since the empirical chapters can be read on their own, this also means they have some overlap, although they mostly report about separate studies (see Table 1.1). Furthermore, they are not presented in the order in which they were written. Instead, the structure of this dissertation is based on the content of the chapters, and divided into three parts that present studies on the policy and healthcare context, individual experiences, and openings to improve physical activity counselling and treatment, respectively. Several intermezzos are presented between the chapters. These are based on exemplary stories and observations collected for this study and aim to further illustrate the topic of this dissertation.

The next chapter, **Chapter 2**, is based on an exploratory survey study of 181 people with type 1 or type 2 diabetes. Based on statements asked about in a questionnaire, this chapter reports how they experienced counselling in physical activity and sport as part of their diabetes care. This survey was conducted at the beginning of the project among people with diabetes in general in order to get acquainted with the study topic. Although we primarily focus on people with type 2 diabetes in the other empirical studies, we included respondents with type 1 diabetes in this chapter as well, because the comparison illustrates some differences and similarities.[11]

The following two chapters aim to sketch the broader ***context*** in which this study was conducted by highlighting certain developments in dominant understandings that relate to physical activity and health or the provision of (lifestyle) care. **Chapter 3** focuses on how 'sport is good for health' arguments have been used by different stakeholders with an interest in governmental interference in sport from the 1950s onwards and how this impacted definitions of sport and sport participation and the interdependent power relations among those stakeholders. **Chapter 4** presents an account of participant observations made during training days for practice nurses. During this training, they were introduced to a new approach of how to provide care to people with a chronic condition, many of who have type 2 diabetes.

Based on in-depth interviews and narrative analyses, Chapters 5 and 6 present ***experiences*** from daily life and work. In **Chapter 5,** experiences of healthcare professionals with the topic of physical activity in type 2 diabetes care are presented. These include nurses working in general practice, diabetes nurses in secondary care, physiotherapists and other professionals involved in either counselling or actually providing physical activity care to people with type 2 diabetes. **Chapter 6** aims to explore how people with type 2 diabetes negotiate the message that 'exercise is a medicine', translate this message into their daily life and experience physical activity care.

The third part of this dissertation is about ***openings*** for change. It presents analyses from extended talking and walking practices that might contribute to an improvement of physical activity care practices. **Chapter 7** presents a detailed narrative storyline analysis of the story of Anja, a study participant with diabetes. Moreover, it focuses on the development of her story over a period of approximately two years in which we kept in touch. During the analysis, in which Anja was involved, we studied the presence and limitations of dominant health discourses emphasising restitution and individual responsibility and options for narrative development. **Chapter 8** is about experiences of two nurses who literally stepped outside the consultation room and went walking with their patients with type 2 diabetes over the course of 20 weeks. Based on participant observations and informal conversations, this chapter aims to examine these (new) care practices and reflect on implications for relations with their patients, their professional role and the provision of physical activity care.

In the final chapter, **Chapter 9**, I use the four theoretical lenses again to provide answers to the three general research questions by bringing together the implications of all studies.

Table 1.1 Empirical studies in this dissertation

		Participant(s)/ focus	Topic	Based on	Theoretical lens	Analysis
Introduction	Ch2	People with type 1 and type 2 diabetes	Experiences with sport and physical activity counselling	Questionnaires	None	Descriptive analysis
Context	Ch3	Sport policy and surveys on sport participation since the 1950s	Changing understandings of sport in relation to health	Existing documents	Figurational sociology and simplification of social life[1]	Content analysis
	Ch4	Training days of practice nurses	Introduction of a new approach in (chronic) care	Participant observations	System and lifeworld	Reflections
Experiences	Ch5	Healthcare professionals	Experiences with physical activity as a topic of care	In-depth interviews	Logic of care	Critical narrative analysis
	Ch6	People with type 2 diabetes	Negotiations with exercise as 'medicine' and experiences with physical activity care	In-depth interviews	Healthism, narrative habitus	Critical narrative analysis
Openings	Ch7	Woman with diabetes	Possibilities for narrative development and care ethics	In-depth interviews and e-mail conversations	Narrative habitus	Narrative storyline analysis
	Ch8	Walking groups for people with type 2 diabetes organised by diabetes nurses	Implications of new physical activity care practices for relations, roles and care provision	Participant observations	System and lifeworld	Inductive holistic content analysis

1. Elias' figurational sociology (1978) and 'simplification of social life' as proposed by Scott (1998) are not included in the main four theoretical lenses of this dissertation but do match the overall theoretical framework. Central to the perspective of figurational sociology is the concept of figurations of interdependent groups of human beings with shifting unequal power balances. This perspective is useful to focus on the interests, perceptions and interdependency of different interest groups, such as those related to understandings of sport and health. Scott's ideas of state simplification of social life to make a social field legible share a focus on rationalisation with Habermas' system world lens, including an overshadowing of lifeworld-based values.

Chapter notes

1. This study reports on physical activity and exercise, as do others. There is no Dutch word that precisely captures the meaning of exercise. In daily language, the phrasing 'sport and physical activity' (*sport en bewegen*) is often used, in which the meaning of sport is broader than in (especially American) English. For instance, 'sport' in the current Dutch context might also include fitness, miniature golf and walking (Mulier Instituut, 2016). For the purpose of this dissertation, an exact definition of physical activity, exercise and sport is not so important. Unless 'exercise' or 'sport' better captures what is meant, the broader term 'physical activity' is used in this dissertation.
2. Type 2 diabetes results from an insufficient production of insulin by the pancreas and/or an ineffective use of insulin by the body. Insulin is needed to transport blood glucose derived from food into the cells to be used as an energy source. As a result, people with type 2 diabetes often have too much glucose in their blood. Other common forms of diabetes are type 1—usually characterised by an absolute deficiency in insulin production—and gestational diabetes, a temporary condition during pregnancy resulting in a long-term increased risk of type 2 diabetes. Based on ADA (2019) and WHO (2020).
3. 'Co-morbidity' is a term that reveals an illness perspective; it departs from diabetes and other conditions or illnesses that might have an (extra) impact on care needs and quality of life. This does not necessarily match with an ill person perspective (Frank, 2000), from a person who, in daily life, might be more bothered by another illness than diabetes, or by precisely his/her combination of conditions.
4. Physiotherapy for people with diabetes is not part of the Dutch basic insurance or integrated care programmes but is reimbursed by optional additional insurance (Zorgverzekeringswet, 2020).
5. Moreover, I also departed from a social class perspective. As part of my 'professional upbringing', I became familiar with several concepts from Elias and Bourdieu, especially habitus, field and power/capital (Elias, 2000 [1939]; Bourdieu, 1984). Both Elias and Bourdieu considered power relational and focussed on social class dynamics and the importance of 'taken-for-granted ways of perceiving, thinking and acting' of people in everyday practices as part of a second nature or habitus (Paulle et al., 2012, p. 71). Given the social class ingredients in this study, especially related to the prevalence of type 2 diabetes and participation rates regarding sport and physical activity, my previous research experiences and interests were important in my decision to focus on care for people with type 2 diabetes within the project 'Sport in Times of Illness' in the first place instead of care for people with depression, breast cancer or HIV.

6. The authors referred to are not necessarily those who introduced the concept but rather those whose body of thought we (primarily) used. There are certainly others who can be heard in these concepts as well.
7. To gain an understanding of (a medicalisation of) lifestyle behaviour in relation to power, the work of Foucault has been an important theoretical inspiration to social scientists, especially regarding (medical) discourses and disciplining through governmental objectives (e.g. Lupton, 1995; Fullagar 2002; Binkley, 2007; Mayes, 2016). Although I do not use his work explicitly, it is somewhat present through the work of others (e.g. Mol, 2006; Cheek, 2008).
8. Instead of, for instance, sociocultural, genetic, biological or environmental causes (Saguy, 2013).
9. Regarding content, our work aligns with Frank's exploration of illness narratives, the importance of narratives in times of illness, the idea of more and less powerful storylines and the concept of narrative habitus (Frank, 1995/2013, 2010). As such, his work served as an inspiration for the theoretical framework described in this chapter. However, methodologically and analytically, we find ourselves more in agreement with the work of Riessman (2008). Although both Frank and Riessman took the dialogical and social environment as important and emphasised sensemaking as the main function of storytelling, the latter approached narrative with a more elaborated methodological focus. Therefore, Riessman's work provided the main basis for our methodology and analytical approach.
10. Note that I am the storyteller of the field notes and the writer of the interview accounts. I discussed each account with at least one of my supervisors before returning it to the participant.
11. Moreover, the distinction between type 1 and type 2 diabetes is not always clear, as is illustrated in Chapter 7.

Chapter 2

Conflict between diabetes guidelines and experienced counselling in sport and physical activity
An exploratory study

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Abstract

According to medical guidelines counselling on sport and physical activity should be part of diabetes treatment. Using an online questionnaire (n = 181), we explored how people with both type 1 and type 2 diabetes experienced this counselling in the Netherlands. Most respondents were critical, indicating that they did not receive proper guidance or helpful advice. A third of the respondents mentioned that there was hardly any attention for the subject during their treatment. This conflict between guidelines and experiences point towards the need for more insight in critical issues in counselling regarding taking up sport and physical activity (again) after diagnosis.

Introduction

In the Netherlands, as elsewhere in Europe, diabetes is a common chronic condition, and numbers—for both type 1 and type 2 diabetes—are expected to rise (Tamayo et al., 2014). Many medical and/or epidemiological studies point towards positive effects of sport and physical activity on the regulation of blood glucose levels for people with diabetes and these findings are incorporated in medical guidelines for diabetes care in Dutch guidelines as well as international guidelines (IDF, 2012; NHG, 2013; NDF, 2015a).

Sport/physical activity is an element of treatment protocols for diabetes at least since the 1980s, however, the recommendations became more specific over the years resulting in the advice to comply to the Dutch Standard for Healthy Exercise in 2000 for both types of diabetes (NDF, 2000). Consequently, we expect that people with diabetes type 1 or type 2 experience attention towards the uptake of sport and physical activity in contact with their healthcare professionals. Moreover, as type 2 diabetes to a large extent is considered to be caused by lifestyle behaviour, its treatment became more explicitly directed at increasing sport and physical activity levels and improving healthy diet. As a result, lifestyle counselling is the first step in current type 2 diabetes care (NHG, 2013). Therefore, our second expectation is that people with type 2 diabetes experienced an increased attention towards the subject of sport and physical activity in medical treatment and/or have more positive experiences with sport and physical activity counselling in the past 15 years.

Several studies, however, indicate that healthcare professionals struggle with lifestyle counselling in diabetes care—i.e. counselling on sport/physical activity and diet—and spend little time on this (Poskiparta et al., 2002). Furthermore, according to Hesselink and colleagues (2013) many people with diabetes rarely if ever discuss lifestyle behaviour with their healthcare professionals. Therefore, the first aim of this short report is to explore and describe how people with type 1 and type 2 diabetes in the Netherlands experience sport and physical activity counselling from their medical professionals in general. Our second aim is to explore if people with type 2 diabetes became more positive in the recent years in particular.

Methods

This study is part of a larger research project on meanings of sport and physical activity for people with a chronic illness. Based on the literature and qualitative pilot studies, we developed an online questionnaire with 5-point Likert scale statements and open questions. Sports were defined as participation in recreational activities according to the customs or rules in the world of sport, like badminton and fitness. Physical activity comprises all forms of human movement, including for example cycling to the bakery, gardening and activity during (household) work.

The online questionnaire was distributed via websites and online news letters of the Dutch Diabetes Association, i.e. the main patient organisation. This association has 50.000 members and 20.000 of these receive their newsletter by e-mail. Furthermore, the Bas van de Goor Foundation and the Dutch Diabetes Federation made an announcement on their websites. We used SPSS 22 to conduct descriptive (bivariate) analyses to describe the characteristics of the respondents and their experiences with sport and physical activity counselling, also in relation to type of diabetes and year of diagnosis. Because these two variables are possibly related to other variables (i.e. age, gender, educational level and sport participation), we conducted multivariate—linear regression—analyses to control for other possible associations.

Results

A total of 181 people with diabetes, both type 1 and type 2, and diagnosed at age 25 or more, completed the questionnaire. 57% of the respondents were female, 94% identified as Dutch and 51% were higher educated (college/university level). Their mean age was 56 years (SD = 12) and the mean number of years living with diabetes 13 (SD = 9). 71% reported other conditions and 72% experienced his or her health as (very) good. 92% was a member of the Dutch Diabetes Association. The findings are shown in Table 2.1.

A quarter of the respondents liked their healthcare professional to stimulate them to do sport and physical activity. This was more the case for people with type 2 diabetes, indicating that they need more external motivation to participate in sport and physical activity than people with type 1 diabetes. However, most respondents were quite critical about their guidance in sport and physical activity as only 16 per cent indicated that they were guided properly after diagnosis.

Moreover, a third of the respondents agreed that there was hardly any attention for sport and physical activity during treatment, irrespective of type of diabetes or, among those with type 2 diabetes, year of diagnosis. Linear regression analyses on the items of guidance and attention, confirmed an overall rather negative evaluation of sport and physical activity attention and guidance in treatment trajectories among all groups, despite increased emphasis in treatment protocols in the past decades. Although the open questions in the questionnaire were not related to medical guidance in sport and physical activity, some respondents formulated the need for more help:

> I hope that with this study, the support in sport and type 1 diabetes receives more attention. I had to sort out everything about continuing sport myself. For me, diabetes often was and is a hindrance to practice sport in an enjoyable way. (female respondent, 57 years old, type 1 since 1997)

> I think there should be more attention for practicing sport with diabetes and the guidance in this. (female respondent, 47 years old, type 2 since 2007)

These reactions illustrate the urgency about this subject.

Discussion

The results of this descriptive and exploratory study indicate that the experienced guidance from healthcare professionals in sport and physical activity does not match the needs of a large body of people with diabetes. Although sport and physical activity received more priority in the treatment protocol for type 2 diabetes in the last decades, recently diagnosed people were similar critical. Moreover, also among people with type 1 diabetes—who seem to have a higher intrinsic motivation to sport and physical activity compared to people with type 2—the majority was not positive about sport and physical activity counselling. The results indicate that both people with and without an affinity towards sport were critical towards this type of counselling. Overall, this study reveals a more general rather negative evaluation of sport and physical activity counselling in diabetes treatment trajectories in the Netherlands. A limitation of this study is that the sample of respondents is rather small and not representative of the Dutch diabetes population: people with type 1 diabetes were overrepresented, whereas people of 65 years and older,

Table 2.1 Experienced guidance in sport and physical activity (%)

		total	**type 1 diabetes**	**type 2 diabetes**		
			total	total	*year of diagnosis*	
					before 2001	*after 2000*
		(n=181)	(n=71)	(n=110)	*(n=52)*	*(n=58)*
I was guided properly in taking up S/PA (again) after my diagnosis	(totally) agree	16	11	19	*19*	*19*
	do not agree/disagree	21	14	25	*27*	*24*
	(totally) disagree	51	62	44	*42*	*45*
	don't know/n.a.	12	13	12	*12*	*12*
There hardly is/was any attention for S/PA during my treatment	(totally) agree	38	46	32	*31*	*33*
	do not agree/disagree	19	24	15	*19*	*12*
	(totally) disagree	39	25	47	*42*	*52*
	don't know/n.a.	5	4	5	*8*	*3*
I find it pleasant that my healthcare professionals exert pressure on me to do more S/PA	(totally) agree	24	15	29	*40*	*19*
	do not agree/disagree	16	10	20	*15*	*24*
	(totally) disagree	37	41	35	*33*	*36*
	don't know/n.a.	23	34	16	*12*	*21*

S/PA = sport and physical activity; n.a. = not applicable.

non-western immigrants and lower educated people were underrepresented (cf. RIVM, 2016). However, the findings are in line with previous studies on experienced counselling on lifestyle in general (i.e. a combination of diet and sport/physical activity recommendations) (Poskiparta et al., 2002; Hesselink et al., 2012). The findings of this study put an important item on the agenda. Whether these findings point towards a lack of attention to the subject from healthcare professionals, difficulties to act on advice by people with diabetes, or both, is unclear. For instance, professionals on the one hand might not be eager to discuss the subject or have limited time or knowledge (Poskiparta et al., 2002). People with diabetes on the other hand might find it difficult to put advice into practice (Wermeling et al., 2014), indicating a discrepancy between 'knowing what' and 'knowing how' (Granger et al., 2009). Therefore, further research is necessary to gain insight into critical issues regarding healthcare counselling in sport and physical activity and to study the perspectives from both people with diabetes and their healthcare providers.

Intermezzo I

Observations and reflections on Dutch type 2 diabetes care

‘And then I entered the diabetes world,’ Mr Cohen tells me. We sit inside a small examination room at his workplace. Mr Cohen, who is 46 years of age, is an optician. He sits on ‘his’ chair, while I, the interviewer, sit on the chair his clients usually take when their eyes need to be tested. In this setting, he shares his experiences of the time he was diagnosed with type 2 diabetes, about 18 months earlier.

> About a year before I met Mr Cohen, I entered the diabetes world myself. Not as a patient or healthcare professional, but as a researcher with a background in medical sociology and sport sociology. From Spring 2013 until Autumn 2017, I collected data in several ways—mainly in-depth interviews and (participant) observations—to gain insights into experiences with and developments of physical activity as an aspect of care for people with type 2 diabetes. During this process of data collection and analysis, I became more familiar with the ‘field’ of type 2 diabetes care in the Netherlands, and I got a better understanding of why diabetes professionals work this way in this ‘diabetes world’. Nonetheless, I also remained an outsider, by literally stepping into and out of the diabetes world, meanwhile wondering about and reflecting on stories and practices of people involved. This intermezzo aims to share some of my impressions. With this, I do not aim to give a complete overview of how type 2 diabetes care works in the Dutch setting. Rather, this more or less random collection of observations might provide readers on the outside with a short introduction and those on the inside with a somewhat poignant reflection on current forms of care.

April 2014, diabetes centre observation. The man, in his forties, received his diagnosis two months ago and has already visited his general practitioner and practice nurse, but is here [in this diabetes centre] for the first time. […] During the conversation, the diabetes nurse uses words like ‘pancreas’ and ‘Langerhans cells’. It is not clear to me whether the man knows what these are, but he does not ask, and the nurse does not explain. At the end of the consultation, the nurse gives him two leaflets. One is about diabetes and sexuality—‘so people know they can have complaints with that and know where to go then’, she tells me afterwards. The other is about type 2 diabetes in general: an explanation about diabetes in ‘simple language’. The man tells the nurse he probably got these leaflets from his general practitioner, but he does not know where he left them. ‘Then you know how things stand,’ the nurse tells me afterwards. She adds this was a relatively easy consultation; the man seemed to understand everything.

A diagnosis with type 2 diabetes comes with a lot of information, in a limited amount of time, defined by the length of consultations. This is information about what diabetes is, what one needs and has to do after diagnosis, what the future might bring. A diagnosis also comes with several healthcare professionals, such as a general practitioner, a practice nurse, an internist, or a diabetes nurse. From the perspective of a healthcare professional, a new diagnosis comes with a new assessment and questions, also in a limited amount of time: Who is this patient? What are the lab results? Which ones need attention? What would be the best treatment? What does (s)he know and understand about diabetes? How to explain? What topics to address now?

January 2014, consultation room observation. The first patient today is a man, aged about 60, with type 2 diabetes. A week before, his blood sample had been collected, and today the results will be discussed. It is mainly about 'glucose sober' and 'HbA1c', two values that come back a lot during the day. His HbA1c is a bit high, and he asks the practice nurse what this means again. She gives him a questioning look: 'you tell me'. She had probably explained this to him before. He sort of manages to give an explanation but needs a little help.

This observation illustrates a patient's education in the medical jargon: patients learn what certain values mean. Or at least in theory, as for most patients I observed that day—and other days—diabetes seemed like something abstract. The consultations were about blood values that were good or not good, blood pressure or body weight that was too high, too low, or okay, but most of the patients did not have complaints related to their diabetes. In daily life, they did not always notice their glucose being too high or too low, or their medication helped them to regulate it well. And if not, other doses or other pills were suggested. When the values were good, the consultation was mainly directed towards preventing worse, but what worse implied was something abstract. It was based on warnings of the practice nurse. However, at times 'worse' secretly entered the consultation room:

May 2016, consultation room observation. An elderly woman comes in. Her lab results are 'like a dream', the practice nurse tells her: they are all within the 'normal'—i.e. non-diabetic—range, without the use of medication. Just like the last time, about a year ago. The woman asks: 'When do I stop being a diabetic? Last time you told me it would take a year.' The practice nurse now says she doesn't know, but she will check if this is possible. Then it is time for a physical check-up. The woman takes her place on the examination table, with her legs in front of her. The practice nurse instructs the woman to close her eyes and tell her when she feels a sting on her feet. She doesn't feel it at all. The nurse asks the woman if she has trouble walking, and she does. She stumbles now and then, she tells the nurse, and finds that quite annoying. The nurse nods and says her the deep feeling in her legs and feet is not okay. When the consultation is over, I ask the nurse whether this was related to her diabetes, something she immediately confirms. But when I ask how this matches with her good lab results, she does not know.

In this situation, there was a clear contradiction between good lab results and physical complaints pointing towards complications of diabetes. In theory, good lab results imply good glycaemic control, and hence control over diabetes, which should prevent someone from developing complications. In practice, however, this is apparently not always that straightforward, and then seems difficult to explain. At other times, what seemed to be a simple and adequate explanation from a healthcare perspective, was not that easily translated into daily life practices:

April 2014, diabetes centre observation. The woman, in her mid-70s, seems chaotic and worried. She says she often forgets to inject insulin, especially during lunchtime, and eats irregularly as well. She likes to go out with her moped to visit little towns with her friends and then she forgets to eat. […] She worries about forgetting her insulin, she has already passed out once, at home, and was in a coma for a few minutes. […] The diabetes nurse explains to the woman that she only has to use the short-acting insulin before she eats, so if she does not eat, she does not have to inject herself. The woman says this was not clear to her, and she seems a little reassured by the explanation. The nurse says the dietician will tell her more about this after this consultation. […] At the end of the morning, the dietician tells me she explained to the woman how to handle her insulin and diet. The woman told the dietician she did not have this information before, but the dietician tells me the patient file states she received this information every year.

This observation shows complexity from both perspectives. People with diabetes need to understand and remember all the information and make an adequate translation into daily life activities. They need to know what, but also how and when. Professionals need to understand how to provide each patient with the right (amount of) information in a clear way, help them translate this into specific daily lives, and then trust their patients to deal with this. As professionals see a lot of patients each day and meet most patients only a few times a year, the patient file serves as part of their memory.

November 2015, consultation room observation. The practice nurse asks the patient about her daily physical activity, and the woman tells her she is on the move the whole day: walking to this or that, doing things at home. She looks agile as well, mainly because of her wild gestures. Afterwards, the practice nurse will tick off the box 'conforms to the Dutch Norm for Healthy Exercise' in the system.

The patient file records not only lab results but also professional assessments, like this indication of a patient's weekly amount of physical activity. The assessment described above seems to be made quite quickly and superficially. Does the nurse make a quick evaluation to leave time for other, possibly more important, topics in this 20-minute consultation? Is it just the 'check' in the system, because it has to be recorded? Or is it what is behind this check, namely the importance of physical activity as a topic in type 2 diabetes care? This probably illustrates a tension that has to do with the system as a means to account for care.

November 2015, consultation room observation. The practice nurse explains to me that the patients she sees are part of the Diabetes Integrated Care, Ketenzorg in Dutch. This means that the general practice receives a fixed amount per year per patient for diabetes care, regardless of the number of consultations needed. In general, patients visit the practice nurse three times a year, and the general practitioner once, but this can be increased or reduced if necessary. For the Integrated Care, the general practice needs to reach 'the benchmark' to get the payments; this means they need to fill in the lab results of at least 80 per cent of the patients in the Integrated Care system by the end of the year. It is November now, and the practice nurse is not sure if she will reach this percentage by the end of the year, also because patients might skip consultations now and then. She intends to schedule the yearly check-ups—the appointment during which these lab results are discussed—earlier next year to prevent herself from being stressed about it again.

This observation illustrates part of the administrative demands healthcare professionals have to deal with. Payments are dependent on 'checks' in the system, and these are dependent on patients (not) showing up and time left to fill in the lab results.

November 2015, interview excerpt. The internist: My first question [to my patients] always is: how are you? And they give me their sugar levels. That's not what I asked. […] Because when I start like: how are your blood sugar levels? While at the same time, their grandchild might have leukaemia, yeah, forget it. General practitioners are much better with this than we specialists.
Me, the interviewer: And practise nurses maybe even better?
The internist: Yes, they do that as well. But our practice nurses are also drilled to focus on bringing those sugar levels down. And we try to teach them [to change this now]. However, by taking care like this, we have created the best diabetes care in the world, from a disease perspective. With excellent results in primary health care! But now it's time not to look at the numbers, but more at the human being behind it.

This interview fragment summarises some tensions the diabetes world seems to be confronted with at the moment. Both professionals and patients are focused on, or have learnt to focus on, blood sugar levels and other lab results. The result of this, in the words of this internist with decades of clinical and research experience, is 'the best diabetes care' in the world, centred on glycaemic control. But these lab results do not necessarily match with daily life experiences or might not be the biggest problem in everyday life. 'Good' care might be to find the right balance between these two, time and time again.

Context

Changing understandings in policy and care

Chapter 3

Sport, health and the genesis of a physical activity policy in the Netherlands

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Abstract

Sport and physical activity have become prominent tools in governmental health policy in the Netherlands. This chapter focuses on developments in dominant understandings of sport and physical activity in relation to notions of health in the field of sport policy since the 1950s. We show that 'sport is good for health' arguments were emphasised and mitigated by different stakeholders with diverging purposes at different moments in time, to stimulate or legitimise interference of the national government in the field of sport. By studying changes in the power balances between the state, the private sport sector and other stakeholders, we explain how, gradually, public health became a, and at times the, major legitimisation for this interference. Furthermore, we demonstrate how these developments coincided with a narrowing of the vision of sport, as frequency and intensity became more important than what was actually practised. In this process, sport became blurred with other terms like physical activity and recreation, and new interest groups entered the field of sport and health. However, these developments had real consequences for the sport sector. This chapter clearly illustrates the unintended and complex outcomes of a policy process with interdependent power relations and interests.

Introduction

Physical activity is considered an important instrumental promise for the creation of a more healthy society in the latest national policy document on health in the Netherlands. As it 'promotes both physical health and mental wellbeing' and 'can have a positive effect' on 'the' five key issues in the government's health policy—i.e. smoking, excessive alcohol consumption, overweight, diabetes and depression—physical activity is introduced as a new focus for (preventive) healthcare (Ministry of Health, Welfare and Sport, 2012, p. 14). While no definition or amount of physical activity needed for good health is given and 'physical activity', 'exercise' and 'sport' are used interchangeably, the clear storyline of this health policy document is that sport and physical activity are good for health (Fischer, 2003; Houlihan et al., 2009).[1]

This chapter focuses on developments in dominant understandings of sport and physical activity in relation to notions of health in the Netherlands. As the government legitimates certain definitions (Monaghan et al., 2010) and suppresses others, this chapter centres on Dutch national policy documents, their influences and the reactions they provoked. Public policies are reflections of how public problems are comprehended (Schram & Neisser in Fischer, 2003). They are shaped by dominant views, understandings and goals in a certain period and they define the aspects of social life that have a positive meaning and the ones that have a negative meaning (de Haan & Duyvendak, 2002).

For a thorough understanding of the current situation, this chapter uses an historical sociological perspective, or more specifically, a theoretical perspective based on figurational sociology (Elias, 1978). Central to this perspective is the concept of figurations of interdependent—groups of—human beings with shifting unequal power balances. Policy arises as a result of certain interests. Yet, the complex patterns of interaction result in unintended as well as intended consequences. As Bloyce and Smith (2010, p. 4) argue, 'Elias's approach indicates how policy processes and their outcomes can be seen as an expression of unequal power relations and differential relational constraints between groups of people whose interests and perceptions are likely to diverge.' Therefore, this perspective helps us to focus on different interest groups and their interdependency.

In this chapter, the Netherlands is presented as a case study. It is an example of a modern welfare state in which health became an increasingly important value for both governments and individuals throughout the past decades (e.g. Cheek, 2008). Furthermore, it is also a country with an extensive infrastructure of sport facilities, with voluntary sport clubs as the most important framework for organised sport activities (van Bottenburg, 2011). Based on the content of the latest prevention policy of the government in which sport and health are clearly connected, while the definition of sport—and/or physical activity—remains unclear, we focus in this study on three research questions, namely:

1) How did notions of health acquire their present place in Dutch sport policy documents?
2) How did definitions of 'sport' and 'sport participation' develop in these policy documents?
3) What are the consequences of these two developments for the field of sport?

To answer these questions, we focus on the figuration which arises from the interdependencies of the voluntary sport clubs, the sport organisations representing these clubs on a national level and the national government—represented by different departments over time, with often different preferences and emphases. Other stakeholders in this figuration are physical educationalists, movement scientists and representatives of the economic sector.

Within this figurational framework, we use the ideas of John Scott (1998) about state simplifications of social life in order to make a social field legible, and hence to be able to carry out policy in this social field. According to Scott, a government is only interested in a certain part of social practises like sport, namely that part related to the government's goals. This may lead to a narrowing of vision or a simplification of the network of meanings and relations in the field. Moreover, in order to determine whether certain goals are reached, the social field has to be made 'legible'; it has to be rationalised to enable monitoring. Yet, state policies based on simplified definitions of a social field may have real, but possibly unintended and unforeseen, consequences for the nature of the field.

On a general level, Scott's main point is that governmental policies only have a chance to succeed if they take the actual working of the society they act upon into serious account, as well as the values, desires and objections of their subjects (Scott, 1998, p. 7). This fits within the assumption of figurational sociology as it coincides with Elias's ideas on the relation between involvement and detachment in scientific thinking (Elias, 1956). Scott's theory refers to figurations in which a powerful government tries to impose a policy in a social field without enough detachment to recognise the fundamental characteristics of that field. This point comes back in Elias's and Scott's shared interest in the policies of Jean Baptiste Colbert (1619–1683), Minister of Finances under Louis XIV of France (Elias, 1969, p. 54; Scott, 1998, p. 75). Colbert developed a fiscal policy solely from the one-sided perspective of the interest of the absolute state. The opponents of this policy, the Physiocrats, argued that one should first study the actual workings of society in order to create a sound fiscal policy (Elias, 1969, p. 54). Scott's work offers a series of examples of the adverse and/or unintended consequences of policy developments in which advice like those of the Physiocrats were neglected.

In this chapter, we argue that health arguments were used by different stakeholders at different moments in time to stimulate or legitimise governmental intervention in sport. Gradually, public health became a, and at times the, major legitimisation for government involvement in the field of sport. Furthermore, we show how these developments led to changes in definitions of 'sport' and 'sport participation' in order to enable the government to monitor its policy effects. As a—probably unintended—consequence, the health-oriented part of Dutch sport policy became incorporated into a more general policy to stimulate physical activity among the population and included new interest groups. These developments had real consequences for the Dutch sport sector. Although health-related aims were not the only objectives of sport policy in the Netherlands in the past decades, the focus on developments in the field of sport and health clearly illustrate the complexity of a policy process in which interests of the different stakeholders sometimes diverge and at other times converge.

Data

This chapter is based on two major series of data, namely Dutch sport policy documents published by the national government and the national sport organisations since the end of the 1950s—i.e. the time the national government became actively involved in the formulation of sport policies—and surveys on sport participation commissioned by the government since the beginning of the 1970s in order to further develop its sport policy.

We used these series to study the intensity of the involvement of the national state in the field of sport and its legitimations in a chronological order. Specifically, we traced the place of health considerations in these legitimations, and we tried to understand the dominance or suppression of these and other legitimations in different periods. Moreover, we focused on arguments and interests of different stakeholders in this health debate. Finally, we analysed how the definitions of 'sport' and 'sport participation' developed in these documents, and what these developments meant for the fields of sport.

Prologue: governmental sport policy until 1965

Sport in the Netherlands developed from the grass roots.[2] As van Bottenburg (2011, p. 25) stated, it has never been a hierarchically governed sector with national authorities acting as an overpowering agency. From the late nineteenth century, sport developed through private initiatives of citizens who organised their sport activities in local sport clubs. Already at an early stage in this development, local governments facilitated and stimulated these clubs. For each branch of sport, national sport organisations were founded by representatives of the voluntary sport clubs in order to coordinate the regulation and organisation of competitions.

Before the Second World War, the national government only paid minimal and ad hoc attention to sport (Stokvis, 1979; van Bottenburg, 2011). This can be illustrated by the heated discussion about governmental support of the 1928 Olympics in Amsterdam, which, in the end, was not provided because it could not be prevented that the Olympics took place on a Sunday, the day reserved for God (Arnoldussen, 1994). The national government was not really a player in the field of sport.

After the Second World War, concerns about the Dutch youth were an important subject of debate, and sport was considered a useful pedagogical device for this problem. A 1952 governmental report on the social problem of 'youth run wild' provoked a reaction of the Association of Dutch Municipalities in which they regarded 'sport as a means to form body and spirit, especially of young people' and a solution to 'the youth problem' (in Stokvis, 1979, p. 102). This concern, together with a strong increase in the number of sport participants and the need for repair of sport accommodations destroyed by the war, resulted in a strong engagement of the (local) government to increase the financial investments in sport. Moreover, because sport clubs were financially unable to maintain their accommodations, this dependency between sport and the government became stronger. Because of these developments, several political parties felt the urge to reflect on the meaning of sport. In their reports, published between 1956 and 1960, sport was considered useful as a means of moral education and the national government seemed able to support this function of sport through financial assistance for accommodations and sport leadership. However, professional sport was conceived as undermining the ethos of sport (Stokvis, 1979).

In 1960, the first national policy document on sport and physical education was published (OKW, 1960). Despite the discussions in the 1950s, no reference to the ‘youth problem’ was made and sport was mainly considered a compensation of monotonous work and a useful activity to spend increasing spare time. The value of sport, according to the minister, was its contribution to physical abilities and the development of certain skills like perseverance and courage, as well as skills related to playing (fair) games. Though, one had to be aware of harmful results of sport for the physical and mental growth of young people and medical examinations were promoted in order to prevent people from unhealthy consequences of sport (OKW, 1960). Positive effects on health, on the other hand, were not a subject in this policy document.

This document provoked a lot of criticism in the media and from sport organisations. For example, the Netherlands Sport Federation, an umbrella of the national sport organisations founded in 1959, stated that this policy showed no relation to social problems (de Haan & Duyvendak, 2002) and that its strong focus on recreational aspects did not do justice to the importance of sport for moral education (Stokvis, 1979). Influenced by growing affluence, spare time and mobility, the governmental focus on sport had shifted from the ‘youth problem’ to new ideas about the importance of sport for well-being and recreation (Stokvis, 1979; de Haan & Duyvendak, 2002). This was further developed by a transfer of the governmental service for sport affairs from an educational frame of reference to a recreational one as in 1965 sport became the responsibility of the Ministry of Culture, Recreation and Social Work.

Until the end of the 1960s, the Dutch national government adapted its sport policy to the popular institution that voluntarily sport clubs and their national organisations had become since the nineteenth century. State policy interventions in the field—such as the creation and maintenance of facilities, administrative support for national associations and courses in sport leadership—were based on the needs of the voluntary sport clubs and national sport organisations. Legitimation for state support was established on the perceived moral and social functions of these organisations. Although the government was relatively powerful in economic terms, it adjusted its policy towards the needs of the private sport sector. The fact that many people were involved in sport-like activities outside sport clubs was noticed by the government (OKW, 1960), but did not influence its policy.

1965–1980: ‘Sport for All’

At the end of the 1960s, the government’s involvement in sport intensified due to several reasons. The Cold War (1949–1989) stimulated the interest of national governments in a strong and vital population. In widely read articles with titles such as ‘The Soft American’ and ‘The Vigor We Need’, US President Kennedy (1960–1963) called for a US population with a good physical condition to be able to fight the Communist threat. In a little more peaceful manner, this movement also started in Europe, best known as the ‘Sport for All’ movement (see also Bergsgard et al., 2007). In 1966, the European Council called for national policies to enable as many people as possible to participate in sport in order to create a fit population with a good physical condition (Stokvis & van Hilvoorde, 2008).

Because of the growing governmental interest in sport, the number of civil servants specialised in sport and recreation started to grow. Furthermore, voluntary sport clubs became more dependent on the government’s financial support for the maintenance of their accommodations. As this support led to a drop in contribution rates and hence a growth in memberships, this dependency grew. This growing influence of the government was revealed through a more goal-oriented state policy aimed at ‘sportive recreation’ (Stokvis, 1979). As implied in the idea of ‘Sport for All’, sport policy now became directed at the established sport organisations as well as people outside of these organisations. This is a first indication of a shift in interest of the government. Since the voluntary sport clubs had become dependent on the government, this change in policy formed a possible threat to the financial support they received from the government.

In 1969, the Minister of Culture, Recreation and Social Work published a ‘discussion document concerning sport policy’ to describe the current situation and denote some policy directions and issues related to sport (CRM, 1969). In this document, ‘sport’ was explicitly placed in the framework of well-being because of its important functions related to increasing spare time and decreasing physical activity in ‘current society’. Besides its educational, social and economic significance, sport was considered important because ‘a right and sufficient amount of physical activity is of essential importance for good physical health’ (CRM, 1969, p. 8). This was the first time sport was explicitly related to health in governmental policy, although no description of ‘right’ and ‘sufficient’ was given. Moreover, the minister also emphasised the importance of medical examinations for a responsible manner of sport participation considering 'the medical risks of sport participation' (CRM, 1969, p. 29).

In a public hearing in 1969, the Netherlands Sport Federation reacted to this policy document. It considered it unfortunate that the government 'hardly paid any attention to the great significance of sport for public health' and stated that the emphasis on the medical risks of sport participation was too strong (Tweede Kamer, 1970, p. 2). The Netherlands Sport Federation announced that the Dutch sport organisations would collectively publish their own sport policy document as a contribution towards the development of a national sport policy (Tweede Kamer, 1970, p. 2). This document, Sport 70, presented the vision of the private sport sector on the role of the state in sport (NSF et al., 1970). It stated that one reason for the importance of active governmental interference in sport lay in its relevance for (public) health, or more specifically in

> The evidently positive influence of sport participation on public health. The preventive function of physical activity in relation to a variety of diseases is highly rated. This is not only of importance for those directly involved. Whoever thinks about the increasing loss of working hours through illness (...), the decrease in the ability to achieve through a deterioration in condition, the increase in death among the productive age groups due to heart and vascular disease, realises that especially the economic life would profit from a Dutch population that is prepared and able to practise sport regularly. (NSF et al., 1970, p. 11; translation by the authors)

According to the sport sector, this economic motive for the furtherance of public health was one of the reasons the government should be involved in sport. Remarkably, in this document, which presented the interests of the private sport sector, both 'physical activity' and 'sport' were used, without any distinction. Furthermore, the sport sector clearly saw new social functions for sport:

> Sport takes on a completely new aspect nowadays. From an individual enjoyment, completely voluntarily played in one's spare time, it becomes a social necessity for the preservation of public health. From the viewpoint of policy, because of this reason alone sport becomes an essential factor for the government. (NSF et al., 1970, p. 50; translation by the authors)

This citation indicates a shift in the meaning of sport, caused by notions of public health. Moreover, with this statement the Netherlands Sport Federation strongly argued that the importance of sport for (public) health legitimised governmental interference. This indicates that the private sport sector tried to increase its impact on sport policy as well as on the importance of sport in governmental policy.

This discussion about sport and the role of the state culminated in the first official departmental memorandum exclusively on sport for the Dutch Parliament in 1974 (CRM, 1974). In this memorandum, 'moral education/ self-development' and 'health' were considered the main goals of a national sport policy (CRM, 1974, p. 11). With regards to the latter, the minister stated that sport participation 'in the less specific forms of sportive exercise and sportive recreation, [was] able to stimulate physical health and prevent us from diseases of affluence' (CRM, 1974, p. 12). This memorandum contained an explicit critique on the private sport sector as too strictly regulated and too much directed towards competition. It proposed the furtherance of 'sportive recreation'; relaxed forms of physical exercise and play directed at people inside as well as outside sport clubs (CRM, 1974, p. 12, 14), illustrating the government's development in the direction of a more goal—or health—oriented sport policy as well as a greater independency of sport organisations.

This was an unexpected and unintended outcome for the private sport sector and it reflected the influence of the first academic advisors on sport policy formation. They were pedagogues and physical educationalists with an orientation towards furthering physical education, sport included, among the whole population (Pouw, 1999, p. 238). These advisors gave a clear direction to the diverging views on sport among state officials. As a result, the state acquired a stronger position in the balance of power (Elias, 1978) with the private sport sector.

A new policy focus on health, unorganised sport and inactive people led to a 1973 governmental programme called 'sportive recreation'. In this year, the government started to subsidise the promotion of sportive exercise and play among inactive groups of the population (CRM, 1973). This programme was considered important because of health motives:

> After all, it is widely accepted that too little or hardly any exercise is one of the causes of the great number of heart and vascular diseases. Likewise, [it is accepted] that sufficient and correctly dosed, correctly accompanied exercise, can prevent us from the development of these diseases. (CRM, 1973, p. 5; translation by the authors)

Although this is a clear health-related argument of the government for the importance of exercise, no further description about 'sufficient and correctly dosed' was given. Apart from health motives, the minister added, moral education, recreational and social motives were also of importance (CRM, 1973).

This new accent on the furtherance of public health as a major goal for sport policy provoked resistance, mainly in circles connected with sport and physical education. Typical of this resistance was the reaction of the 'Workgroup Recreation Sport'. This group represented an international company of pedagogues and physical education experts who opposed sport in an organised context because of its orientation towards performance, systematic training and competition (Dieckert, 1973). It tried to propagate forms of sport which were characterised by pleasure, relaxation and an absence of obligations towards clubs or teams. The new national sport policy had borrowed much from the programme of this group, yet its members were not satisfied with the goals of the new state policy. They argued that although the health motive 'may represent a general social value; it is not suitable for a propaganda directed at recreation sport' (Kamphorst et al., as cited in CRM, 1974, p. 13). Another governmental advisory committee held the opinion that sportive recreation should be a value in itself; it should not be instrumental for other goals, like public health (in CRM, 1977, p. 8). These physical education experts supported a sport policy directed at the whole population and not just at the members of sport clubs. However, for them the health legitimisation of this policy was against the idea that physical exercise formed a value in itself. Nevertheless, the government was not convinced by these critiques of the health focus as a motivation for its sportive recreation policy. In a reaction, the minister stated that 'sport participation in fact contributes to the promotion of a good physical health. Because of this, the health aspect of sport still remained an important consideration for the formulation of [governmental] sport policy' (CRM, 1974, p. 13).

This discussion clearly illustrates the changing attitude of the national government towards sport policy. While the government started with its sport policy in order to support the sport sector, it shifted more and more towards the formulation and realisation of its own goals, e.g. directed at the whole population instead of members of sport clubs solely, and related more to health. Remarkably, as we showed before, these health-related aims were emphasised at first by the national sport organisations as a legitimisation of governmental interference in sport. As we will show in the next section, this new attitude of the government towards sport policy created a greater need for a new definition of 'sport' and 'sport participation' in order for the government to be able to establish and monitor its goals. Therefore, we go slightly back in time and show how these definitions developed from the 1960s onwards.

Making sport legible: definitions and numbers in the 1960s and 1970s

Defining sport in a way that covers its differentiated and changeable world of activities is a permanent problem in sport policy and sport research (de Knop, 2006). In the 1960 sport policy document, the minister stated that it turned out to be extremely difficult to define the concept of sport in 'a generally acknowledged' manner. Therefore, he only described its main aspects: sport was considered a recreational pursuit with elements of play, an orientation towards physical activities and an element of performance, although this was not to be confused with competition (OKW, 1960). In this document, the minister remained close to the idea that sport was what happened inside the private sport sector, except that he kept some distance from the competitive aspect of sport in an organised setting. The level of sport participation was based on the administration of national sport organisations, i.e. on membership numbers of the sport clubs.

The definitional problem was not solved in the following policy document in 1969 as the (next) minister explicitly referred to the discussion in 1960. She stated that 'the concept of sport, as used in ordinary terms, in the literature and the press, [evoked] a rather clear image of what in general [was] understood by the notion of sport' (CRM, 1969, p. 6). The minister considered the recreational element most important, while the other aspects—competition, play and performance—were present to a varying extent. Moreover, while the 1960 policy explicitly excluded passive forms of sport, like playing chess, by the element of 'physical activity', the 1969 policy included these as well.

In the 1969 document, reference was made to the first Dutch study on 'active sport participation', which was conducted in the summer of 1963 and based on a survey (CBS, 1964, p. 5). According to this study, 38 per cent of the population practised sport 'in any way', 66 per cent of whom did this outside the context of a sport clubs. Although the minister considered the definition of sport participation in this study 'open to question' because of its wide interpretation, she emphasised the finding that many people practised sport outside the context of sport organisations (CRM, 1969).[3] Furthermore, the government expected this portion to increase, for instance because of the 'tightly bound character' of the sport sector. Therefore, the minister commissioned a study into the nature, scope, motives and developments of unorganised and recreational sport participation (CRM, 1969, p. 24).

This study, Sport participation and its degree of organisation, was conducted in 1973 (Manders & Kropman, 1974) and illustrates how sport was made legible for the state by simplifying its definition (Scott, 1998, p. 3). Based on a survey, Manders and Kropman defined sport participation independent of its organisational context. Their main criterion was the number of times one practised sport in a year and they considered someone who participated in sport at least ten times a year a sport practitioner.[4] According to their survey, a quarter of the population met this criterion of sport participation, half of the population participated in sport only incidentally—i.e. between one and ten times—and the remaining quarter did not participate in sport at all. In the new sport policy document of 1974, the minister underlined that half of the population participated in sport 'only incidental, without a—from the viewpoint of health to be recommended—sufficient regularity' (CRM, 1974, p. 9). Again, no explanation of 'sufficient' was given. Furthermore, the minister referred to the finding that 53 per cent of these 'incidental sport participants' practised sport exclusively outside the context of sport clubs. This part of the population and the 25 per cent that did not participate in sport at all were considered central categories for sport policy, with an important task for—amongst others—the government (CRM, 1974). This was an explicit shift in sport policy from an emphasis on an organised to an unorganised sport context. With this, the government explicitly distanced itself from the private sport sector.

In order to stimulate the 'Sport for All' policy of the national government, the field of sport was redefined and refashioned (Scott, 1998, p. 3). Sport participation was no longer associated with voluntary sport clubs only, and the meaning of sport changed. For instance, its initial meaning in terms of moral education and social cohesion faded into the background. Furthermore, although the health argument was considered important in this new approach to sport participation, no amount or definition of sport for good health was given. Consequently, meeting the criterion of doing sport at least ten times a year was implicitly considered 'good for health'. Finally, new terms, like 'sportive recreation', 'exercise' and 'physical activity', gradually entered the field of sport policy and research, used by both the government and the sport sector. While the government used them to broaden its area of policy, the private sport sector had to subscribe to these new terms in order to keep involved in these new developments because of its dependency on governmental subsidies. Hence, sport became more detached from its original context. This was also realised in a governmental document of 1983:

> Twenty years ago, especially elite and competitive sport were considered as 'sport', however, since then the concept of sport has become considerably more broad, particularly in the direction of relaxing recreation. (…) At present, it is hard to indicate what exactly is considered sport, recreational sport, or sportive recreation. (…) [A choice for either term] remains a product of time. Partly due to the developments in the domain of sportive recreation, the concept of sport has become more general. (WVC, 1983, p. 6; translation by the authors)

Besides a change in definition, this quotation also implied that voluntary sport clubs were no longer the only 'targets' for the government, as the governmental sport policy goals were also—or sometimes even better—within reach outside the organised sport context. As we show in the next sections, this process of detachment—especially regarding the definition of sport—further developed, especially from the 1990s onwards.

The 1980s and 1990s: a lower health profile in sport policy

Economic decline at the end of the 1970s and beginning of the 1980s led to a lower public sport profile in the 1980s and early 1990s (van Bottenburg, 2011). In 1982, sport became the responsibility of the department of Welfare, Health and Culture, and therefore more explicitly part of public health policy. This department had no financial means to execute new policy plans in the field of sport; however, a 'memo accents sport policy 1984 and further' was published in 1983 (WVC, 1983). The promotion of a healthy lifestyle was considered an important motive for the stimulation of permanent sport participation.[5] Furthermore, in contrast to former policy documents, this one contained a more precise description of the contributions of sport to certain aspects of health, namely the reduction of risk factors which contributed to heart and vascular diseases (WVC, 1983, p. 7).

In the beginning of the 1990s, after the economic recession of the 1980s, the private sport sector took the initiative to form a powerful lobby to promote sport, supported by important and popular persons from politics and the entrepreneurial world. They established a steering committee 'Sport and Society' and in 1992 a report entitled Sport as a source of inspiration for our society was published (Kearney, 1992). The purpose of this report was to demonstrate the growing importance of the social role of sport in Dutch society and to argue that all those involved in sport policies should work together to exploit the social potential of sport.

In this report, the level of sport participation was defined in terms of the number of memberships of voluntary sport clubs, based on the administration of the national sport organisations, i.e. the same definition as applied in sport policy documents in the beginning of the 1960s. Although the number of participants in an unorganised setting was also estimated, the focus of this report was on sport in an organised setting. The steering committee accentuated the pedagogical, moral and social importance of sport, while 'health promotion' was considered just one of the reasons why the government should take more interest in the stimulation of sport. In addition, the committee emphasised the social value of elite sport, a topic which was mostly excluded in the debates before. This new interest reflected a more general realisation that the world had changed into a more globalised and competitive society during the crisis of the 1980s.

It took some time before the government reacted to the ideas of this powerful lobby. In 1994, sport became an explicitly visible governmental domain, as the responsible department changed its name in the department of Health, Welfare and Sport. This also illustrated the predominance of health over welfare (de Haan & Duyvendak, 2002; Waardenburg & van Bottenburg, 2013). The government published a new sport policy memorandum for the Parliament in 1996 (VWS, 1996). Noticeably, the State Secretary responsible for this memorandum, a former successful Olympic swimmer, had much affinity with the lobby of the sport sector. Consequently, it did not come as a surprise that the new state policy document clearly showed the influence of this lobby. This again illustrates a change in the balance of power (Elias, 1978) between the state and the private sport sector, this time in favour of the latter. During a period of a weakening in power of the government, mostly because of a decrease in financial means, the sport sector spotted a chance to—successfully—impose its own ideas about sport policy. The prestige of the politicians and entrepreneurs supporting the lobby and its report could not be neglected by the government.

The 1996 Dutch sport policy memorandum can be interpreted as a compromise between the interests of the private sport sector and those of the state. First, the state adopted one of the central purposes of the sport sector, namely the furtherance of elite sport, as one of its own policy goals. The public interest connected with this new state policy goal lay in its (supposed) contribution to the prestige of the Netherlands in the world and the promotion of the self-consciousness of the Dutch population. Second, the furtherance of social cohesion, a goal which had never completely disappeared from the sport policy agenda, was considered important. The voluntary sport clubs were provided with an important role in order to achieve this goal. Third, in contrast to former policy documents, the importance of sport for health was only dealt with after an extensive description about the social advantages of organised (elite) sport. Regarding the issue of 'health and sport', the 1996 policy document discussed four themes, namely the promotion of physical activity, the prevention of injuries, doping and sport medical care. An important starting point for this sport policy area was based on a study by Mosterd et al. (1996) which reported that 'the greater part of the Dutch population, from the perspective of health, exercises too little' (VWS, 1996, p. 37). From this viewpoint, sport was considered a form of physical activity important in the contribution to a decrease of health risks (VWS, 1996).

After 1996, Dutch sport policy was more strongly aimed at elite sport—a focus which matched with an interest of the national sport organisations—and increased its budget for it. However, other (new) interest groups—especially those stressing the importance of physical activity because of health effects—gained influence upon developments in sport policy as well (van Bottenburg, 2011). It is these developments we focus on in the next section of this chapter.

Developments since the 1990s: a new field with specific health-related guidelines

In its 1996 sport policy document, the government announced the periodical evaluation of data about physical activity and health and its most relevant developments (VWS, 1996). These two-yearly 'Trend Reports Physical Activity and Health', published since 1997 (Stiggelbout et al., 1997), were produced by an institute conducting research on health and work, not on sport. This clearly illustrates a shift in interest groups in the field of sport policy.

Based on international studies, the authors of these trend reports proposed a guideline for the amount of physical activity needed for health promotion and in 2000 the 'Dutch Standard for Healthy Exercise' was established. This standard prescribed the intensity, form and frequency of physical activity needed for good health in terms of energy consumption, i.e. number of calories burnt, and expressed in metabolic equivalents (METs), minutes and days a week (Kemper et al., 2000). In addition, a method to measure whether people conformed to this norm was introduced and validated in 2000 (Douwes & Hildebrandt, as cited in Hildebrandt et al., 2013). Together with the so-called 'Fit Standard', i.e. vigorous intensive physical activity at least three times a week, these formulations became the standards in Dutch policy and studies on physical activity and health (e.g. Hildebrandt et al., 2013).

According to the new guidelines of the Dutch Standard of Healthy Exercise, health-related physical activity should be integrated in daily life and it certainly did not only comprise participation in (organised forms of) sport (Kemper et al., 2000). From this new viewpoint, sport became interchangeable with other forms of physical activity like gardening or housekeeping and measured in terms of calories burned. Furthermore, researchers found that sport participation only had a limited share in meeting the standard for healthy exercise: just 3 per cent of the Dutch population reached this standard by sport participation alone (cited in Hoekman & van den Dool, 2010, p. 110). Related to health, sport in sport policy was replaced by physical activity, i.e. simplified into terms of frequency and intensity only, because it matched the governmental goals (Scott, 1998).

The development and publicity of these guidelines was stimulated by publications of academic departments for human movement studies, especially those of the University of Maastricht and the Free University in Amsterdam. These departments directed their research efforts more and more towards relations between physical activity and health. They propagated an active lifestyle by demonstrating the health effects of, for instance, taking stairs instead of elevators (Engbers et al., 2007), having parking places at a greater distance of private houses (den Hertog et al., 2006) and keeping coffee automats and printers at a distance from places of work (Jans et al., 2007). Furthermore, sitting became defined as a health risk (e.g. Jans et al., 2007; Hendriksen et al., 2013).

In 1999, another new interest group in the field of physical activity stimulation was established, namely the Netherlands Institute for Sport and Physical Activity (NISB). This institute was founded by merging five older institutions with activities in the field of sport, physical activity and health. Its mission became to promote sport and physical activities, and to contribute to health, participation and well-being by encouraging an active lifestyle. The activities, courses, campaigns and propaganda of this institute also contributed to the publicity for and the implementation of the new guidelines. At the celebration of the 10th anniversary of the NISB, the Secretary of State stated that while before 2000 physical activity was hardly discussed, in 2009 it had obtained a place on the policy agenda (Bussemaker, 2009).

In 2001, the government published a policy document entitled Sport, exercise and health, the main objective being 'the increase of health profit through sport and exercise' (VWS, 2001, p. 6). From the governmental perspective, the economic profits of this policy were also considered important. In this document, a precise definition of sport and physical activity was given:

> In this memorandum, 'physical activity' and 'sport' are, in principle, understood as the complete range of moderate intensive to intensive physical activities in which the participation adds to fitness and health: from vacuuming, taking the stairs, doing odd jobs, gardening and walking, to dancing, cycling, fitness and sport. All forms of moderate or intensive physical activity can add to a better health, however, in order to experience 'evidence based' health effects, a certain dose and frequency must be reached. (VWS, 2001, p. 9; translation by the authors)

This dose and frequency referred to the Dutch Standard for Healthy Exercise, and the aspired part of the population which complied with and knew about this standard became the new objective for health-related sport policy (VWS, 2001, p. 14). This was the first explicitly quantified target in this policy area, and it is still to be found in current documents (e.g. Ministry of Health, Welfare and Sport, 2008b; VWS, 2012). Moreover, for the first time, in this policy document reference was made to many scientific references in order to ground the governmental objectives. All these new agencies and research institutions, which were mainly subsidised by the state, supported the government in its simplified notion of sport as one of several types of physical activities promoting health among the population. As a consequence, the balance of power between the state and the private sport sector again changed to the advantage of the state.

Health promotion never became the only goal of the state to promote sport as the moral and social value of participating in voluntary sport clubs were always more or less deemed important and the promotion of elite sport became a new objective since the end of the 1990s. According to a memorandum for the Parliament in 2005, the three main aims of sport policy were 'the improvement of health', 'the increase of social cohesion' and 'the stimulation of elite sport, as a source of national pride and prestige' (VWS, 2005, p. 17).

Regarding the health-related aims, the 2005 'National Action Plan for Sport & Exercise' was explicitly aimed at increasing the part of the population meeting the healthy exercise standard. According to this plan, the sport organisations were allotted a task together with neighbourhood organisations, schools, workplaces and healthcare centres. These 'partners' were addressed towards their responsibility and supported in their activities to realise a turn in the exercise pattern of the Dutch population. Furthermore, the government argued that 'the [organised] sport supply itself should be made (more) suitable for people with an exercise or health deprivation' (VWS, 2006, p. 10). This illustrates that the voluntary sport clubs were explicitly confronted with the changed vision of sport as well, and with policy goals which poorly matched the objectives and origin of these voluntary organisations (van Bottenburg, 2011), i.e. offering a specific sport for people willing to practise it. As their governmental subsidy became more dependent on their contribution to sport policy goals instead of the number of members as used to be the case, the sport clubs were stimulated to adopt more instrumental policies in order to contribute to state objectives. In the long run, the balance of power between the government and the national sport organisations had fundamentally changed. In this new mutual dependency, the government demanded the private sport organisations help in order to achieve its goals, while these organisations had to comply with this request because they had become more dependent on the government for their existence.

Epilogue: the integration of health in Dutch sport policy

This chapter focused on the way in which notions of health became part of Dutch sport policy and its consequences for the field of sport. We tried to explain these developments by focusing on changes in the balance of power (Elias, 1978) between the state and the private sport sector. Moreover, Scott's concepts of legibility and simplification (1998) enabled us to analyse how the growing power of the state was reflected in the way sport was redefined and to recognise the consequences of these redefinitions.

By studying policy documents and reports of different interest groups, we showed that health-related arguments were used by different stakeholders at different times to strengthen or weaken the need for governmental interference in sport. We demonstrated that the voluntary sport sector was the first to explicitly emphasise the importance of health gains from sport participation to make a case for the involvement of the government in sport at the end of the 1960s. The dominant idea became that sport participation was good for public health; however, what sport activity and especially how much participation was good for health remained unclear for a long time. Until the 1990s, it was mainly based on general statements with little to no reference. This lack of foundation is in agreement with other studies in the field of sport policy (e.g. Bloyce & Smith, 2010; Bloyce & Lovett, 2012; see also Coalter, 2007).

As the government further developed its sport policy since the 1960s and integrated health-related aims more and more, it—at least partly—shifted its focus from sport participation in the contexts of sport clubs towards participation in unorganised settings. This coincided with several developments: a broadening of the definitions of sport and sport participation, changes in the interdependency between the government and the sport sector, and the entrance of new interest groups in a new field of health, sport and physical activity. In sum, it resulted in a more complex network of relationships and changes in the balance of power (Elias, 1978) which ultimately were in favour of the state. Gradually, the field of sport policy development illustrated more and more the unequal power relations between and diverging interests of (Bloyce & Smith, 2010) the two interest groups most involved: the government and the private sport sector.

As we showed in this chapter, the government was not the only initiator in this field as it reacted to social developments like the increase of participation in sport outside the formal context of a sport club as well as a notable decrease of physical activity in daily life. However, it certainly was an important player with much (financial) power and had an active involvement in discussions about definitions of sport and sport participation. For the government, health-related sport became important in terms of the participation rate—ranging from ten times a year in the 1970s to five times a week since the 1990s—and, with the establishment of specific guidelines in the 1990s, intensity. Increasing the number of people adhering to these guidelines became an explicit goal of governmental sport policy. However, these developments had real consequences for the field of sport, especially for the Dutch voluntary sport sector. Public health did not only concern the members of sport organisations, but also—or maybe more—the other part of the Dutch population. This meant that the state support for sport became only partly directed at the private sport sector. Therefore, the initial health-related arguments of the sport sector to increase the governmental involvement in sport had an unintended and reverse outcome as this involvement was not directed at the sport sector itself (Elias, 1978; Bloyce & Smith, 2010). It illustrates a gap between the intentions of the sport sector and the actual results (Dopson & Waddington, 1996). More importantly, whether the health-related guidelines were adhered to by practising sport at a sport club or by gardening was not of importance. In this sense, Scott's theory about state simplifications of a social field to make it legible and to be able to monitor policy effects can be confirmed: a 'single element of instrumental value'—i.e. sport, or physical activity, as a means to keep or get a healthy body—was isolated from the complex set of relations the field of sport consisted of (Scott, 1998, p. 21). Related to health, sport was stripped from its social and moral meanings, and defined in terms of frequency and intensity.

Although this chapter considered the Netherlands, the developments presented here are not unique. A governmental focus on physical activity levels of the population in a framework of health promotion is found in developed countries in general (Bloyce & Smith, 2010) and many international organisations have arisen in the field of health and physical activity, like the International Society for Physical Activity and Health (ISPAH), the European Network for Acting on Aging and Physical Activity (EUNAPAAA) and the European Network for the Promotion of Health-Enhancing Physical Activity (HEPA Europe). Moreover, 'blurred boundaries' between sport and physical activity are also found elsewhere (Bergsgard et al., 2007; Bloyce & Smith, 2010), as part of a process in which physical activity became important for a daily (healthy) lifestyle of which sport was just a component. This possibly points towards similar developments in which the 'sport is good for health' argument developed. By precisely studying the underlying developments, arguments and balances of power between significant parties involved, this study shows how this specific argumentation was used by different stakeholders at different moments in time to legitimise governmental interference in sport and how the present political narrative about sport, physical activity and health was established.

Chapter notes

1. Although this is a dominant understanding in current societies, it is not undisputed (e.g. Waddington, 2000; Cheek, 2008).
2. For a description of the organisation of sport in the Netherlands and a review on general developments in Dutch national sport policy, see Waardenburg & van Bottenburg (2013).
3. In the CBS study, the authors assumed that 'when in certain play activities also elements of competition and performance were present, these activities could be called 'sport, even when it was not a physical performance. (…) In the end, it was up to the persons questioned to determine if they practised a certain branch of sport as a sport or not' (CBS, 1964, p. 5).
4. More precisely, Manders and Kropman defined a sport practitioner as someone who practised sport at least ten times a year, outside holidays

and with a specific intention, like competition or performance (Manders & Kropman, 1974).

5. More specifically, the government formulated four accents for sport policy: the first two were explicitly related to health and the other two were not so much related to the content of sport policy, but focused on its organisation (WVC, 1983, p. 7).

Chapter 4

‘Oh gee, is this comment GG?’ Observations during training days for practice nurses

Mirjam Stuij

Translated from *‘Oh jee, is dit eigenlijk wel GG?’ Observatie tijdens de POH-dagen van de ROHA*, published at www.rohamsterdam.nl/document/verslag-poh-dagen/, online publication, 8 January 2016

Introduction

On the website of the ROHA, a care group in the region of Amsterdam, I happen to find an announcement for 'POH days'—training days for practice nurses—with the theme Health and Behaviour. 'The ROHA goes GG'. That sounds interesting. (…) To get a better picture of the profession of the practice nurse, and to gain insight into how they deal with this specific theme, I send an email to the organisation to ask if I can attend the days. An enthusiastic response follows, and I report to the location on the days in question. There are three POH days with the same programme, but different groups of practice nurses; there are about 90 participants in total.

The programme starts with a presentation by honorary chairman, Louis Overgoor, director of Big Move, alternated with some practical assignments from his colleague. An example of such an assignment is asking someone else to explain in one word what health means. When a few words are exchanged in plenary, everyone mentions something else: safety, happiness, complaint-free, relaxation, quality, understanding, life, priority, balance. Louis continues: 'Health is an experience, not something objective. So, health can mean something totally different to yourself than to the person opposite you.' This turns out to be an important starting point for his story today.

During his career as a general practitioner in a 'multicultural' practice, Louis often felt that there was so much more to be achieved: he saw people with many problems and complaints who turned out to enjoy life outside his practice. How was that possible? This observation provided the basis for Big Move and the so-called GG vision. As this vision originally focused on mental health care, the aim of these POH days is to translate this to the work of the practice nurse working in general practice.

An introduction to ZZ and GG

Louis presents his vision of health in the form of a football field with GG ('*Gezondheid en Gedrag*' in Dutch, meaning 'Health and Behaviour') in the attacking zone and ZZ ('*Ziekte en Zorg*' in Dutch, meaning 'Illness and Care') in the defence field. 'ZZ, that's where we work. ZZ is vital for our existence, and very well regulated in the Netherlands. We are doing well and we can be proud of that.' According to Louis, this field is based on a problem, followed by an analysis and then a solution, preferably one that is 'evidence-based'. A goal on this side means 'game over'; death awaits.

The practice nurse, working in primary care, encourages patients just beyond the centreline in the ZZ field, shown on a slide with a woman shouting into a megaphone. The practice nurse has an important assignment, says Louis: 'If you do well, few people will move on to secondary and tertiary care. That is why you also have an essential function for the future. You must start shaping your role.' By that, he means that the practice nurse must also assume a role in the attacking field and must focus on GG. The GG field consists of all sorts of systems that enable people to function—such as the neighbourhood, work, sport, and well-being—with just before the goal the things you do about health yourself, like those related to exercise, food, and relationships. A goal on this side equals 'life!'

According to Louis, two concepts are important in the attacking field of GG. The first is the Complex Adaptive System, or CAS for short. This is 'a system with many processes that constantly adapts to the environment', comparable to a flock of birds. Its essence is unpredictability: it is not at all clear what the next situation will be. However, a CAS always has the urge to do it as well as possible: 'If you look at patients like that, well, that's actually very nice, because you can do something without having much knowledge of it. After all, you don't know what will happen with the advice you give.'

The second concept is 'self-perceived health: a central measure in which the patient is the specialist. People seem to be able to estimate their perceived health pretty well. Research has shown that self-perceived health has a strong relationship with absenteeism, care use, and risk of death', says Louis. He asks me to explain this from a research perspective and I tell about the research project Sport in Times of Illness, which is not only about diabetes care but also about care for people with breast cancer, HIV, and depression. In a survey study, we asked people with one of these illnesses to rate their perceived health on a scale of 1 to 5. This answer turned out to be related to many other answers, and especially to someone's outlook on life and living with an illness.

During the coffee break, a message follows about a newly introduced 'chain information system' that is not yet functioning properly. This offers me a glimpse into a part of 'the system' in which the practice nurse works, something that turns out to be a frequent topic of discussion during each POH day. To get a bit of 'positive energy' again a practical assignment follows: we need to walk around in different manners. For example, while we say goodbye to each other, with both arms wide, giving someone a little nudge or a push against, guiding someone else, or just following.

The responses show that these assignments are experienced very differently. One person leaves room for others, another takes up the room, and yet another seeks the space. Some kept aloof because they did not see the point of the assignment. One person says she finds it uncomfortable to give a push, while another likes it. And the distinction between following or leading is not always clear, as the statement 'I thought I followed, but my leader didn't think so' illustrates. Louis makes a connection to work: 'In relation to your patients, it is also about following, leading, daring to act crazy, and making or taking up space.'

Instead of a 'disease approach', he argues for a 'health approach' in which the professional has a role that is more following than leading. It is aimed at increasing health rather than reducing disease, and improving the functioning of the person opposite you. He continues: 'The practice nurse has opposite tasks: s/he must work both as a ZZ professional and a GG professional. In ZZ, you know what to do, namely measuring, examining, and solving a problem. But in GG, you don't know what to do, because it's all about the interaction with the patient. GG and ZZ are both needed, but take them apart and play with them.'

Intermezzo: news from the care chains and lunch

Then there is some time to exchange news from the different 'care chains' (*ketens* in Dutch): COPD/Asthma, diabetes, and the new chain of cardiovascular risk management. These 'chains' are integrated care programmes for each of these illnesses, based on arrangements between the care group and health insurers. For each of these, the latest developments are presented, including additional training opportunities, changes in insurance payments, plans to better coordinate the care of the various chain partners, obligations for each of the chains in the contract with the insurer, new courses to be followed, and minimum benchmarks to be kept. This part of the programme does not seem very 'GG' to me. If I put all lists side by side, I wonder how there is room for (development of) GG in a consultation.

After a long morning full of information, lunch follows. On one of the days, I get into conversation with two practice nurses who mainly see people with a non-Western migrant background in their consultation hour. They name many specific problems, such as language difficulties, social isolation, and other views on nutrition. A third practice nurse joins the conversation, and they exchange tips on how you can best influence the system, for example, by removing a patient from the chain. There is uncertainty about this: when is that allowed, and when not? But it turns out a practice nurse can create some space and influence the system with a bit of creativity.

Concluding discussion: how can the practice nurse become GG?

The afternoon starts with two workshops, and then it is time for a discussion: how can the practice nurse become GG? Due to the size of the group, we start with ourselves on days two and three: what did this day bring you? What are you going to do with it? What do you need? These answers are then exchanged in small groups, and then in plenary. Occasionally, someone asks out loud: ‘Oh gee, is this comment GG?’ The topic seems to give food for thought.

On day one, the group consists of about 20 participants and the discussion is in plenary. The participants give each other suggestions and exchange examples. For instance, someone talks about a first conversation she recently had with an 80-year-old woman. The practice nurse told the woman she had the time, and at the end of the conversation, the woman had told her whole life story and thoughts about what she wanted to achieve. An excellent example of GG, others react. ‘Do you believe in GG?’ asks Louis, and the answer is ‘yes’. ‘But how is that possible with all the boxes we have to fill in for each patient? If we don’t do that, they will stay red,’ someone wonders aloud.

Louis indicates that a switch to GG cannot be made in one day. He has been working on it for quite some time now and still finds it difficult. ‘There is no ready-made answer, but I sense that you want to continue with this. The question is: how?’ If this question is also approached in a GG way, the ROHA must lean back, and the practice nurses have to come up with an action plan, he continues. ‘Maybe a think tank?’ someone suggests. A few enthusiasts write their names on the board. But how do they develop something that fits within the care group and the system? Louis: ‘A CAS needs boundaries because otherwise it is scary. Then you must take space within those limits. The care group, the insurers, the government, you name it; they set your boundaries for the limiting conditions that exist.’ And to conclude: ‘The only thing that helps in behavioural change is to take a step. A small step. Time for drinks!’

To conclude: research reflections on three days full of ZZ and GG

During the three POH days, it regularly came across that it is quite difficult to bring about change in patients’ behaviour. There are success stories, indeed, and they are shared and seem recognisable to others. But at least as often it emerges that it is challenging to continue to motivate patients. For example, I heard the expression ‘pulling a dead horse’ several times. This might be the reason the practice nurses generally react positively to the view of GG. ‘An eye-opener,’ said a participant. There are, however, several comments that came up in the discussions each day.

The first is ‘the system’, whatever that includes. Whether it is about the health insurer, the ROHA, the health centre, or the doctor, this system wants numbers, such as the HbA1C level, and it does not want experiences. The subjectivity of experiences versus the objectivity of numbers appears to be complex. The first is intangible, but the insurer primarily wants the second, the tangible. And the ROHA seems to want that too, in the experience of the practice nurses.[1] ‘The system’ is aimed at ZZ. Several times, the tension between ZZ and GG is expressed in ‘red and green bars’: have all the required lab values been entered in the patient file, meaning that all red bars turn green, and is there still time left to ask about GG?

Some participants seem to be bothered more by what they have to fill in than others. This seems to be dependent on the room they have to organise their own consultations, both in terms of duration and organisation. Another point of discussion is if you do have to check all the boxes during all consultations. An unclear division of tasks with other professionals, such as the general practitioner, also frustrates some practice nurses. During these discussions, I regularly see comparisons between the patient and the caregiver when it comes to the GG vision. I wonder if there is also a kind of ‘self-perceived health’ for the professional. And would that be a good predictor for work pleasure and absenteeism, for example?

A second point of discussion is which questions you must ask if you want to be GG. Many examples that are suggested, such as ‘how come your sugar is too high?’, secretly appear to be ZZ because they are based on a medical-oriented problem. A switch to GG requires a lot of practice. That doesn’t seem so strange to me either. As a caregiver, you have a lot of knowledge about illness and care, from training and experience, but with GG, you suddenly have to let go. Based the stories shared on the POH days, that requires not only a different approach from the caregiver but certainly also from the patient. S/he comes up with a problem and wants a solution, doesn’t s/he? Then it may first have to be clear that this solution is not to be found in ZZ.

‘GG-permissible’ tips are regularly exchanged, such as mirroring the patient’s behaviour, applying the four-second rule or motivational interviewing, or sticking a Post-it on your computer with the question ‘what does the patient want?’ A critical comment in this regard is whether something is used as a ‘communication trick’ because another approach does not work or that the actual intention is to listen to what the patient wants.

A third recurring point is how you can use measured values in GG, and which are necessary. On the one hand, there is a discussion about whether you can take ‘self-perceived health’ as a starting point. A frequently mentioned objection is that it is subjective. And a snapshot, as the answer can be different an hour later. But that also applies to glucose sober, someone argues. Someone else mentions that it is a beautiful idea(l), but difficult to put into practice. Here again, a tension emerges between ‘the system’ and connecting with the experiences of the patient.

On the other hand, there is a discussion about whether the values that must be entered for the insurer and the ROHA can be useful in GG. Louis indicates that you also measure in GG, but then to see if something has an effect and to improve things if necessary. In itself, measuring is a positive action, but as an instrument, and the outcome measures should be determined by you, he adds. To that end, it seems to me that a significant cultural change is needed.

According to Van Dale, a Dutch dictionary, a ‘benchmark’ is a ‘standard against which performance of organisations is compared’. That sounds like something very different from being able to determine the effect of care provision.

These discussion points illustrate tensions between GG and ZZ. The representation as a football field is catchy and well managed, but also clearly shows a separation. GG and ZZ completely exclude each other. Indeed, football is a fight in which both parties are out to score. If that is about a difference between ‘life’ and ‘death’, it makes quite a difference. I find that confusing and it makes it difficult to really understand the somewhat abstract concepts of ‘GG’ and ‘ZZ’. Also, the complexity of daily practice and the influence of the context, for example, the role of the insurer, is not visible in the football field.

On these three POH days, the responsibility for implementing GG is mainly placed with the practice nurses. And that makes sense, because this is the person closest to the patient and probably the most GG in terms of work. However, there are still general practitioners, the health centre, the care group, the insurer, and the government, which also have change to their behaviour. The care group at least embraces the theme and wants to offer support, as it turns out during the days. But a real change requires more and small steps require a long breath. I am therefore curious whether this introduction in GG will encourage action and change in practice. I hope so.

Chapter note

1. Although occasionally it seems unclear who or what the ROHA is: is it a bulky body that determines everything for the caregivers or is it the caregivers themselves? Everyone’s answer to that question probably has to do with how much influence one feels; for example, by employee participation in the organisation of care and care chains (*ketens* in Dutch) and joint influence on agreements with the health insurer.

Intermezzo II

Exercise as medicine, but not as prescribed

‘I went to the general practitioner on 1 October last year, and I was diagnosed with type 2 diabetes because I was just very sick, and well, that was a bit of a shock… And then I immediately had to take the medication, because yes, I mean, they said; ‘you are hereditary on both sides, eh’—my mother’s side and my father’s side—‘so there is no other way’. They initially wanted to start with insulin right away, but I didn’t think that was a great plan, so I started on metformin. Then I did talk to the practice nurse, but she was like ‘medicine, that’s the best’. So, I was very disappointed in, say, the official care.

Then I started looking for alternatives via the internet, but also at my gym. My gym manager came up with this specific programme for me. Well, I immediately started, and the first day was already a success! Because I measure my sugar before I do exercise, well, and it was way too high, and you burn a lot of sugars during that hour, and then it was good after training. But it also stayed good for the next twenty-four hours. So, it has a very stabilising effect, even the days after. And since I started that training, my sugar has never really been above ten again. Within six weeks, I was able to begin reducing my medication, and I am now without medication. The way I live now, I live like before I was ill: being active and able to do the things I want.

I did a lot of sport [before my diagnosis, I have always been] quite, just, always been active, also because I have the predisposition to get a bit fat. I did not think I would get [diabetes] because I was pretty active. I already had thyroid problems, also hereditary from both sides, and that was why, that was 13 years ago or something, that diagnosis, when I had gained ten kilos within six weeks, because that [thyroid] suddenly stopped working. I went to a dietitian and started exercising more and since then I have been very conscious about food and sport (…) but I did no strength training five times a week. I went running three miles three times a week, plus spinning twice and doing yoga once or twice, so yes, you think, ‘I’m doing a good job’. I also kept to the guidelines of the Netherlands Nutrition Centre. I did eat too much, that’s a fact, but it wasn’t very extreme. I was also slightly overweight, a BMI of 27, so just too much, but not that you say, that at the age of 46, you will already be diagnosed with diabetes. So that made me pretty… well, really, really disappointed.

The only fundamental thing that has changed in my sport behaviour is that at some point I just couldn’t do my cardio trainings anymore, so I had to go to the doctor. Even when climbing stairs I became breathless. Well, and then it turns out that for good control of diabetes and also for the prevention of it, you have to do strength training. So, my gym manager and I looked up scientific research, and it is just this specific strength training programme three times a week, and I’m doing that now. Then a specific hormone, eh, IGF-1, I don’t know if you heard about that, a growth hormone, well, it increases a lot in six weeks with these trainings, and this replaces the insulin a bit.

[Pointing to her papers:] So at this point was the diagnosis: everything terrible, all sugar very high, those are my daily measurements. Then I started doing strength training here, this IGF strength training, well then you see that it is 13 before my training and then 9.8 afterwards, so immediately, after such training, you immediately lift it from the red to the green. And after a few weeks, it is almost entirely green, yes, in the afternoon [my value] was always good.

[My blood glucose] sober remained difficult for a while, but I now also have that under control by training sober once every two weeks, a bit of liver cleaning. Because with me, if I start exercising in the morning, my liver will dump sugar, so your sugar will go up, and if you get rid of it by a workout before breakfast, your liver will be cleaned a bit for the rest of the week. I once came across an article about that with someone who had done that, so I thought, let's just try if that works for me. Because yes, well, everyone is different and not every diabetic is bothered by a sugar that goes up in the morning, but that turned out to be the case with me. Well, and my goal is just to make sure that the liver is a little clean and doesn't have too much of that stored sugar.

There are a lot of people who just don't know, and stand on a cross-trainer for an hour, three times a week, and think they're doing the right thing. Just as I thought I was doing well, but I ended up getting very sick. Now it has become sport as a medicine for me, instead of that medication with side effects, I do three training sessions a week. So yes, for me more people should know that, at least caregivers should know that strength training is the best choice and then it is up to the patient whether or not to do it. Because yes, my brother also has sugar and my sister who is pre-diabetes, because I had warned her, she will now go to the gym and then she will do strength training. And he's like, 'yes, I do work in the garden and stuff like that'. Then I think 'that is not specific enough', because I also worked hard five times a week in a gym. You really have to do this training very correctly. He does indeed have that scenario medicine, medicine, medicine, medicine, medicine. He has no insulin yet, but yes, within now and a year or so that will probably be the case. But yes, that is the patient's choice, I think, if he has been informed. But, well, make sure they are informed. Now I had to search a lot, and I happened to be lucky that my gym manager had experience with this and had a training and the scientific studies of the IGF-1 hormone because I had never heard of it, I must say, of that hormone.

That's why I also participated in [this] study, because I thought, well, you can collect all that kind of information and get it to those caregivers. Because when I see what's going on with those caregivers, well, that's really eh… I've seen a presentation given to trainers. It starts with such a picture of someone who is very obese, like: that is your patient. Then I think, well yes, diabetics that I know are pretty much like me, not light, but also not super fat or something, they are just average Dutch people, and yes, they are sick, and they need help. And if you inform them well, I think most patients are interested in doing that. I do it fairly intensively because I just wanted to get rid of it very quickly, but you can also do it, if you read that research, it is enough to do a round of ten exercises three times, with ten repetitions. So, then you do ten exercises, repeat everything ten times, well, then that is just half an hour. If you do that three times a week, yes, to be medicine-free, I think it would be worth it.'

Ms Borst
May 2015

Experiences

Healthcare dilemmas and daily life narratives

Chapter 5

‘Physical activity, that’s a tricky subject.’ Experiences of healthcare professionals with physical activity in type 2 diabetes care

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Abstract

Background: Based on a growing body of epidemiological and biomedical studies, physical activity is considered a cornerstone in type 2 diabetes treatment. However, it is also a practice embedded in daily life and, as such, may produce certain frictions as a topic in healthcare. The aim of this chapter is to give in-depth insight into experiences of healthcare professionals with the delivery of physical activity counselling to people with type 2 diabetes.

Methods: This study is based on in-depth interviews with 24 Dutch professionals providing care to people with type 2 diabetes. They were asked to tell about their experiences with physical activity in different roles, both in their professional and personal lives. The interviews were audio-recorded and transcribed verbatim. Data analysis followed a narrative approach with not only a focus on what was told, but also on how this was constructed in interaction with the interviewer, the cultural resources that were drawn on and inconsistencies or alternatives that were presented. This narrative focus was used to explore how professionals made sense of their experiences with physical activity counselling within the wider sociocultural context.

Results: While the professionals view physical activity as a foundation of type 2 diabetes treatment, they experience it to be a tricky subject. Two main areas of tension were identified: (1) the understanding of patient behaviour; and (2) professionals' views on responsibilities, both on their responsibilities as professionals and their notions on who is responsible for behaviour change.

Conclusions: Healthcare professionals providing physical activity counselling to people with type 2 diabetes have to navigate between possibilities within the diabetes care framework, options for an embedding of physical activity in the patient's lifeworld, and the professionals' opinions on and experiences with physical activity and healthy living from their own lifeworld. This makes physical activity a complex topic of care.

Background

Physical activity is considered a 'cornerstone' in type 2 diabetes care, along with diet and medication (Pedersen & Saltin, 2015): one of the starting points for treatment is to 'stimulate the patient to be sufficiently physically active and to work on the improvement of one's fitness' (NHG, 2013, p. 6; IDF, 2012). This is based on numerous biomedical and epidemiological studies that point towards positive effects of regular physical activity on blood glucose control especially, as well as several other parameters important in type 2 diabetes treatment (Thomas et al., 2006; Lee et al., 2012).

This emphasis on physical activity fits within a larger care framework on self-management, a key aspect of type 2 diabetes care (Gomersall et al., 2011;

IDF, 2012; Elissen et al., 2013). Self-management is defined as the individual's ability to gain control over an illness, amongst other things, by managing lifestyle changes and in conjunction with healthcare professionals and relevant others (Richard & Shea, 2011). This, in turn, fits in current dominantly neoliberal government and health policies, in which the responsibility for well-being primarily lies with the individual and 'consumer choice' and 'empowerment' are considered central values (Vassilev et al., 2017).

In medical guidelines for diabetes care, professionals are instructed to advise, encourage and provide ongoing counselling on the topic of physical activity, as part of 'diabetes education' (IDF, 2012). Overall, these strategies are directed towards increasing patient knowledge, for instance, on the benefits of physical activity and the possibilities to practise it. The assumption is that the patient will make the 'right' choice when offered enough information. This matches with a 'logic of choice' in which scientific evidence is considered neutral and clear, and people make independent, informed and rational decisions with a presupposed predictable outcome (Mol, 2008). The task of professionals, then, is to provide their patients with this knowledge so that these can decide for themselves what might be the best treatment or way of life.

However, the same global guideline that stresses the importance of diabetes education also refers to its 'patchy evidence' on effectivity, especially doubts about its long-term effects, and acknowledges that promoting knowledge alone is not enough (IDF, 2012). In fact, many studies point towards the difficulty of behavioural change. A study among almost 5000 women demonstrated that a diagnosis with diabetes or another chronic disease did not impact on their level of physical activity significantly (Dontje et al., 2016). Related to type 2 diabetes, this is even more complex, as physical inactivity and obesity are considered important causes (WHO, 2016a). This means that professionals are instructed to stimulate people who generally are not inclined to be active.

However, a complex combination of other factors are found to be important in the causation of type 2 diabetes, like genetic susceptibility, diet, in utero and early malnutrition and environmental factors (Chen et al., 2012). This is further intertwined with intersecting social categories like socio-economic status and ethnicity. In high-income countries, type 2 diabetes is more prevalent among people with a lower socio-economic status, measured by education, occupation or income (Agardh et al., 2011), and people with a specific migrant background, like people from Turkish, Moroccan or Surinamese descent in the Netherlands (Bindraban et al., 2008; Ujcic-Voortman et al., 2009). In general, these people have more problems related to health and daily living conditions, like housing and work, than others (CSDH, 2008). These problems are also considered to preclude much attention to healthy living (Heutink et al., 2010).

Physical activity is a practice embedded in daily life. Therefore, a focus on physical activity counselling provides an example in which biomedical guidelines and daily life have to be brought together. This might produce certain frictions. A meta-analysis of qualitative studies about patients' and professionals' views on type 2 diabetes medication adherence, for instance, showed that professionals generally limit their focus to clinical issues, while patients mention problems from a much larger perspective including the personal, social and practical challenges of living with diabetes (Brundinisi et al., 2015).

Moreover, physical activity is also something that professionals have personal experiences with, whether positive or not, and whether recent or long ago. These experiences might influence their tendency to address the subject at all, for instance, because of a personal affinity (Hébert et al., 2012). Furthermore, professionals probably also have personal opinions on the importance of physical activity, possibly influenced by a larger social discourse emphasising that 'sport is good for health' (Wheatley, 2005). Hence, the daily life of the professional might—implicitly or explicitly—also be present in the consultation room, or, in contrast, consciously left out (Laws et al., 2008).

Finally, professionals work within an established framework of care with a certain protocol and amount of time. In a systematic review, a lack of time was identified as the most common barrier for professionals to provide sufficient physical activity counselling in clinical practice, followed by a lack of knowledge or training and a lack of reimbursement (Hébert et al., 2012). Related to the care framework, Dutch nurses specialising in diabetes are 'trained to organise their care efficiently' (Raaijmakers et al., 2013). They are considered able to deliver effective and efficient care for people with type 2 diabetes, with 'effective' referring to the improvement of certain measurable parameters like HbA1c (Houweling et al., 2009). These studies fit within a larger social and political discussion about increasing healthcare costs, considered relevant to diabetes since its prevalence is expected to increase in the next decades (Tamayo et al., 2014). In this sense, physical activity might be considered a cheap 'medicine'.

Notwithstanding these guidelines and all kinds of possibilities, difficulties and limitations, healthcare professionals have to act; they have to deliver physical activity counselling or care to their patients. Most studies among diabetes professionals aim to improve patient outcomes or adherence; for example, by identifying barriers and enablers to physical activity counselling (Hébert et al., 2012) or factors influencing physical activity promoting practices (Huijg et al., 2014). They do not examine the experiences of professionals. Insight into these, however, might provide us with valuable information about frictions and concordances in diabetes care from a professional perspective. This might lead to a better understanding of what 'good care' implies and what is needed to offer this (Mol, 2008). In the long term, these understandings might add to the well-being of both professionals and their patients.

Type 2 diabetes care in the Netherlands is found to be of a very high quality (Garrofé et al., 2014). There is a National Care Standard for type 2 diabetes (NDF, 2015b), which is strictly followed by primary care providers (Garrofé et al., 2014), and a specific guideline on type 2 diabetes for general practitioners and practice nurses (NHG, 2013). These both emphasise the importance of physical activity as a topic of care. Since self-management is found to be an explicit focus in Dutch diabetes care (Wensing et al., 2014), it is expected that physical activity is a standard topic of care. This makes the Netherlands an interesting case for this study. Therefore, the aim of this chapter is to give in-depth insight into experiences of Dutch healthcare professionals with the delivery of physical activity counselling to people with type 2 diabetes.

Methods

Design

To gain profound insight into the experiences of healthcare professionals, this study has a qualitative and narrative design. It is based on in-depth interviews with professionals providing care to people with type 2 diabetes. These interviews were considered stories in which the professionals selected, connected and evaluated experiences they considered meaningful in the context of this study (Riessman, 2008). This narrative focus is useful to explore how professionals make sense of their experiences with physical activity counselling within the wider sociocultural context (Riessman, 2008). This is of importance because this context offers possibilities, difficulties and limitations related to physical activity and physical activity as a topic of care.

Pilot study

In 2012, a pilot study was conducted by another researcher (van den Berg, 2012). This study was co-supervised by the author. Professionals were recruited through the networks of the researchers and the Internet. In total, 22 were approached and 11 agreed to participate. Four of them were practice nurses in a health centre or diabetes nurses in a hospital and the others offered actual physical activity care, like physiotherapists. The main interview topics concerned personal and professional experiences with sport and physical activity. The interview took place at the respondent's workplace, and was recorded and transcribed verbatim. The transcript was sent back to the respondent as a member check and reactions were added. This pilot served as input for a research proposal to extend the study on this topic and to test the interview format. Based on this, the format was adjusted; however, the background of the study and the general interview topics remained the same.

Therefore, the transcripts of the pilot study interviews were added to the main study during data analysis.

Data collection of the main study

The main study was conducted in 2014-2015 by the author. She has ten years of experience in qualitative research in the fields of sport and health. Sixteen professionals were approached by email or telephone. They were recruited through several (diabetes) organisations ($n = 9$) or the Internet ($n = 7$). Sampling was purposive in nature. Some professionals were asked because of specific experiences; for instance, because they offered a discussion group for people with diabetes or organised a weekly walking or exercise group. The aim was to include a wide range of professions within diabetes care. However, there was an emphasis on practice nurses and diabetes nurses—since they generally provide most of the care to people with diabetes in the Netherlands—as well as on those who offer actual physical activity care, like physiotherapists. Furthermore, the aim was to include at least eight professionals providing physical activity care and eight professionals offering physical activity counselling. Professionals were not asked about their own physical activity levels or experiences beforehand. Thirteen professionals agreed to participate; the others did not respond.

At the beginning of the interview, the respondent was encouraged to tell about his or her experiences and told not to expect many questions (Nijhof, 2000). Using cards representing different domains—such as work, home, leisure time, experiences as a patient, and sport and physical activity —the respondent was asked about different roles in life. This was meant to stimulate the professional to shift ‘narrative positions’ throughout the interview and think about experiences with physical activity and sport from different perspectives (Holstein & Gubrium, 1995). The respondent was asked to tell about their role(s) at work and experiences with offering physical activity counselling, followed by physical activity experiences outside the work domain and a reflection on intertwinements between these work-related and other experiences.

Dependent on the available time of the respondent, the interviews lasted between 30 min and two hours, with an average of an hour. Two interviews took place at the respondents’ homes, the remainder at their work places. Afterwards, the interviewer noted down experiences with and feelings about the encounter in a reflexive account and transcribed the interview verbatim.

Data analysis

Data analysis started after the first interview. After listening to the audio and re-reading the transcript, the author wrote the story as told by the professional, staying close to the words of the respondent and the order of the conversation. This story also included questions asked, to show how it developed in interaction. Furthermore, it included a preliminary analysis. This account was discussed with one or two other researchers involved in the larger project and sent back to the respondent as a member check. Three of the respondents did not respond after a reminder. Since a reaction was voluntary and they had not withdrawn from the study, their transcripts and stories were included in the data analysis. The reactions of the others differed from 'difficult to read my own spoken language' to 'very nice account'. Besides some minor suggestions, all agreed on the account as presented.

From the first interview onwards, specific areas of tension or dilemmas related to the professionals' experiences with physical activity counselling seemed to arise. In subsequent interviews, these were confirmed, enriched and supplemented. After 13 interviews, data saturation was observed. Although new stories were told during the last interviews, the main difficulties and areas of tension related to physical activity counselling or physical activity care were the same.

The overall analysis consisted of an iterative process—moving back and forth between stories and transcripts and between individual and general level—aligning with a narrative approach: with not only a focus on what was told, but also on how this was constructed in interaction with the interviewer, the cultural resources that were drawn on and inconsistencies or alternatives that were presented (Riessman, 2008). Data were coded using MaxQDA, version 12.0. This was mostly inductive, with the aspects of the narrative approach in mind. The stories were first coded, followed by the transcripts to check if all important information was present. At this stage, the transcripts of the pilot interviews (van den Berg, 2012) were added. These further confirmed the findings. Within this diverse group of professionals, data saturation was felt to be reached. Nonetheless, for a specific comparison between different groups of professionals—which was not an explicit aim of this study—more professionals within the groups should be interviewed.

In the end, two main areas of tension were identified. These were: (1) the understanding of patient behaviour; and (2) professionals' views on responsibilities, both on their responsibilities as professionals and their notions on who is responsible for behaviour change. To check the analysis and interpretations, earlier versions of this chapter were discussed with several other researchers from different disciplines, like sport sociology, care ethics, anthropology and health psychology. To illustrate the findings, and especially reveal the complexities the professionals testified about, some of them are quoted at length in the results section.

Ethical considerations

This study is part of a larger project, Sport in Times of Illness, which was approved by the Medical Research Ethics Committee of the VU University medical centre. The respondents received a letter with information about the aims of the project, the interview, and details concerning anonymity, confidentiality, audio recording and the option to withdraw at any time. They signed informed consent. All transcripts and stories were anonymised and participants were assigned pseudonyms.

Participants

The total sample—pilot and main study—comprised 24 Dutch professionals providing care to people with type 2 diabetes: eight physiotherapists, five practice nurses working in a healthcare centre, three diabetes nurses working in a hospital, two general practitioners, an internist, a nurse specialist, a dietician working in a diabetes centre, an exercise coach, an exercise expert working in an obesity clinic and a health specialist working in a health centre. Seven of them were male, their mean age was 44 years (range 25-64) and they had 15 years of work experience on average (range 1-40).

Results

Regarding the place of physical activity in diabetes care, most of the professionals noted it was something they almost always mentioned to their patients or asked them about, as ‘the foundation of treatment’:

> *For all topics [in diabetes care] the same applies: there are always more or less the same advice, namely, do more physical activity and take care of your diet. But physical activity, that’s a tricky subject. It is not something people are easily inclined to. It’s difficult to change, always. (Gemma, nurse specialist)*

This quotation is illustrative of the findings in several ways. It underlines the importance of physical activity in diabetes care according to the professionals, but the use of ‘tricky’ refers to difficulties and tensions that accompany physical activity counselling, at least from the perspective of the professionals. It seems to be something that challenges them. This is exemplified by the two main areas of tension found in the professionals’ stories: the first is the understanding of patient behaviour and related difficulties that the professionals encounter; the second is the professionals’ views on responsibilities, both for behaviour change and as professionals. These two areas overlap at times and are further explained in this section.

Understanding patient behaviour

The stories displayed a lot of references to understanding patient behaviour, varying from some understanding to none at all. The analysis revealed that these references mainly reflected differences the professionals had experienced between themselves and their patients, both implicitly and explicitly mentioned. These were differences in experiences with and meanings assigned to sport and physical activity, opinions on healthy living and taking personal responsibility for health, and social positions. Understanding was influenced by both personal and professional experiences that made it more or less easy for the professionals to identify with patient behaviour.

For instance, some professionals had personal experiences that increased recognition of their patients' difficulties to become more active. Three professionals could not practice their favourite sport anymore because of an injury or illness and discovered that they 'hated' to go to the gym. Two others had other priorities at the moment—a mother being ill, a young child at home—and noted that they would like to be more active, but were not able to realise it. A general practitioner explained that she started running and found it very difficult, especially because of the muscular pain. This made her realise that her patients needed someone guiding them, for example, a physiotherapist, to tell them, 'This is normal… You need a week to get used to this'—an addition that may also reflect a distance between her, having a lot of experiences with sport, physical activity and probably aching muscles, and her patients, mostly without these.

Based on their work experiences, several professionals came to understand that the goal of the medical guideline—being moderately active for 30 min a day (NHG, 2013) —was 'unrealistic' for many of their patients. They emphasised that 'small steps are also steps' and discovered that for most patients, especially those who were not used to being active, it was important to 'think' in small steps. These were preferably steps that could be integrated in daily life, like cycling to the store instead of taking the car. Some professionals mentioned that they often tried to slow patients down, because otherwise 'they've all kinds of excuses why they didn't succeed the next time'. Nicole (dietician) emphasised the importance of small, realistic goals, while she also noted that many of her patients did not know they should be active for an hour a day to lose weight. A goal quite difficult to attain, she added.

Some other professionals, especially the physiotherapists, did keep the norm of 30 min a day in mind: they provided trainings for three months twice a week and encouraged patients to do something else at home in order to meet the standard. However, some of them experienced this to be quite difficult for patients without positive physical activity experiences: 'It is a utopian dream to think you have it fixed in twelve weeks.' This shows a tension between guideline and practice that leads to other understandings of what to expect from patients.

Another tension was related to differences in views on healthy living. Some professionals held quite strong views about their patients, especially the physiotherapists—who seemed to experience the greatest differences between their own and their patients' behaviour and to disqualify the lifestyle of their patients most strongly:

> *Every now and then I have conflicts with those people, because they have a totally different approach on how to keep your body healthy. And that's difficult. (…) I find health a privilege. (…) I think that if you get a good package from home, you need to treat it decently. So that means: don't stuff yourself with that much food and burn enough calories. (…) I find it very hard that people have so much difficulties with this. (John, physiotherapist)*

> *The average diabetic is not willing to be active. Now, I put it very black and white; that's not nice to say. The average diabetic has overweight[ness], comes from a lower SES group. In general. He has no money to do sport, or isn't willing to pay for it. Because they have money for a big flat screen. But yeah, they give low priority [to physical activity]. You have to see it this way, or I see it this way. (…) It irritates me. Of course, you have problems with your ankles and knees, you are 30 kilos overweight. (…) I think: 'That's just not necessary, that you became that fat. Where did it go wrong?' I experience this from my own perception, my own situation at home with two incomes, nice house. A totally different perception than from someone sitting at home. And I cannot look behind the front door, that's the problem. (…) Everybody can be active (…) just walk or cycle. (…) Priority, that's what it is all about. (Marcel, physiotherapist)*

Especially, Marcel seemed to have difficulties in understanding his patients, while also being conscious about his different social and economic position. In the story of Krista (physiotherapist), the tension between understanding patients who are not willing to do something for their health on the one hand and realising the difficulties of behaviour change on the other seemed to be the most palpable:

> *Actually, given the fact that I'm working in a deprived area [where a lot of people with diabetes live], I find it surprising how difficult it is to get a group of people together [for my training programme]. And then, it's often difficult to let people be here every time. Easy excuses to not be there again, you know. Not legitimate reasons, in your eyes, but yeah, what's legitimate? For someone else, well, 'the neighbour is here to drink coffee [so I cannot be there]'. (…) So how important is physical activity for you? To keep on going, that's quite difficult [for me], to keep the motivation up. (…) And I let them pay 25 euros, as a sort of promise [to keep coming]. But there is a lot of moaning—that's a big word, but they find it a burden. And then I think: 'Well, hello, you can do trainings for three months for this 25 euro[s].' (…) I don't totally understand this. Do you*

> *really want to change something about your health or not? And isn't this worth it? While you might make other decisions you easily pay 25 euro[s] for. (…) You flog a dead horse sometimes, to put it disrespectful[ly], and you don't feel like it. I want to give some input, but you have to want to be here yourself. (…)*
>
> *But it is quite difficult to do exercises at home consequently. I find that hard myself, too. Sometimes I think: 'Now, I'm going to do stomach exercises for a while.' Well, a week is over before you know and you think: 'Ooh! I'd do those exercises! Wait, it is like this for that patient as well…' (…) So I get that for someone with already a difficult body, to realise this, that's far from easy, when you're 140 kilos, to start being active. We'd carry three backpacks, or maybe even four. 'Go and train on that cross trainer.' Well, that's hard (…) And that stupid homeopathic pill I needed to take twice a day, how many times did I forget it? That really was an eye opener for me. What are you expecting from everybody? So, you can say, 'Do your exercises daily or go and be some more active every day', but between good intentions to do so—because I really wanted to take that pill—and doing it, that's not so easy. It's quite difficult. Man is such a creature of habit.*

She seemed to be disappointed and frustrated by the lack of enthusiasm for the programme she offered. However, some of her own experiences made her gain an understanding of her patients' difficulties as she could better identify with these. This quotation clearly illustrates certain contradictory feelings related to the understanding of patient behaviour and the difficulties professionals experience.

Most of the professionals balanced a bit between understanding and at the same time not really understanding the behaviour of their patients. Several emphasised that 'physical activity is something extra, it comes on top of it all', as people with type 2 diabetes also have to take care of medication, diet and sometimes try to quit smoking. Three others mentioned that most of their patients do not feel ill or are not bothered by their diabetes in daily life, which makes it 'hard to constantly keep the focus on diabetes' or see the necessity of continuing physical activity. Many noted the importance of positive childhood experiences in sport and physical activity, something they almost all had themselves, but knew many of their patients did not. Financial barriers were mentioned a lot, and a general practitioner added that sport can be quite expensive, especially when you are not used to paying for it. Some professionals referred to socio-economic or cultural differences between them and many of their patients, like a lower socio-economic status, living in a deprived neighbourhood or having a non-Western background, especially for women. These patients were thought to have more difficulties in understanding the messages, to set certain 'priorities' and to implement physical activity in daily life. Although this seemed to result in a sort of understanding or acceptance on the one hand, it also made it difficult for the professionals to really understand the difficulties on the other hand, because they were not familiar with these circumstances.

These differences were also visible in the way the interviewer was sometimes included in the story of the professional: ‘of course, we easily talk about physical activity’, Paul (physiotherapist) said to the interviewer, without knowing anything about her physical activity story. This illustrated a presumed difference between him and the interviewer on the one hand and his patients on the other hand. Sarah (practice nurse) formulated it this way:

> *You just have two categories of people: those who sit behind the wheel, who want to have control over their life, have their own responsibility and take it, and there are people who sit in the back of the bus and let themselves be driven, who let it happen. And if those people don’t undergo a change [in attitude], they have a long way to go before they get in at the front of the bus, sit there. Then you have such a different way to go before you even talk about physical activity.*

Sarah was very active herself, in contrast to a share of her patients. Although she was conscious of this difference and reflected on it throughout her story, at times she had difficulties in understanding patients who seemed to have another view on taking responsibilities for their health. This is where the tensions between the themes of understanding and responsibilities overlap.

Responsibilities for behaviour change and professional responsibilities

Within the theme of responsibilities, several questions or tensions seemed to arise: who is responsible for behaviour and behaviour change? What are professional responsibilities and what are not? How far do these responsibilities go? Several professionals talked about changes in their profession over the years related to this theme; for instance, in the way of communication with a growing emphasis on ‘motivational interviewing’—instead of telling patients what to do, they have learned to ‘lean backwards’ and let patients tell them what they want to do. Alice (diabetes nurse) experienced a transition from being a professional who knows what to do towards being a kind of counsellor now. She also saw the attention to behaviour change in diabetes care increase a lot. The three physiotherapists with more than 25 years of work experience noticed a comparable transition—from giving massages and ‘fixing’ patients to letting them be active during therapy and searching for a solution, namely becoming more active in daily life, together.

Overall, tensions related to responsibilities developed mainly from doubts or ideas about when it is time ‘to let someone go’. As Emma (just started working as a physiotherapist) put it:

> *That's frustrating sometimes, that the general practitioner, the practice nurse, the physiotherapist… Everybody puts so much energy, time and enthusiasm into it. And if someone really doesn't want to, do we have to keep on trying? Or do we need to say, 'It ends here'? Luckily, I didn't experience [that someone really didn't want to]. (…) I didn't see them, but I believe they exist.*

This quotation also illustrates a professional image of specific patients: those who do not want to be active. In the end, the professionals considered it to be the responsibility of the patient— 'if people don't want to, that's fine, then it stops'. However, they seemed to differ regarding the possibilities they could offer as a professional. For Nicole (dietician), it was clear that her patients needed help, otherwise they would not come and see her, although the only things she felt she could offer were advice and discussions about the topic. After 40 years of work experience, Willem (internist) had 'little illusions' left:

> *Type 2 diabetes is a consequence of our lifestyle. So here you see the development of a chronic illness as a consequence of your own behaviour. (…) Getting people to be active is a public healthcare responsibility. My responsibility is to offer these people, when they have developed diabetes, their care as good as possible (…), not to change their behaviour. Even if you do your absolute best, it won't happen. That doesn't mean you don't have to try, especially with younger people and people you can have a good conversation with, it sometimes happens. But the alteration of people is strongly dependent on the environment they want to and can live in, and that's something I cannot change from my healthcare position. (…)*
>
> *I quit saying, 'It's nice to do some exercise'. Sometimes, I propose: 'How about cheating? Let me send you to a physiotherapist, so you have to do it for a while.' But then [when the insurance fee ends after three months] people tell me, 'I quit, because I didn't get it paid anymore'. Well, yeah, you can walk outside, guys. That's what you get, especially people with type 2 diabetes, nine out of ten revert to the same habits. So, I'm pessimistic about it. But in this case, it's realistic. (…) I do my best for the people I see, but, in the end, I won't create a solution with my advice.*

He mentioned the need for professionals to see some results of their efforts in order not to lose motivation, a 'what's in it for me?' for professionals. Although he hinted at the rare possibility of results, he seemed to have let go of feeling responsible for the behaviour change of his patients, as he experienced it to be beyond his reach. He was the only professional who explicitly expressed this view. He did not consider behaviour change the responsibility of his patients alone, either, but also of public healthcare, although the 'you can walk outside' remark reveals an ambivalent attitude towards this.

As a limitation to professional responsibilities related to physical activity counselling, several professionals mentioned characteristics of the healthcare system, like lack of time, low frequency of appointments or a focus on protocols instead of people. Especially, Gemma (nurse specialist) considered ‘the system very difficult at the moment’, with an increasing emphasis on administration and high demands of insurance companies. Willem (internist) mentioned both time and the focus on protocols as difficult:

> *I’ve only ten minutes and more to discuss. So that’s too little [time] to seriously talk about it. (…) My first question is: ‘How are you?’ And they give me their sugar levels. That’s not what I asked. (…) Our practice nurses are also drilled to focus on bringing those sugar levels down. That’s why we have the best diabetes care in the world, but now it’s time to look more at the person instead of its numbers.*

Elena (practice nurse) admitted that she needed the protocol as something to hold on, but at the same time found it difficult because ‘that whole list is not the list of the person [themselves]’. She found a way in between: after finishing the protocol, she asks people how they are.

The limited overview and possibilities of physical activity options to refer patients to were also mentioned several times. Professionals considered the possibilities as often temporal because of subsidies that ended, and therefore found it difficult, and also not necessarily their responsibility, to keep the overview up to date. A frequently mentioned subject was the temporariness of physiotherapy—because insurers cover three months of training—and the difficult task for patients to continue to be active afterwards. This was not so much mentioned by the physiotherapists themselves; most of them told about their patients being enthusiastic during trainings, but losing them out of sight afterwards. However, the other professionals—those who referred patients to the physiotherapist and saw them back afterwards—experienced that only few people were able to continue to be active on their own.

A specific theme that emerged among the ‘consultation room professionals’—those who did not offer physical activity trainings—was a tension between the wish to offer people something more than only advice or to consider this not a responsibility at all.

> *If the step to start is too big, I cannot do anything else. I can hardly take them by the hand and go with them, can I? So, then it’s with them. I can give some advice, but they need to get going themselves. I’d prefer to say, ‘You have to do this and that’s it—easy’. But it doesn’t work this way and that will always be difficult. (Alice, diabetes nurse)*

> *I'm a general practitioner, so I'm not someone who actually goes along with people if they have to be active. A general practitioner often gives advice, discusses resistance, doubts or constraints and gives explanations about the importance of being active. (Thomas, general practitioner)*

At the moment of the interview, however, Thomas was involved in the organisation of a walking group. However, he tried to do this together with volunteers and social work, as he did not consider it a responsibility of him and his colleagues to keep such a group going. Elena (practice nurse) started a weekly walking group herself, because she wanted to offer her patients something concrete and accessible instead of 'only telling them to be more active'. Marjolein (practice nurse) also started such a group. Both spent some of their spare time on the organisation. They were enthusiastic about their group, and felt it offered something important for some of their patients, both because of the physical activity and the social aspects. However, they also considered it quite a lot of effort to keep it going and find new people to join, and sometimes felt frustrated by this. Especially, the story of Marjolein seemed to represent different tensions related to the theme of professional responsibilities and the motivation to keep going as a professional:

> *Actually, people prefer to be picked up at home, taken by the hand and properly brought back home again. Yeah, society changed; that's not possible anymore. (…) So now I'm letting it go a little bit; it needs to be initiated by the patients as well. And sure, I can meet someone halfway, help them to get on board, but people who are not motivated to be active, that's such a waste of time. Really, that's not fun for both of us. (…) At the front door, you need to be able to assess if someone is motivated or not. And with those who are, you go on. And those you think are not, or people who think they won't achieve anything, you have to let them go. That's the tendency at the moment. (…) I've heard all [the] excuses by now. So that makes it very, very difficult to stay motivated [for me]. To get going every time. To keep on walking. (…)*
>
> *Sometimes, it just doesn't work. There are people who say, 'I don't feel like being active, I don't see the benefits'. Then you talk about this several times to make the benefits clear. And if they still don't want to, well, fine, then it ends. Then it's not my responsibility anymore. I tell people sometimes: 'It's your chronic disease. You can see me as a kind of supermarket to get knowledge and information from, but you have to deal with this. (…) But don't say that you didn't know later on.' Because this is something that is made understood good and proper to such an extent, that nobody can say that. So, they know, but it's just what they want with it themselves. It doesn't make me feel forced to… well, I always talk about it, but if they don't want to… (…) I need to be sure they understand they can do something about their illness themselves*

> *by being more active and eating healthier. But if they know and do nothing about it, well, then it's their own responsibility. (...) I mean, I won't get paid any less or something.*

This 'letting people go' and assessing the motivation at the beginning, was something she learned over time: 'Yeah, you also change in this process.' Some other professionals also told about this:

> *I learned it not to be my responsibility. In the beginning, you want to save people. (...) There is so much possible! You can do so much about it yourself! So, you are inclined to expect someone else to have your own norms as well, norms about health and taking responsibility yourself. (Sarah, practice nurse)*

This illustrated a shift in feelings of responsibilities over time, something Krista (physiotherapist) deemed necessary to 'stay healthy as a healthcare professional'.

Discussion

Physical activity is part of the medical guidelines on type 2 diabetes and as such needs to be integrated in the diabetes care framework with certain protocols and amounts of time per patient. However, it is also part of the patient's lifeworld as a daily practice, either as something being practiced or not, and something someone wants or intends to do more or not. Healthcare professionals are positioned in between this medical world and the patient's lifeworld (Mol, 2008). Moreover, they also have experiences with physical activity and opinions about healthy living and related responsibilities from their own lifeworld. In the healthcare setting, professionals have to navigate between these different worlds. This makes physical activity a complex topic of care, as is illustrated by the results of this study among 24 professionals working in type 2 diabetes care in the Netherlands.

This study revealed that this complexity arises from a professional view on physical activity as a 'foundation' of diabetes care on the one hand and an experienced 'trickiness' of the subject on the other hand. It is shown in tensions concerning difficulties in understanding patient lifestyle behaviour, and the professionals'—at times ambiguous—views on the responsibilities of patients and themselves. The professionals expressed rather ambivalent feelings about these themes, like the internist who had few illusions left regarding his possibilities to help patients change their physical activity behaviour, although he still stressed that one always needs to try. Or the practice nurse who started a walking group to extend her offer, although she found it hard to not lose motivation herself.

These tensions seem to increase when the professionals' own behaviour and opinions differ more from those of their patients. Lifestyle practices, like sport and physical activity, as well as views on healthy living and responsibilities for health are related to social positions; in the Netherlands, as in other high-income countries, people from the lower social strata are generally less active and tend to attach less importance to healthy living and individual responsibility (Wardle & Steptoe, 2003). These factors are intertwined in an intricate way, and also present in the healthcare setting. Experiences with and benefits from healthcare closely link to social positions (CSDH, 2008). Tronto stated that we preferably take care of those close to us, because their needs are easier to assess (Tronto, 1993). Dutch professionals working in type 2 diabetes care—higher educated, and more often white people—differ from a share of their patients in background characteristics and living conditions, since type 2 diabetes is more prevalent among people with a lower socioeconomic status and a specific migrant background (Bindraban et al., 2008; Ujcic-Voortman et al., 2009; Agardh et al., 2011).

Although this study shows that professionals are aware of these differences and take them into account, the results also indicate that these differences make real understanding of the conditions patients live in and their physical activity behaviour difficult. This seems to make it complex for professionals to identify with patient choices and establish their precise needs. While many studies point towards a positive relationship between a professional's personal interest in physical activity and the inclination to address the subject in the healthcare setting (Brotons et al., 2005; Laws et al., 2008; Hébert et al., 2012), this study demonstrates this might also make it more difficult to understand those patients who are not active.

Especially, the (male) physiotherapists seem to experience great differences between their own and their patients' physical activity behaviour. Their personal interest in sport probably contributed to their choice of profession, while they particularly see those patients who have trouble being active. They offer physical activity care for twelve weeks because of insurer options and lose most patients out of sight afterwards; they offer an exercise 'bubble' in a treatment context, but do not see much of the 'battle' patients experience at home (Danielsen et al., 2015). However, their sole focus on getting people more active and the realisation that they cannot 'fix it' in this short amount of time might add to their frustration.

A quantitative study suggested that primary health professionals hold their patients, and especially those with type 2 diabetes, responsible for lifestyle change, but also experience this to be an unrealistic expectation (Jallinoja et al., 2007). The current qualitative study provides more insight into this dilemma. While professionals experienced an increased attention to behaviour change in type 2 diabetes care over the years, their main repertoire—giving advice, discussing the topic with patients, providing them with information, and referral to (or, for some, offering) temporary physical activity trainings—seems insufficient to meet the needs of a share of their patients.

This is something professionals are aware of and struggle with. Based on their experiences, they know that providing knowledge and advice alone is not enough, but they have limited alternative options. Some extend their offer, for example, by organising a walking group, investing some of their own spare time, but they also experience difficulties and frustrations. This points towards the need of support and education for these professionals, to enable them to better meet the needs of their patients, especially those from lower socio-economic status groups or with migrant backgrounds. Support might be the availability of time or help from others, preferably those with expertise on the topic of physical activity and type 2 diabetes.

The professionals also seem aware of the importance of other factors, like early childhood experiences, financial barriers and socio-economic or cultural aspects. These are all found to be related to sport and physical activity behaviour (Salmon et al., 2003; Wardle & Steptoe, 2003; Telama et al., 2005; Korkiakangas et al., 2009), and it seems necessary to increase the expertise of professionals on these topics in order to better meet the needs of these patients. For instance, by better integration of these topics in education or extra training, or by the inclusion of specific experts in the healthcare team, like exercise experts or people with experiential knowledge. The latter might also enable professionals to better understand their patients.

Recently, the Netherlands Scientific Council for Governmental Policy cautioned the government that the current emphasis on individual responsibility and ability to manage oneself seems to be too difficult for part of the population. They concluded that knowing what to do—for example, adopting a healthy lifestyle—does not equal knowing how to (WRR, 2017). This was also suggested by a study among patients with chronic heart failure: patients did not need more information on what to do related to healthy living, but on how to do this in their daily life (Granger et al., 2009). The current study shows that this is also applicable to healthcare professionals as it comes to the topic of physical activity in type 2 diabetes care: deeming physical activity counselling important is not the same as knowing how to offer this within the current diabetes care framework, with a certain available repertoire, other topics to be addressed, limited amounts of time and options to which to refer, and an emphasis on efficiently organised and effective care.

This makes professionals reflect on when it is time to ‘let a patient go’ and leave the responsibility to the patient. This study shows how professionals struggle with this, probably because it is contradictory to what they are trained to do (Jacobs, 2011). According to Mol, what ‘good’ care exactly implies is not something universal, but needs ‘tinkering’: a process in which patient and professional together make a local fine-tuning of the guidelines by adjusting them to the daily life of the patient (Mol, 2008). This requires not only listening to but also hearing patient stories, and trying and evaluating what works and what does not (Mishler, 1984; Frank, 1998; Mol, 2008). At times, ‘letting go’ of the topic of physical activity might also be good care, although professionals need to stay attentive to changing patient needs. Self-management practices are found to be ‘contextual, unlimited, and changeable’ (Rosenbek Minet et al., 2011). Consequently, care practices need to have those characteristics as well. Moreover, as physical activity is not a ‘simple’ medicine to prescribe, this asks for sufficient equipment of, and time for, professionals.

Recommendations

Three recommendations arise from this study. First, it points towards the importance of healthcare professionals being aware of their own norms, opinions and experiences that might impact their physical activity counselling practices and relationships with patients. A concrete suggestion for reflection might follow from the interview format used in this study as a means to think about or start a dialogue on care and counselling experiences as well as physical activity experiences in other life roles and possible intertwinements between these.

Second, walking groups organised by healthcare professionals seem to be an interesting extension of physical activity counselling. However, professionals might need extra education and support in order to enable them to better meet the needs of their patients. This is an interesting topic for further research.

Third, a risk of the current emphasis on physical activity, individual responsibility, and cost-efficient care combined with the tensions professionals experience in providing physical activity counselling is a demotivation of professionals. Given the expectations of an increasing prevalence of type 2 diabetes, this might become an even more urgent topic in the future (Tamayo et al., 2014). Therefore, healthcare professionals need sufficient equipment and time to offer physical activity counselling and/or options to which to refer. Above all, they require recognition for the complexities they face in providing physical activity counselling—both for their own and their patients’ well-being.

Strengths and limitations

This study has some limitations. First, the sample of respondents might, unintendedly, have a relatively positive attitude towards physical activity. Although participants were not selected based on their sport and physical activity behaviour, they received information about the study beforehand and the topic might have been a motivation to take part. However, only three professionals did not reply to a request to take part in the study: an internist, a physiotherapist, and a practice nurse with a walking group for patients. Furthermore, although other studies showed a positive relationship between a personal interest in physical activity and experiences with physical activity counselling (Brotons et al., 2005; Wheatley, 2005; Raaijmakers et al., 2013), this study revealed insight into specific frictions related to personal physical activity experiences of professionals.

Second, the sample of 24 respondents is not representative of all professionals working in type 2 diabetes care in the Netherlands. Although saturation was felt to be reached during data analysis, the emphasis was on the experiences of practice nurses, diabetes nurses and physiotherapists. These are the professionals mostly involved in providing physical activity counselling or care. Therefore, in order to better represent the experiences of other professionals, probably more interviews are needed. This would also offer the option of comparison between professionals.

Third, in qualitative studies, the researcher is part of the process. This requires a reflexive awareness from the researcher. Therefore, several measures were taken to develop this: decisions regarding data collection and analysis were noted down as well as experiences with each interview; the individual stories of the respondents and earlier versions of this chapter were discussed with other researchers; respondents were given the opportunity to react on their accounts; and the findings were illustrated by long quotes from the respondents and related to the wider social context in which they were shaped. Furthermore, the personal and social characteristics of the author might have influenced the processes of data collection and analysis. She has a relatively privileged social position based on educational level, socio-economic status and ethnicity, like the respondents of this study and the interviewer of the pilot study. For instance, this might have made it easier in the interview setting to connect with the respondents. However, due to physical discomfort, she no longer participates in sport. This might have influenced her interest in this study in the first place.

Fourth, the professionals who participated in this study work in a specific diabetes care framework, namely in the Netherlands. This raises questions about the transferability of the findings to other contexts. Although this study is intended to offer in-depth insights instead of generalisable findings, it concerns themes that are currently emphasised in many countries, like self-management, individual responsibility for health, a search for an efficient and effective healthcare system and a tendency to consider physical activity as a means to become healthy. Therefore, the insights offered might also be of interest for healthcare professionals and researchers in other countries.

A considerable strength of the current study is the interview format, which invited the professionals to reflect on experiences with physical activity from different roles, both in their professional and personal lives. This made them reflect on the topic from different perspectives and evaluate their experiences from a broader point of view.

Conclusions

This study provides in-depth insights into difficulties that Dutch healthcare professionals experience with the topic of physical activity in type 2 diabetes care. These insights reveal that physical activity can be experienced as a ‘tricky’ subject of care, because of two main areas of tension. The first encompasses difficulties of professionals in understanding the physical activity behaviour of their patients. These mainly seem to reflect differences that professionals experience between themselves and a share of their patients, especially in actual physical activity behaviour, opinions on healthy living and related social positions. These differences might cause certain frictions in the healthcare setting. The second is related to questions about and struggles with professional responsibilities, especially regarding doubts and ideas about when it is time to let go of the topic and leave the responsibility to the patient. These two areas of tension arise in a field in which professionals have to navigate between possibilities that the diabetes care framework offers, options for the embedding of physical activity in the patient’s lifeworld, and the professionals’ opinions on and experiences with physical activity and healthy living from their own lifeworld. This makes physical activity a complex topic of care.

Chapter 6

Negotiating exercise as medicine
Narratives from people with type 2 diabetes

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Abstract

The dominant notion that ‘exercise is medicine’ puts a strong normative emphasis on individual responsibility for participation in sport and physical activity. The aim of this chapter was to explore how people with type 2 diabetes, a condition strongly linked to lifestyle behaviour both in origin and in management, translate this notion into their daily life. Based on a critical narrative analysis of stories of 18 Dutch people diagnosed with type 2 diabetes collected between 2012 and 2016, we found a range of meanings given to sport and physical activity. In addition, almost all respondents seemed to subscribe to the notion of exercise as ‘medicine’ on a general level, either quite explicitly or in more subtle ways, for example, elicited by the interview setting. However, they employed different strategies to negotiate with the translation of this notion into their daily life, ranging from (almost) total acceptance to resistance. In addition, nearly all stories revealed mostly negative experiences with care and professional support regarding the uptake or continuation of sport or physical activity participation after diagnosis.

Introduction

Physical activity and exercise, including sport, are considered important instrumental promises in relation to health. Based on numerous medical and epidemiological studies pointing towards the health benefits of regular physical activity (e.g. Pedersen & Saltin, 2015), this is increasingly translated into popular discourses, like ‘Exercise Is Medicine’, in healthcare settings and beyond (Cheng & Mao, 2016; Cairney et al., 2018). This medicalisation of physical activity—a redefinition of a daily life aspect as medically essential (Malcolm, 2017) —is further supported by studies in leading medical journals about a so-called ‘physical inactivity pandemic’, warning for ‘harmful health consequences’ and increasing healthcare costs (Kohl et al., 2012; Pratt et al., 2012; see Piggin & Bairner, 2014).

A particularly interesting example is type 2 diabetes, a chronic condition that has become firmly linked to physical inactivity and overweight in both its origin and management (O’Donnell, 2015; WHO, 2016a). Consequently, all clinical type 2 diabetes guidelines emphasise the importance of exercise during treatment (Colberg et al., 2010; NHG, 2013; IDF, 2017). Therefore, it is to be expected that people with type 2 diabetes are frequently confronted with discourses emphasising that regular exercise is good for them.

In their critical consideration, Cairney et al. (2018) argue that using or promoting exercise as medicine is ‘a practice of faith grounded in morality’ (p. 392). Supported by a firm body of scientific knowledge, exercise is framed as an effective means to live healthily. With this, the normative aspects often remain unstated or obscured because 'the (in)decision to be physically (in) active is projected as an essentially personal and individual (ir)responsibility' (Malcolm, 2017, p. 88). This resonates prevailing neoliberal discourses of healthism that place the responsibility to be(come) healthy at the level of the individual (Crawford, 2006; Baum & Fisher, 2014).

It is unknown how people with type 2 diabetes perceive and act upon discourses emphasising the importance of regular exercise and individual responsibility in diabetes management (Wiest et al., 2015; Kristensen et al., 2016). Therefore, the aim of this chapter was to explore how Dutch people diagnosed with type 2 diabetes translate these discourses into their daily life.

A critical narrative approach

Storytelling offers people the opportunity to reflect on, make sense of and connect events to give experience meaning (Riessman, 2008; Gubrium & Holstein, 2009). Although embodied experiences of illness are unique to an individual, these are only made meaningful in the social context, where certain discourses and prominent types of narratives prevail (Abma, 1998; Gubrium & Holstein, 2009). In constructing their story, individuals are attracted more towards some narratives than others. These comprise a sort of inner library—a body of stories one is familiar with and shares with others—as part of a narrative habitus that serves as an unconscious basis for storytelling (Bourdieu, 1984; Frank, 2010).

Healthism, for example, is presented as a discourse that constrains and enables daily lives, albeit in largely unconscious ways because of its close alignment with the neoliberal emphasis on individual responsibility (Wiest et al., 2015). In this way, it is ingrained in the narrative habitus. However, as healthism, and the prescribed lifestyles, primarily fit with middle-class norms on health and healthy living (Greenhalgh & Wessely, 2004), it tends to privilege certain groups over others (Wiest et al., 2015; Cairney et al., 2018; Jaye et al., 2018).

Moreover, individual stories often resonate medical narratives, for instance, by the integration of jargon and science (Frank, 2013; Kristensen et al., 2016; Jaye et al., 2018). From the early 20th century onwards, when type 2 diabetes became increasingly common among the lower social strata instead of the higher, the accompanying medical lexicon became to centre on control and management and underlined diabetes management to be a private matter requiring strict adherence to lifestyle advice with physicians in control over diabetes outcome policies (O'Donnell, 2015). In addition, self-management education and support became important healthcare domains (e.g. Beck et al., 2017). Healthism echoes in this shift from the doctor as a protagonist in treatment (cf. Frank, 2013) towards the patient being responsible for diabetes control in daily life.

Although the narrative habitus sets certain limits, individuals can take various approaches to stories, interpret them differently and challenge or resist dominant narratives in artful and creative ways (Bourdieu, 1984; Frank, 2006, 2010; Fleetwood, 2016). For instance, individuals are found to blend their interpretations and perceptions of healthism in manners that work for them in their daily life, using strategies like negotiation, resistance, ambivalence and zealousness (Wiest et al., 2015; Kristensen et al., 2016; Jaye et al., 2018).

Moreover, the process of defining which story does (not) fit is shaped by embodied experiences, and vice versa: embodied experiences are dependent on the stories one selects and rejects, and, at the same time, these affect embodiment, producing more stories that further predispose someone towards certain stories and not others (Frank, 2006). For instance, exercise can offer a means of controlling diabetes and hence reinforce the appeal of the dominant narrative. However, embodied experiences with diabetes may also challenge physical abilities that were formerly taken for granted (Corbin, 2003; Frank, 2013) and prevent someone from continuing sport participation. These experiences impact the story a person tells.

Methodology

This study is part of a larger research project, Sport in Times of Illness, for which the requirement of full medical ethical approval was waived by the Institutional Review Board of the VU Medical Centre in Amsterdam. This chapter is based on a narrative analysis of interviews with 18 Dutch people diagnosed with type 2 diabetes (see Table 6.1). All names are fictitious.

Table 6.1 Characteristics of the respondents

Pseudonym	Age	Years with diabetes	Employment	Country of origin/ nationality	Other conditions or impairments
Ms. Borst	46	0.5	quality manager	Netherlands	condition of the thyroid gland
Ms. Jonker*	49	0.5	interim team leader in healthcare	Netherlands	n.m.
Mr. Cohen	46	1.5	optician	Israel	n.m.
Mr. Martens*	54	2	coach in a large company	Netherlands	high blood pressure
Mr. Bakker	59	4	career coach at a secondary school	Netherlands	n.m.
Ms. Mohan	39	4	unemployed, declared unfit	Netherlands (Hindustan)	hyperventilation, neuropathy, heel spur
Mr. Tahiri	46	7	unemployed, declared unfit	Morocco	renal disease
Mr. Jansen*	54	9	works at an office, declared partially unfit	Netherlands	cancer, COPD, heart failure, herniated cervical disc, glaucoma
Mr. Evers*	62	10	civil servant	Netherlands	n.m.
Ms. Hoekstra	47	10	caregiver, works in shifts	Netherlands	high blood pressure, high cholesterol
Ms. Vonk	61	10	civil servant	Netherlands	NASH (liver disease)
Mr. Hendriks*	60	12	engineer	Netherlands	arthrosis, high cholesterol
Ms. Dekker	54	13	unemployed, does voluntary work	Netherlands	neuralgia
Ms. Schmidt	62	13	unemployed, declared unfit	Germany	knee problems
Ms. Gerritsen	65	14	retired	Netherlands	n.m.
Ms. Sital	56	15	works in child care	Surinam (Hindustan)	n.m.
Mr. Postma*	60	16	works in an administrative department	Netherlands	gout, arteriosclerosis
Ms. Mulder	46	18	pedicure, self-employed	Netherlands	n.m.

n.m. = none mentioned
* These respondents told their story in a pilot study

Data collection

Six interviews were conducted during a pilot study in 2012 (van den Berg, 2012). Their transcripts were included during analysis. The other interviews were carried out by the first author (M.S.) between 2014 and 2016. Eight participants were recruited through an advertisement in a local newspaper in Amsterdam (over 400,000 households) asking for people with type 2 diabetes who wanted to tell about their experiences. A gift voucher of €15 was offered as an incentive. With this, we aimed to include respondents with different cultural, socioeconomic and sport/exercise backgrounds in order to collect a broad range of stories. Four participants were included through our network. All were informed about the study's aims and ethical aspects—such as confidentiality and the possibility to withdraw—in writing and face-to-face before they provided informed consent.

The interviewer started by saying, 'You have diabetes, can you tell me what happened?' Some topics, such as living with diabetes, healthcare experiences and the role of sport/physical activity before and after diagnosis, were asked later if the respondent did not mention them spontaneously. Respondents were encouraged to take their time in telling their story and not to expect many questions (Nijhof, 2000). Near the end, respondents were asked to visualise their life at different moments, to reflect on what they had just told. This allowed the interviewer to ask further questions.

Most conversations took place at the respondents' home. One arranged for a private room at his work and another wanted to meet in a public area. The mean duration was an hour (30–180 minutes). The interviewer wrote a reflexive account after each interview, describing the setting, atmosphere and interaction; what was said off the record; and her feelings about the conversation. All sessions were audiotaped and transcribed verbatim by the interviewer.

Data analysis

Data analysis started at the level of each interview. The interviewer wrote the story down in the narrator's words and order. This was concluded by an initial interpretation and, together with the transcript, discussed with another researcher (A.E. and/or T.A.). This account was sent to the respondent as a member check. A few did not respond after a reminder, some made some minor textual corrections, but most stated that the account reflected their story well.

We were aware of certain complexities in member checking. For instance, respondents might not be interested or reluctant to disagree (Sandelowsky, 2008). Therefore, we were careful in our descriptions, tried to write comprehensible theoretical informed interpretations and added that reactions were not obliged. We strongly feel that this extensive procedure strengthens our analysis, as it prevented us from 'simply gather[ing] data on others to fit into our own paradigms once we [were] safely ensconced in our university libraries ready to do interpretation' (Borland, 1991, p. 73). More importantly, we wanted to 'take our work back' to the respondents because of ethical reasons (Riessman, 2008, p. 198) and offer them an outsider reflection on their story.[1]

In our narrative approach, we studied each story as a whole, including its tensions, complexities and contradictions (Riessman, 2008). We paid attention to the plot structure by looking at character, acts, context and goals (Murray & Sools, 2015), with a focus on the integration of sport/physical activity practices and embodied experiences. Moreover, we were attentive to emotion, phrasing, temporal orientation and co-construction of the story (Sparkes & Smith, 2005; Riessman, 2008).

During data collection and analysis, we met regularly to discuss the stories and consider them from our perspectives of medical and sport sociology (M.S.), critical sport scholarship (A.E.) and medical humanities and care ethics (T.A.). Moreover, we reflected intensively on how our social positions might impact the analysis (see Chapter 7). We gradually moved from individual stories to an overall analysis, in which the transcripts of the pilot study were included. In this process, we tried to understand the different plot structures to illuminate how the respondents related to and negotiated with the notion of exercise as 'medicine'.

Findings

Many respondents told about a period after diagnosis when they searched for the right type and amount of medication before they felt able to more or less control their blood sugar level without excessive side effects. Most of them also made some lifestyle changes, especially regarding their diet and exercise. These stories were about finding a new balance in a life with diabetes and strongly preoccupied with control and management (Karas Montez & Karner, 2005). For more than half of the respondents, this resulted in a life in which diabetes was always there, but not as a real impediment, as Ms Gerritsen (65/14y: 65 years, 14 years with diabetes) explained: 'Diabetes is part of my life, but it doesn't have a real impact anymore. I know I have it, and I need to take it into account, but apart from that, it's in the background'. Nonetheless, what this required varied from person to person.

Almost all respondents considered sport and/or exercise means 'to take diabetes into account' on a general level, subscribing to dominant discourses emphasising that exercise is a type 2 diabetes 'medicine' and individual responsibility. However, the stories illustrated many different ways of translating these discourses into daily life, ranging from (almost) total acceptance to resistance and subtler gradations in between. These are captured in seven different storylines below. Intertwining these storylines, nearly all stories revealed mostly negative experiences with healthcare and support in becoming active (again) after diagnosis.

1. Appropriating exercise as medicine, but not the prescribed standard

Ms Borst (46/0.5y) felt uncomfortable with the message of her healthcare professionals after she was diagnosed: she had to start on medication, and this would doubtless increase in the future because 'diabetes was in [her] family'. She also could no longer continue her fitness routine and asked her gym manager for advice. Based on a scientific study, they developed a schedule that worked for her: three weight training sessions a week 'to increase the insulin-like growth factor 1 (IGF-1) hormone levels, which sort of replaces the insulin and helps to stabilise your sugar' and a training session on an empty stomach once every two weeks to 'clean [the] liver for the rest of the week'. To ensure that her body 'continued to respond to training', she changed her weight lifting programme every four weeks:

> *By training the opposite muscles and changing the tempo, your body is used differently and with this training, my sugar is stable throughout the weeks. (…) For me, it's exercise as medicine. Instead of medication with side-effects, I do a work-out three times a week.*

Ms Borst trained five times a week before her diagnosis, and it took her little effort to adjust her schedule. She used a scientific, systematic approach to get the results she wanted: she kept track of her blood glucose levels before and after training, experimented with different loads and used an app to note her exercise and eating behaviour. She adopted quite a mechanistic view of the body in which exercise—through the production of IGF-1 hormone—'fixed' a failure of the pancreas (Frank, 2013). This approach seemed to fit with what Jaye et al. (2018) call zealousness. The embodied experiences of Ms Borst matched with the notion of exercise as 'medicine': 'The way I live now, I live like I did before I was ill: being active and able to do the things I want'. Furthermore, she expressed a feeling of certainty regarding her approach: 'As long as I can keep on like this, my diabetes won't trouble me.'

Ms Borst was the only respondent who fully embraced the exercise is (the only) medicine thesis. However, she resisted the standard exercise advice for diabetes prevention: '[Many people] are just on the cross trainer, three times a week for an hour, and think they do great. Just like I did, but I got very ill nonetheless.' With this, Ms Borst questioned and appropriated the standard advice.

2. *Exercise is too demanding to implement as medicine permanently*

The requirements of diabetes management were not easily fulfilled by everyone. This is illustrated by the story of Ms Hoekstra (47/10y), who alternated between greater and less control. She lost 11 kg through a 6-month fitness programme, which enabled her to cut her medication in half. She hated the gym but noted the positive effects. However, when the programme ended, she was unable to continue the four intensive training sessions a week on her own, with her irregular shifts at her physically demanding work as a caregiver and adolescent daughter at home. She also noticed she was active during work all day: 'Sitting down is out of the question. You would expect I get my exercise, but apparently, this is not the exercise you need.' This illustrates a further refinement of the exercise as 'medicine' notion.

By the time of the interview, Ms Hoekstra had regained 6 kg and her 'sugar level was way too high' again, but she felt unable to do anything about it. She did not feel she had found a balance after ten years of living with diabetes: 'Sometimes I'm doing reasonably well, sometimes totally not.' Because her internist always seemed to have so little time, she did not talk about this or dare to ask for help. Her living conditions, previous exercise experiences and socioeconomic status seemed to interfere with her wish to manage her diabetes by doing exercise (Baum & Fisher, 2014). Therefore, exercise seemed to be an impossible necessity for her.

Mr Martens (54/2y) also alternated between being in and out of control, although he ascribed this to his dietary habits mostly. At the moment of diagnosis, he was not active, but the spectre of his mother who died from diabetes-related complications made him change his lifestyle:

> *[I did not like exercise,] but that has changed! I started to lose weight and got on that home trainer and cross trainer [that I kept in the attic]. And I still do so six days a week. Still. At a certain moment I started to lose weight. But I gained weight as well. So I wanted to take it up again. That's why I made another appointment with [a dietician]. So, I started to do exercise and I felt I was losing weight quite quickly, but my sugar level also plummeted because of the exercise. So I knew, with the Sword of Damocles of my [diabetic] mother above my head, I thought: darn it, that won't happen to me. Look, if something happens, it happens. But something that you can control yourself, I try to prevent.*

Exercise seemed to have become a new necessity in the life of Mr Martens, who clearly subscribed to the notion of individual responsibility. However, his whole story was imbued with the difficulty of maintaining constant control over his glucose level and weight. His use of both past and present tense underlined this and made it difficult to follow his exercise notions and actual behaviour. He systematically kept track of his behaviour, weight, glucose levels and feelings in a diary he showed during the interview. After losing more than 10 kg, he could do without medication for a while, but then 'things sneaked in, that's purely my own doing', and he noticed the symptoms—thirst, fatigue—himself. He repeatedly emphasised his need for support: 'I know for sure, when I have a good dietician, I will get rid of those medicines again.' But at the moment of the interview, such support was not covered by his health insurance.

At times, both Mr Martens and Ms Hoekstra managed to control their diabetes, offering hope for a more balanced life. But their stories also radiated despair and fragility, mostly because they were not able to successfully self-manage their diabetes at all times. Both acknowledged they could not keep control over their diabetes on their own; however, there seemed to be no prospect of long-term professional support, and they seemed not able to organise such support themselves as Ms Borst did. This emphasises their individual responsibility.

3. When exercise used to be more than medicine

The notion that exercise is 'medicine' frames exercise as a means to (re)gain health, but leaves other meanings, like enjoyment, performance or social aspects, largely aside (Wiest et al., 2015; Malcolm, 2017; Cairney et al., 2018). Indeed, the 'Exercise Is Medicine' proponents put it the other way around by stating that 'regular exercise can be fun, if you let it be fun!' (Jonas, 2009, p. 7), implying that exercise is more important than or comes before fun. However, embodied experiences with diabetes can also interfere with taken-for-granted physical abilities (Corbin, 2003), hindering someone from continuing sport participation. This might result in a confrontation with formerly important meanings of sport, like fun. Ms Dekker (54/13y), for instance, recently had too much pain in her legs to continue horse riding, something that made her emotional during the interview:

> *That is what hurts most (…) you don't have the fun anymore, but I also have to do some extra effort to make up for that part of my body [i.e. glucose regulation], you know? And it will never be that fun anymore. That is the pain, it really is pain.*

She told about the present with references to the future and past. Throughout her story, feelings of loss clearly emerged, for instance, related to physical abilities and activities that used to be important for her. However, she did not ask her healthcare professionals for help because she had overall negative experiences with them: 'You have to be lucky to meet the right professional.'[2]

For Mr Jansen (54/9y), who also had cancer, chronic obstructive pulmonary disease and heart failure, meanings and possibilities also changed. He used to be a member of a cycling club, but resigned because he could not keep up with them—as ‘that would not be wise’—and still missed the company. For him, sport is a ‘nice addiction’, especially related to performance. In fact, he was particularly angry about and resisted the widespread image of the ‘lazy, fat diabetic, that does not do sport’, because he used to run marathons and participated in the Dutch *Elfstedentocht*, a 200-km ice-skating tour. However, at the moment of the interview, he experienced a kick when doctors were astonished about his performance in the bike test. Although he participated in sport all his life, its meaning seemed to have shifted from sport-related to exercise-related performance, with health promotion as a major goal now.

4. Exercise as an unfulfilled promise

Besides a shift in meanings, there was another layer in the story of Mr Jansen, one that challenged the promise of exercise as a ‘medicine’. Although his diabetes was under control now, he said,

> *Sporty [all my life], yes, and still all those problems. (...) It’s a matter of time. Your pancreas is going to do its work less and less. You can say: go on doing sport. But in the end, you lose and have to give in. I know this time is coming, but I postponed it for quite a long time [by being sporty].*

This quotation clearly illustrates the unpredictability or even the predictable decline of the body. Mr Jansen directly referred to a time in the future when loss seemed inevitable. For him, sport offered a means of postponing this. However, he received contradictory advice from his doctors: one told him to do less, another that he could do more. He concluded by saying he had to work this out for himself ‘because in the end, nobody knows’.

The unfulfilled promise of exercise was particularly marked in the story of Ms Mulder (46/18y), who experienced completely uncontrollable blood glucose levels during her periods:

> *You can wake up with the wrong sugar and do whatever you want all day, but it’s just going to be a terrible day. (...) I can go to the gym: my sugar won’t fall. I can go for a walk: my sugar won’t fall. Nothing helps, until the week is over.*

This story shows an alternation between the disciplined and the chaotic body: outside her periods, Ms Mulder was able to control her diabetes with insulin, healthy food and exercise—a lifestyle she established herself, as food and exercise were not a topic during her consultations. Moreover, her doctors could not explain her uncontrollable glucose levels and told her to wait for the menopause. In this sense, she hoped for a better future. However, this was mixed with fear of future complications: ‘You know it only gets worse: your eyes will deteriorate, you get neuropathy, there are so many things in your body that break down. That frightens me enormously.' Overall, Ms Mulder's story radiated a great deal of despair:

> *You are occupied with it all day long: how much exercise? What to eat? How much insulin? But I did it all right, I did exercise, I ate healthy and still [my blood sugar level is] 14. (…) How to get it down? I feel so miserable. I feel scared. (…) My kids are 16 and 18 now, and I often think: thank God, if something happens to me, they can manage on their own. I can't bear to think about it, but I'm quite often very ill and this sugar brings so much misery.*

The story of Ms Mulder clearly countered the dominant narrative of the individual's ability to discipline the body. As she experienced little support, she had been left to her own devices with this.

5. Be put on the defensive by presenting exercise as a medicine

The message that exercise is a 'medicine' might be experienced as a confrontation with current behaviour and result in a defensive reaction. For instance, Mr Hendriks (60/12y) and Ms Sital (56/15y) both felt annoyed by the steady stream of messages of their healthcare professionals. The latter explained:

> *They ask me what I do, and what I don't do. I still smoke, [so they ask] if I don't want to quit smoking. That sort of stuff. How I eat. That I need to do a lot of physical activity, something I already do. That I need to quit drinking alcohol. Just a little while and I'm ready to go to the convent.*

Mr Hendriks—who told he did not do 'any real exercise at the moment'—even seemed to be annoyed by the questions of the interviewer:

> Mr Hendriks: 'You sometimes hear that people's toes die. Well, I don't have that problem yet. And I hope I never will. I don't have problems with my eyes or something either.'
> Interviewer: 'And what are you doing to make sure things stay that way?'
> Mr Hendriks: 'Well, not that much. Are you trying to convince me I should do more?'
> Interviewer: 'No, that's absolutely not…'
> Mr Hendriks: 'Because the practice nurse asks me exactly the same thing.'

This excerpt reflects the presence of the Exercise Is Medicine discourse in the interview setting and, more implicitly, how this might be experienced in the consultation room.

Mr Evers (62/10y) also seemed to be put on the defensive during the interview. Although he was told by his healthcare professional that his sugar levels and blood pressure were 'good', he said,

> *I am not sport-minded at all, there you go, physical activity. I cycle every day, to and from work. That's about 15 or 16 kilometres daily, there and back. That's my exercise, actually. And then the diabetes nurse says: that's enough, that amount in a day. So, what can I do more? [They offer fitness classes at my work.] I did try that, but I need guidance if I'm going (…) to do that much [exercise], and I don't get any guidance at all. I need to do it myself, and that's a bit difficult for me. It's also a matter of discipline. I don't want to shirk my responsibility, but still.*

This quotation also gives a glimpse of how the dominant discourse affected the interview setting at times as Mr Evers seemed to feel that he had to justify his level of exercise behaviour although his nurse told him he was active enough. This was mixed with feelings of uncertainty regarding the right thing to do; he admitted that it would be good if he lost 10 kg, but mentioned that his brother—who also had diabetes—was very slim, while some of his colleagues at work were 'very fat and had no problem at all'. This seemed to make him feel guilty, on the one hand, and unwilling or not knowing how to do more without support, on the other.

6. Resisting exercise as medicine

Some respondents resisted the idea of exercise as a 'medicine' in their own life. Mr Cohen (46/1.5y), for instance, told about the time after his diagnosis:

> *In the beginning, I secretly didn't participate (…). You are examined, but for those people working in the hospital (…) it is all self-evident, because they do this for a long time already. [I'm just another person with diabetes.] They say: 'You have to lose weight and do more exercise.' (…) They check your information, fill in a questionnaire and that's it. And then, three months later [they say]: 'It's not good, isn't it? Well, do your best!' That's it.*

He talked about 'the diabetes world' he felt he entered, a world in which 'healthy living is something obvious', but a world he did not feel part of. This illustrates a possible distance between patients and their healthcare professionals in their degree of (unconscious) acceptance of dominant health discourses, which is also experienced by the latter at times and intertwined with their personal sport/exercise experiences (see Chapter 5).

Mr Tahiri (46/7y) found a solution in the combination of medication and cutting out sugar. He used to go to the gym, quite often, but quit about twelve years ago because he became a father and worked in irregular shifts, leaving too little time. Therefore, certain life-changing events already impacted his exercise behaviour (Allender et al., 2008), before he was diagnosed with diabetes. Moreover, as a Muslim, Mr Tahiri believed that people have to become ill and that one can prevent worse by avoiding stress and fear. This moral claim clearly counters healthism and Exercise Is Medicine discourses (Pitaloka & Hsieh, 2015). Mr Tahiri added, 'I have a good life. I am ill, but I'm fine', indicating that he found a balance in living with diabetes.

Interestingly, both Mr Cohen and Mr Tahiri emphasised the importance of physical activity in their lives during the interview, but, at the same time, were a bit vague about their actual practices and also admitted they did not do much. 'This has always been a problem for me', Mr Cohen added. Their comments seemed to be motivated by a feeling that being active was socially desirable and, again, the presence of the dominant discourse in the interview setting. They seemed to acknowledge the norm that exercise is a 'medicine' on a general level, but not in their own lives.

Another form of resistance is illustrated by the story of Mr Postma (60/16y), who found another way of managing his diabetes:

> *When you start eating, your pancreas says: 'Hey, carbohydrates are coming in. That many? Then I need to make that much insulin.' So, for me, it works exactly the same way. (...) When I eat a bag of crisps, I check the amount of carbohydrates on the bag. And while I eat these crisps, I inject myself with the corresponding amount of insulin. (...) You need to know how to handle this. And in ten, fifteen years we'll find out if I did it the right way, is the only thing I can say. But for now, I can live like I want to. And that's the most important thing for me.*

He told a story about a broken body, unable to make insulin itself. When he injected exogenous insulin, his body functioned like a normal, non-diabetic, body again. As a result, exercise was not needed as a 'medicine'. Mr Postma used to do a lot of sport when he was young: he took part in the Dutch Swimming Championship and wanted to become a physical education teacher, but had to stop his education because of knee problems:

> *In the course of time, this [sport participation] went from 100 per cent to nothing, basically. And really, I know that if I were more active now, it helps to lose weight. And the lower your weight, the less trouble you have with this*

> *sugar. But yes, then it is a matter of: do you want that? If I can control it the way I do now, I don't need to lose weight. Because I can control my sugar precisely.*

On the one hand, Mr Postma acknowledged the Exercise Is Medicine discourse, but on the other, he resisted the idea of exercise in his current life. Given his previous athlete career and relatively privileged social position, one might have expected a different story.

7. When exercise cannot be medicine

Finally, there is a storyline in which exercise cannot be a 'medicine'. This is illustrated by the story of Ms Mohan (39/4y), whose story was chaotic (Frank, 2013), both in content and in structure as she rambled from one subject to the other and from past to present. This also seemed her way of storytelling, something she admitted near the end of the interview. Despite this, she concluded that she experienced a lot of stress—she had no job, a lot of health problems and her mother was ill—but did not feel able to reduce it. Diabetes was something 'large' in her life, and her glucose levels remained high. She confirmed that her diabetes nurse touched on the subject of physical activity sometimes, but because of a heel spur, this was not an option for her. And this set her of telling about medical issues during its treatment and her current status:

> *I couldn't anymore, I was just completely worn out. I do not feel anything, in my foot, not anymore. So yeah, that's my impairment. I have special shoes as well. So yeah, it is very difficult with me, at the moment. I also have many, look, I've all those spots. That's because of my sugar. They also said I have a diabetic foot, because I have neuropathy (...).*

In sum, her circumstances left no room for physical activity in her life.

Discussion

In this chapter, we presented a wide variety of meanings of sport and physical activity in the lives of people diagnosed with type 2 diabetes, ranging from an instrumental sense where exercise was used to manage diabetes (Ms Borst) to loss of or change in meanings because diabetes interfered with former physical abilities and sport practices (Ms Dekker, Mr Jansen); from a new to an impossible necessity (resp. Mr Martens, Ms Hoekstra); from something to feel guilty or annoyed about (Mr Evers, Ms Sital, Mr Hendriks) to something unable to fulfil its promise (Ms Mulder); from something not needed (Mr Cohen, Mr Tahiri, Mr Postma) to something impossible to integrate in daily life (Ms Mohan).

Notwithstanding these differences, our findings illustrate that the normative notion of exercise as ‘medicine’ is ingrained in the narrative habitus related to living with type 2 diabetes. It permeated all stories, either quite explicitly or in more subtle ways, for example, elicited by the interview setting. However, people employed different strategies to translate this norm into their daily life, in ways that confirmed, challenged or resisted this.

Generally, nearly all respondents considered exercise a useful means to manage blood glucose levels and postpone possible complications—this meaning was shared by those who practised it, wanted or intended to practice it (more), or did not want to. Even the latter did not doubt the promise of exercise. In other words, they seemed to subscribe to the message on a general level, but this did not correspond to their own daily life informed notions and experiences (Wiest et al., 2015; Malcolm, 2017). However, as the promise of exercise as ‘medicine’ is strongly related to control over diabetes, and hence feeling well—at least in theory—it might be questionable whether it is possible to resist this discourse on a general level.

Nearly all respondents in the present study talked about rather negative experiences with ‘physical activity care’, despite its given importance as a topic throughout treatment in clinical guidelines (NHG, 2013; IDF, 2017). In a way, this further emphasises the individual’s responsibility in the uptake or continuation of exercise after diagnosis. It clearly illustrates the close intertwinement between the neoliberal discourses of healthism and the notion of exercise as a type 2 diabetes ‘medicine’ (Cairney et al., 2018).

These negative care experiences might be explained by the diabetes medical environment, which is highly protocolled, limited by a strict time frame, and has a strong focus on blood glucose levels, other measurable parameters and self-management support (Karas Montez & Karner, 2005; O’Donnell, 2015; see Chapter 5). A translation from exercise advice as a standardised healthy lifestyle recommendation into person-centred care and support might be difficult in this medical setting.

Our findings suggest that people with type 2 diabetes might experience certain differences between themselves and their healthcare professionals. This is illustrated by the stories of Ms Sital, Mr Hendriks and Mr Evers, who at times felt the need to defend their behaviour or became annoyed by the messages about the importance of exercise. Mr Cohen summarised this in his image of the ‘diabetes world’ of which he did not feel part. Healthcare professionals are also found to ‘feel’ this and to acknowledge these differences to some extent (Chapter 5).

This experienced distance might be better understood in the light of other differences between (mostly ‘White’ and higher educated) healthcare professionals and a share of their patients, for instance, in socioeconomic and cultural living circumstances, notions on healthy living, and their sport, exercise and illness biographies (Greenhalgh & Wessely, 2004; Chapter 5). For instance, people from the higher social strata have a lower risk to get type 2 diabetes (Ujcic-Voortman et al., 2009; Agardh et al., 2011) and tend to participate more in leisure-time physical activity (Beenackers et al., 2012).[3]

To improve the connection between healthcare professionals and patients, an acknowledgement that the notion of exercise as 'medicine' is not merely a neutral and evidence-based message but an inherently normative one seems necessary. This normativity primarily lies in the emphasis on individual responsibility, although this mostly remains unstated because of the close alignment with neoliberal healthism notions (Wiest et al., 2015). These are, as Mr Cohen explained, notions from a world in which healthy living is something obvious.

This seems more urgent given the increasing emphasis on exercise as 'medicine', illustrated, for example, by the publication of a Dutch 'Physical Activity Care Standard' for healthcare professionals (NHG, 2015) and the foundation of the Dutch Lifestyle Medicine Innovation Centre (NILG, 2018). These developments might lead to a further obscuration of the normative aspects and, in the end, increase inequalities (Baum & Fisher, 2014). This also might result in the norm that exercise is the best 'medicine' for type 2 diabetes.

Therefore, reflexivity on the normative aspects of the notion that exercise is a type 2 diabetes 'medicine' seems a prerequisite for the provision of 'good' physical activity care. This normativity is shaped in practices and depends on the context and persons involved. It might include, for instance, reflexivity of healthcare professionals on their personal sport and exercise/physical activity biographies, notions on healthy living, relatively privileged positions and on how these impact relationships with their patients.

This requires attention to other ways of knowing besides the medicalised views on illness and exercise that include more lifeworld-led care (Dahlberg et al., 2009) and attention to the broader socio-cultural and economic contexts people live in (Jaye et al., 2018). This chapter illustrated a great variety of (embodied) experiences and living circumstances, resulting in different (im)possibilities and wishes regarding sport and exercise. Getting to know someone's story and critical reflection on its co-construction, both in face-to-face interaction and in relation to prominent narratives, might add to 'good' physical activity care.

Chapter notes

1. See Chapter 7 for a detailed example of what this member check process brought about both regarding the development of our own thinking and in the daily life of one of the participants.
2. The story of Ms Dekker is elaborated on in Chapter 7.
3. Interestingly, this type of physical activity is nowadays proposed as 'good' for health, in contrast to so-called 'occupational physical activity' (Coenen et al., 2018), a scientific finding that was rapidly taken up by media worldwide (BMJ, 2018), without much attention to relations with living circumstances. This further affirms certain dominant exercise notions and sets new norms regarding 'good' and 'bad' physical activity.

Intermezzo III

When exercise is too demanding to implement permanently as medicine

‘What did it do to my life, of course, you wanted to know? Yes, you have to be careful to take your pills on time, live a regular, sensible life, eat regularly, watch what you eat. I find that difficult. It is much more complicated than just diabetes. That is not fun to have, but I have a lot of other things. And you have to find a little balance in that. Did that succeed in those ten years? No, actually not. Sometimes it goes pretty well and sometimes it doesn’t go well at all. What is the reason for this? I work in healthcare, which is quite tough. I do irregular shifts. Of course, I have those side issues. I have to take those pills regularly. You have to make sure you eat a little bit healthily, that you do exercise and things like that more. And stress… These are all things that make it difficult. I am getting older, so I get more troubled by certain things. And diabetes also affects your blood pressure, your cholesterol, and things like that. So, if your sugar isn’t right, your cholesterol and blood pressure will go up too. Well, you name it. So, it’s just one interplay. And of course, you can take pills, and that helps, but it does not get any less. It only gets less when you have less stress. If you live well, healthily and regularly and exercise a bit. Then it will work. But yes, with a hectic life, an adolescent daughter, work rummaging through cutbacks—I’m not fired yet, but you never know—that’s tough. And your body reacts very much to that.

I try to be active, and I manage to do so reasonably well, according to circumstances, but I really should exercise more. I noticed that when I did an intensive sports programme and half of my pills got off. But then, when the programme ends, you start exercising less, then you have a lot of things on your mind again, well, then you start eating more again, then you get fatter again, your sugar goes up. It’s a spiral because you have to be so careful with everything, and yes, that is not possible in this society. And I’m doing my best, but yes, it is difficult to match things well. So, I don’t feel like I’m in control. It fluctuates a lot with me. Sometimes, my blood glucose sober can be very high, and then the day has yet to start. When you have a hectic life, you don’t really have much time to think quietly about what to do. So, I find it heavy. You try to do something about it, but actually, you are not strong enough to arrange it properly. Because it is very sharp, it comes close. Yes, if you don’t have to do anything, it’s not that bad. But I can’t say, ‘Well, today I don’t feel very well; I don’t do anything.’ Yes, you can do that, but you may not feel well the next day again. And then things pile up, and that also gets you into the stress, and stress is bad for your diabetes again.

I go to the internist once every three months. She checks everything, and you are outside again within ten or fifteen minutes. That is not so bad if everything is going well, but for me, it is not always going well. I think a nurse has more time for that, although nowadays everything is being cut, so we notice that too. So, I don’t know if I miss [a nurse specialised in diabetes], but I think it’s short, ten minutes, fifteen minutes. You discuss the blood values, go on the scales, she has a quick chat, but that’s it. Then she says: ‘Well, your sugar is high, I would just take an extra pill.’ Or, ‘You should measure your blood pressure more often.' That kind of tips. Then I think, 'I just have to get rid of that stress and that kind of a mess, and it doesn't matter whether you measure your blood pressure more often or whether you eat less or exercise more.' I think it is too basic. I wish they had a little more time for you.

[That sports programme,] that was six months, and then you started training very intensively, in groups. Four times a week for an hour. From spinning to Zumba. That was quite intense. At first, I didn't like it at all; I hated it. I did not do exercise beforehand, and then you suddenly start training intensively four times a week. But I did keep it up. I didn't like it, but it did quite well: I lost fat, half of my medication was allowed to drop. But at some point, that programme has ended. Okay, you still have a few months that you can exercise for free, I did, but you don't go four times a week. Well, I have been exercising for a while, although less intensively, but I have learned that you have to exercise at least twice a week; otherwise, it will not be successful. I did that a bit, but then there was a lot of stress again, your sugar goes up again, you gain weight again, things don't go well anyway. In the meantime, I have gained another six kilos from those eleven kilos. That is, of course, not good, and my sugar is far too high. When I finished that sports programme and when that subscription ended, I thought, 'Okay, it's very good, but I can't make it.' So now I do Zumba twice a week, low level in the community centre. I thought, 'If I do Zumba twice, it's okay.' I knew it was low level, but all muscles are covered. And of course, it has to be more intensive, but I don't have the strength and energy for it. I thought that was a bit doable, but no, it is not. At least, I need to add something. And perhaps the other thing was too intensive, of course, that is also possible. [Because] what I did back then was crazy. I managed to do it all, and it worked out very well, but you can't organise your life like that. That's just too much. Because you put everything in it and it has an effect, that's what I did it for because I didn't like it at all, but it works like a charm.

So now I have registered for something similar, three times a week. I have had an intake, and they will start again soon. Yeah, I'm going to do that. The internist will soon say: 'You have gained weight again; soon, you will have to start with insulin injections.' And I just don't want that. Because I work in healthcare, I administer injections, so I know all the bells and whistles, and that it is even heavier than taking a pill in the morning and the evening. A pill solves it; you just have to remember it. [So, I have] a stick behind the door, because I don't want to inject insulin. But sometimes the stick is better and bigger than the other times. Sometimes you are just really broken, and then you also have to exercise for an hour. Sometimes you manage to do so, and sometimes you don't.

[Sport or exercise was never part of my life before my diagnosis,] because I was way too busy. And as long as you don't have any health problems, you don't exercise. At least some people like it and get a kick out of it, but as long as you don't have any medical stuff, a lot of people don't. I don't know if it's in your upbringing. But three-quarters of people don't really do a lot of sport regularly. Only when you have health problems, do you think 'I have to do something about it'. No, I never really did a sport or anything like that because I didn’t like it. I still don’t like it, but I have to, and it has an effect, and that motivates me to do it. Because I don’t like it at all. Yes, I used to do badminton. I liked that. But that is just nice, and it may be good for your arms, but as they did with that sports programme, that was just really very intensive exercise. Before that, I only played badminton because I liked it, and for the rest I just did nothing.

You walk a lot in healthcare, but that is a different type of exercise. You’re barely sitting on your butt, yes, during the transfer, or if you need to jot down something, but if I’m working eight, nine hours, I’m just walking or doing. Sitting is not there. Then you would expect that I am moving enough, but that is not the movement you need to burn calories. Exercise is good, but apparently you have exercise and exercise. Whether you say: ‘I walk to the metro’ or ‘I am running’, that is different.’

Ms Hoekstra
Spring 2016

Openings
Extended walking and talking practices

Chapter 7

Developing a relational narrative about diabetes
Towards a polyphonic story

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Abstract

The restitution story, the type of illness story about living a healthy life again, is the most prominent type in Western society. Patients who are unable to realise a restitution story might need an alternative ‘corpus of stories’ to draw on, for example narratives that more explicitly incorporate quest and/or loss. In this chapter, we present the narrative of Anja, a woman with diabetes who wanted, but was unable to live the restitution story. Although she seemed to have all characteristics in favour of ‘restitution’, such as willingness, capacities, and a higher socioeconomic background, she encountered losses and was not able to go back to her ‘normal life’. Through a sociological lens, her narrative habitus was influenced by her privileged position and expressed in her emphasis on ‘starting all over again’, departing from dominant health discourses that emphasise restitution and individual responsibility. The encounters with the voice of the researcher(s) made her aware of the dominant storyline and, as an incidental outcome of the research process, enabled her to reconstruct her story. Along the way, Anja’s story became more polyphonic, as she began to incorporate the voices of the researcher(s) and others. A detailed elaboration of this specific case shows the relational dynamics of narrative development and interpretation, and offers important implications for healthcare. It points towards the importance of attentiveness, responsibility, and responsiveness as well as solidarity with a broader group of people with diabetes, including those in less privileged positions.

Introduction

An illness, or first signs of an illness, may signify a biographical disruption or a moment of re-orientation as well as a confrontation with formerly taken-for-granted life and bodily ability (Bury, 1982; Corbin, 2003). In such times, when expectations for continuity are disrupted, (re-)constructing a story can help someone to make sense of events and find new destinations (Frank, 1995; Mishler, 1999; Riessman, 2008). This construction is not only a personal issue, but also a social one: stories are told to someone, either directly or indirectly, and created in a certain social context that defines what is appropriate to tell and what is not (Frank, 1995). Furthermore, stories can be (co-)constructed in interaction (Mishler, 1999), for instance in interaction with a healthcare professional.

Today, the most prominent and culturally recognised type of illness story is the restitution story, with the underlying storyline emphasising recovery from illness and living a healthy life again: ‘Anyone who is sick wants to be healthy again. Moreover, contemporary culture treats health as the normal condition that people ought to have restored' (Frank, 1995, p. 77). Interestingly, this aim is also underlined by the expression of 'health'-care.

Although restitution might seem incompatible with a chronic condition like diabetes, diabetes treatment generally is directed at maintaining the blood sugar level within the 'normal' range in order to minimise symptoms and future complications. Therefore, certain treatment strategies—like insulin, medication, following a healthy diet and/or being sufficiently physically active—are prerequisite. Implementation of these strategies is aimed to result in a kind of restitution: in feeling healthy and being able to live a nearly 'normal life' again.

In order for this implementation to be successful, these treatment strategies must be incorporated in daily life. Therefore, part of diabetes treatment is aimed at 'behavioural change', or, more precisely, changes regarding smoking, exercise and eating behaviour, respectively (NHG, 2013, p. 516). To achieve restitution—to get and keep control over one's blood sugar level and feel healthy again—the individual with diabetes needs to become active and make these treatment strategies part of 'normal life'. This fits within a larger neoliberal political and social discourse that strongly emphasises individual autonomy and places the responsibility for health, and illness, with the individual (Wheatley, 2005; Crawford, 2006; Cheek, 2008).

Although advice regarding diet and physical activity behaviours are embedded in treatment protocols for people with type 1 and type 2 diabetes, it is especially emphasised in the protocols for the latter, as both the origin of and 'medicine' for type 2 diabetes are to a large extent considered to be related to lifestyle behaviour. The prevalence of type 2 diabetes is much higher among people from lower social classes and ethnic minorities (Dalstra et al., 2005; Ujcic-Voortman et al., 2009). Moreover, in high-income countries in general, people from the higher social strata tend to be more active and attach more importance to individual responsibility and healthy living (Wardle & Steptoe, 2003). Therefore, many elements in this study are related to intersecting social status positions.

Elements of the restitution story are recognised by many people with a chronic condition like diabetes (Stuij et al., 2014). A downside of the dominance of this type of story is the potential limited availability of other storylines when restitution does not work, or is not working anymore (Frank, 1995). In this chapter, we present the story of Anja, a woman with diabetes who wanted and tried to, but was unable to live the restitution story. Her story illustrates the necessity, but scarcity, of other storylines to fall back on and to remain or regain a sense of self. Furthermore, it shows the importance of relational narrative autonomy, the bringing of actions in line with a sense of self and life story, using the support of others (Abrams, 1997). As Anja's story further developed in interaction with the researcher(s), the aim of this chapter is to give an interpretation of this relational process of narrative development, and to offer implications for the improvement of healthcare.

Storytelling and narrative habitus

According to Arthur Frank, people use commonly available narrative ideal types, like the restitution story, as resources to create their own individual story (Frank, 1995, 2010). These are part of what he calls the 'narrative habitus', based on Pierre Bourdieu's concept of habitus. Bourdieu defined this as a durable internalisation of all sorts of habits, a 'second nature' that serves as an unconscious basis for behaviour, thoughts and emotions (Bourdieu, 1990). Frank (2010) identified the following core elements of the narrative habitus:

> knowing a corpus of stories; feeling comfortable telling and hearing certain stories (and not others); and sharing with others a sense of where events in a story are likely to lead. This issue is not only expectations for how plots develop in stories, but also expectations for how people ought to emplot their lives (p. 195)

In other words, these habitual dispositions lead to a sort of continuity in the stories a person tells (Smith, 2007; Taylor, 2007). Furthermore, related to healthcare, it points towards the importance of a shared repertoire, as this offers a certain familiar basis to build on together. Moreover, Frank adds the concept of the 'inner library' as the organisation of the narrative habitus: 'people make sense of a story by placing it among similar stories (…) stories they know, including stories they might have heard, or that are resonant in stories they once heard' (Frank, 2010, p. 55). Therefore, people are predisposed to pay attention to some stories and not to others.

This predisposition is related to and reflects social status, as people with similar intersecting social positions—like class, ethnicity and gender—partly 'know' one another's experiences and face similar (im)possibilities and living conditions (Bourdieu, 1990; Reay, 1995; Townsend, 2012). Furthermore, the narrative habitus is also influenced by political hegemonic stories, like those emphasising health and individual responsibility as important values. According to Marjo Buitelaar, in order for a personal story to be convincing, the narrator needs to make use of the 'collective voice' of the group he or she belongs to, by 'using the rules, conventions and world views that dominate in that group' (Buitelaar, 2002, p. 77). These are established in the narrative habitus, and expressed through a 'voice' that has appropriated the collective story.

Despite its durability, someone's habitus is neither unchangeable nor all decisive (Bourdieu, 1990). This means that in spite of a certain tendency to fall back on familiar storylines, there is room for development outside this known repertoire, for instance when a story is not sufficient anymore. Therefore, the concept of narrative habitus might offer us a focus to search for underlying plots in a story that are well-known, powerful and persistent, as well as possibilities for changes or resistance to these or other plots that could help us to see openings for narrative development.

A case study on multiple voices

The story of Anja was collected as part of a larger research project on meanings of sport and physical activity for people with a chronic illness, called Sport in Times of Illness. We selected this particular story because it presented an 'opportunity to learn' (Stake, 2005, p. 451); it is not a story representative of all the stories collected, but one with specific tensions and complexities, and a story that further developed as a result of an ongoing interaction between the storyteller and the researcher(s). It is precisely the detailed interpretation of this interaction, including attentiveness towards the wider social context in which this interaction took place, that provided us with 'a concrete demonstration' of opportunities for narrative development (Mishler, 1984, p. 182).

During the first meeting between Anja and Mirjam, the first author of this chapter, Mirjam asked Anja the 'grand tour question' 'you have diabetes, can you tell me what happened?' (Spradley, 1979, p. 86). She introduced some follow-up topics during the course of the conversation, however, Anja was strongly encouraged to tell her own story and to take her time in doing so, and prepared not to expect many questions (Nijhof, 2000). The session took two hours, was audio taped and transcribed ad verbum. Then Mirjam wrote down the story, mainly in the words and order of Anja, and concluded it by a first interpretation based on Frank's work and some other literature. She discussed the transcript and the account with the other researchers, Agnes and Tineke, and sent it back to Anja as a 'member check'. This was followed by a short email conversation, a second meeting a year later, and another email conversation.

To illuminate the narrative habitus, we look at different voices—informed by different intersecting social status positions—present in this process of narrative development.[1] First, there is the voice of Anja. To present this voice, we used the account of her story and several 'narrative summaries' that we wrote based on a close analysis of her words (Murray & Sools, 2015).[2] The email conversations also provided us with fragments of her voice. Moreover, Anja was actively involved in writing this chapter, as she provided valuable feedback on several versions.[3] Second, the voice of the researchers, who, by accident, became part of this process of narrative development, is of importance. They are also the tellers of this process. Finally, the third voice in this chapter comes from the perspective of several care ethicists. We need this to place the other voices in a broader context and offer recommendations for healthcare.

A short introduction to the voice of the researchers

Although Anja is the main character in this chapter, her story, necessarily, is told through the voice of the research team. We—Mirjam, Agnes and Tineke—are three white, higher-educated women, from middle-class backgrounds, and without any chronic conditions. Based on Reason and Torbert (2001), this voice consists of different levels which are interdependent. There is 'my' voice, the voice of Mirjam (33). I graduated in medical anthropology and sociology and then started to work as a sports researcher focussing on social class differences—related to habitus—and dominant discourses concerning health, body weight and self-control (Stuij, 2011, 2015; see Chapter 3). With Agnes and Tineke, I was involved in the set-up of the research project *Sport in Times of Illness* and currently I am one of the executing researchers in this project. I practised sports—gymnastics and badminton—until ten years ago, when I decided to quit because of the strain on my hypermobile joints.

My voice is influenced by the combined voice of the research team. Agnes (47) is a critical sport scholar with a long career in competitive sports. Tineke (52) identifies herself as an engaged and interdisciplinary scholar in the fields of social sciences, humanities and medical sciences. As a research team, we discussed the transcripts of the conversations with Anja, the account of her story and this chapter several times. Our combined reflections influenced my—Mirjam's—voice during the conversations and correspondence with Anja, and while writing this chapter.

Our voice as a research team, in its turn, is influenced by the broader theoretical and empirical research framework we are familiar with: it is the literature we refer to in this chapter but it is also the literature we are influenced by, but not explicitly aware of. As Annemarie Mol (2002, p. 16) states,

> there are so many [links to the literature], so many more. They are *embedded,* indeed, in the questions asked, the topics raised, the words used throughout [a] study. Is it possible to make all the partial connections between a text and its relevant others explicit? I don't think so.

These links are part of our 'researcher habitus', with its specific inner libraries.

Anja's voice—mediated by the voice of Mirjam

After reading an online call to participate in the project, Anja emailed me that she wanted to tell her story because she recently had to quit horse-riding due to physical discomfort and this decision caused her pain. At that time, she was 54 years old and diagnosed with type 2 diabetes twelve years earlier. She had lived with the same man for 25 years and had two daughters of 17 and 20 years old. They are a white, middle-class family. Anja completed her higher education and worked several years as a manager, but resigned when her second daughter was born, stayed at home, and started to do voluntary work a few years later.

Sitting in her backyard, she told me about her life with diabetes, her experiences with healthcare and the meaning of physical activity in her life. She described herself as 'always busy, I always look for something to do'. She enjoys activities 'that may not be called sport, but are active, just during the pleasure of everyday life'. This has always been part of her life; she did gymnastics in her youth, regularly went (roller-)skating since she was young, and emphasised that she had never had a sedentary job because she was always 'on the road, walking stairs at peoples homes'. Lately, along with her continuing enjoyment of roller-skating, she especially liked cycling and horse-riding with her daughters.

Her story consisted of four general storylines, namely with respect to the period of her first complaints and diagnosis, diabetes related healthcare experiences, current complaints relating to menopause, and her decision to quit horse-riding. These all fit under the theme 'pick up the pieces and start all over again'. She mentioned this several times. Responding to her diagnosis she said:

> *At the moment you hear that you have diabetes you have tears in your eyes and think: 'It really is true.' You have this for life and you don't know where it ends. But well, then I started to collect all information available and thought: 'What next?' So, then you go for it. That is my attitude: if it doesn't work out, I go and look for what I can do. Picking up the pieces and starting all over again, literally.*

This fragments shows some elements that return more often in her story. It illustrates a certain attitude that is oriented towards the future and aimed at doing something to solve a 'problem'. Furthermore, it shows her need to collect and have information to make decisions, as is also illustrated by this narrative summary:

> *So then I determined my own programme about what I wanted and how I wanted this*
> That I would have such a type of diabetes wasn't expected. I was really young, not overweight and I didn't have any other symptoms. There was little experience with this in the countryside where I lived. I got a lot of medication right away, tablets, but with this, I couldn't influence anything. I couldn't decide to go cycling very fast after dinner, because then my sugar would decrease too soon. That's why I collected information myself and told my general practitioner that I wanted to use insulin. They didn't think it was wise, because you can't go back, but I did do it. It has been difficult for a while, but it did give me much more freedom. So I was very happy I did it, but it was without any support. Overall, I find the support minimal, and actually, when you are young like me, it is limited and short-sighted.

This summary illustrates an important experience for Anja: the feeling that her healthcare practitioners didn't respond well enough to her needs. She told me that 'you needed to be lucky to have a good healthcare professional'. She elaborated on this a bit more and said that, after having experienced resistance several times, she didn't ask for a referral to a professional specialised in exercise this time, 'because care is always very person-dependent, so you're very dependent on your care taker'. By 'short-sighted' support, she referred to some 'strict regimes' she was told to follow by a dietician, that didn't bring her enough relief. With 'limited' support, Anja found that she experienced limited possibilities for help, especially when she didn't know what to do. This was the case at the moment she applied for participation in this research project. The essence of that moment is captured by the following narrative summary:

> *The fun has gone out of it*
> I started horse-riding when I was 46. It was a wish come true, from my childhood onwards. My children started horse-riding and they told me: 'We'll give you a sample lesson for your birthday.' I started and then, in fact, it started wrong right away. After an hour, I totally did not feel my lower legs anymore. They did an examination of my blood vessels, that was all fine. That's about seven years ago, it went fairly well for quite some time then. I did it with so much pleasure, we had so much fun. My daughters and I, we [rode] at a riding school, for the fun and doing something together. I also experienced that my blood sugar levels decreased because of this, that's just an extra. However, I had so much trouble with my legs during the past year, I just can't anymore. So, then the fun has gone out of it. I held on until the summer. I told myself: 'This is not going to work, you have to quit, you have to prepare yourself for

> this.' I truly did. I cried a lot about it, still, I really find it awful, but yes, that's how it is. It was picking up the pieces and starting all over again.

She added to this that she recently 'started over again' by doing yoga, not because she liked it—actually, she didn't—but because she hoped this would strengthen her body and make it more flexible and enable her to do more intensive activities again. Here, again, her daughters were of importance, because one of them practiced yoga already, albeit 'a very intensive' kind, that Anja felt she would 'never' be able to practice because of the troubles with her legs. Instead, she did a 'simplistic' form of yoga, together with 'people aged 70 and older'.

Some elements in the story of Anja returned in all four storylines, albeit with slightly different details and emphasises. Firstly, they all concerned living a 'good life' which, for her, was being able to be active 'in everyday life', experience pleasure, and have sufficient freedom to do what she wants. Secondly, taking responsibility for her own health, mainly by strictly controlling her blood sugar level, was an important element. This was revealed by sifting through and considering all information available, measuring her blood sugar level every morning and accurately keeping track of all measurements from the beginning, not only to set her insulin level for the day, but also in order to follow the trend. Finally, there was an element of loss that clearly emerged throughout her story. Not only because of what she told me—such as the loss of fun and doing things together, physical abilities, activities, feelings of youth—but also because she was sometimes emotional during the conversation. Together with her email, I felt a kind of urgency for Anja to tell her story. She also made an appeal to me, when I asked her at the end of the interview what she thought about it. She seemed to search for a means of making sense of the things that had happened in her life, as she said:

> *I'm always curious to find out how someone else looks at it. (...) I do see that this doesn't happen as it is not how it should be in an interview like this, but I would have liked to get some reply. (...) Because you're always in your own circle and there are really few people who can offer you that reply, knowledge-wise.*

I told her that I would send her an account of our conversation and that I would keep this request in mind.

Where voices meet: polyphonic voices

As stated before, our 'member check procedure' included a reflection from us as researchers on the individual story and this offered me the opportunity to give a reply. I found it quite difficult to write the story, so I sent an email to one of the other researchers:

> Attached you find the story of Anja (…). I would like you to read it (…) because I find it quite a ‘heavy’ story and reflection. (But this is probably also because of my tendency to prefer restitution terminology and, at least in part, a positive story to send back, as, in the end, I am part of society as well.) Besides this, I would like to offer her something more concrete in the reflection, because of her explicit request for help/a reply. But I don’t know what, exactly. And of course, this is not the aim of the member check, but maybe you have some suggestions?

We decided to aim for recognition: maybe for Anja it was helpful to read her story herself and to see the reflection from an outsider perspective. In this reflection, which consisted of more than four sides, I mentioned the elements stated in the former section as well as:

> Anja mainly departs from the dominant storyline (…): the restitution story (Frank, 1995). (…) This is dominant because it is the type of illness story most told and the one people prefer to hear. Her departure is displayed in a lot of different elements, but mainly in the strict control and regulation of her blood glucose level and by taking responsibility for this herself. She clearly strives towards restitution, for instance by starting to practice yoga in the hope that she regains control. Furthermore, her story mainly is a linear story, in which she keeps harping on ‘picking up the pieces and starting all over again’ after several events. Therefore, it is a future oriented story: Anja doesn’t seem to be thinking about the ‘what’ and ‘when’, but mainly about a solution, the ‘what next’. However, as Frank argues, a major limitation of the restitution story is that if it doesn’t work anymore, there is no other story to fall back on. This seems to be the case for Anja right now, indicated by the many aspects of loss in her story and her explicit request for help. (…)

I emailed my account to Anja and she quickly replied:

> What a story. I needed to sit down to read it. (…) My first impression is that it is useful for me. It clearly displays how you see this moment in my life. If I also see it that way, I might be able to do things differently. Make it easier for myself. (…) At that part about the restitution story and finding another form, maybe Eastern wisdom can help. I do have a passionate yoga teacher, which is inspiring. I need to reread your piece and think about it carefully. (…) Thank you very much.

A year later, out of curiosity, I asked her how she was and whether she would like to meet again. She answered:

> I would like to meet again. (...) The last year, several 'small' things have changed in my life. Even the diagnosis of my chronic illness. Funnily, the only thing left is sport. I still practice yoga.

We met again and she told me about these changes, amongst others concerning her diagnosis. Based on an article she read, she 'felt' that something was wrong and strongly insisted on a referral to the internist, who immediately changed her diagnosis into type 1 diabetes.[4] Furthermore, because of several major events concerning both herself and people close to her, she noticed that 'at the moment, physical activity and diabetes are relatively small in my life, just because the other things take up a great deal of time'. However, during this conversation she did imply a sort of change in attitude. An example is her decision to quit her voluntary work and do nothing:

> *Everyone immediately asked: 'What are you going to do next?' (...) And I told them: 'I'm just going to do nothing, I'm just going to leave it at that.' (...) That's very hard, because everyone looks at you like, that is also what you mentioned in your account, what is expected from you, that's what you're going to fulfil. (...) Of course you have the tendency to do so [but I didn't this time].*

Moreover, she added that although she still did not like yoga, she experienced her yoga teacher as someone helpful:

> *[She helps me] to gain insight into what particular outlook you have on life, how you handle things and how you should handle things. I cannot explain it precisely, but this made that I'm looking at things more easily now, how difficult they might be. (...) It is here and it is now, and it is not yesterday and not tomorrow. And of course, you anticipate what happens in the future, you cannot live by the day, but it is very important to look at this day and to keep close to yourself and not always place oneself in someone else's position. (...) That really was very helpful to me.*

When we said goodbye, she mentioned that she would like to stay involved in the research project. A few months later, I wrote a conference paper about her story and our interaction and I sent it to her, being curious about what she would think of it (Stuij et al., 2016). In her reaction, she acknowledged that 'the essence of the paper was put into words very well'. And we, again, had a short email conversation in which I told her about the aim of the conference and she answered:

> [It is] nice to know what you're working on. Now, I am able to place it better. I also find it good for myself, because then I also look at myself more critical.

This reaction indicates an ongoing process of narrative development.

Over time in the course of our interaction, both of our voices became more 'polyphonic', because they became 'characterised by overlaid, interwoven and (...) contradictory' (Ezzy, 2000, p. 613) voices and values, influenced by other voices.[5] To put it in black-and-white, I started as an 'observing' sociologist, interviewing people in order to analyse their story with a certain theoretical framework and making recommendations for healthcare. An interview setting is quite a fixed setting in which one person asks questions and another answers. This was also recognised by Anja, when she realised that asking for a reply 'is not as it should be' in such a setting. However, Anja told me a very personal story that moved me. It touched on other facets of me as a person (Abma, 2005). Therefore, I felt a moral responsibility to do something with this story and give her something in reply. My voice further developed during the discussions with the other researchers, in which I became more aware of the importance of an elaboration on narrative development for the aims of the research project.

Anja, at first, presented herself as someone feeling the need to know, decide and do everything concerning her diabetes herself. Individual autonomy and informed decision making were important to her. This was probably partly because of her experiences with healthcare: she didn't experience the care and expertise she felt she needed, and the regimes she was told to follow didn't fit with her notions about living a good life. But over time, when her attitude seemed to have changed, her voice also became more polyphonic; to a certain extent, she seemed to accept some uncertainty about what the future might bring (Ezzy, 2000; Abma, 2005). Furthermore, she was aware that she needed to take care of herself as well.

Implications for healthcare practices: voices of care ethicists

Although both Mirjam's and Anja's voice became more polyphonic over time, for the purpose of healthcare practices especially, the changes in Anja's voice are of importance. Departing from dominant health discourses, which emphasise restitution and one's own responsibility, in her story, told during the first conversation, Anja repeatedly emphasised to 'start all over again'. Based on her reactions to the account of this conversation, she was not explicitly aware of this. It seemed to be a familiar storyline to fall back on, as part of her taken-for-granted narrative habitus. However, at the moment of the interview, this storyline did not seem to work for her anymore and she asked for help, even if the interview setting was not an appropriate one. In a sense, she changed the context into a therapeutic one. In this section, we draw from the voices of care ethics to understand what happened next and discuss some implications for healthcare.

The essence of what happened seemed to be the development of a 'relational narrative' that we composed together (Gadow, as cited in Lindsay & Graham, 2000, p. 152). This type of narrative 'yields ethical knowledge that is co-authored, contingent and contextual' (Lindsay & Graham, 2000, p. 152). Firstly, the co-authoring refers to 'the joint and collaborative development of ways to handle [this particular] situation' (Abma, 2005, p. 345). This was started by Anja's request for a reply, which changed, to some extent, the purpose of our interaction. This co-authoring is intertwined in the extracts included above and it is explicitly visible in Anja's comment: 'that is also what you mentioned in your account'. Secondly, contingency emphasises that a narrative can always change; it doesn't have a final answer (Abma, 2005). This was shown by the ongoing interaction between us, in which we both continue to develop our voices, influenced by a broader chorus of voices. Thirdly, it was contextual as it depended on certain particularities (Abma, 2005). What these particularities were is not easy to pin down precisely, however, some elements might be considered.

Most importantly, although Anja and Mirjam did not know each other before the first meeting, there was an environment in which Anja felt safe enough to tell a personal story, to be vulnerable. This might be because Mirjam travelled more than two hours to visit Anja at home and emphasised that she didn't have any other appointments to go to. In other words, she wanted to hear the story and had the time to do so. Or, because Anja knew about the topic of our research project, and she therefore knew Mirjam was interested in her story. Or, because Mirjam asked open-ended questions, didn't interrupt Anja and mainly let her decide the course of the conversation. Or, because there was an interpersonal 'fit', partly fostered by having several social characteristics in common—level of education, social class, gender, ethnic background—as a 'familiar' basis for interaction. Or, perhaps, all or some of these factors combined together.

Furthermore, some of Mirjam's personal experiences, that Anja wasn't aware of, might have influenced her interest in this particular story. Although it wasn't her first interview with someone with diabetes, it was the first 'difficult' story; a story that didn't have a foreseeably 'good end' and a narrator that was at times emotional. Moreover, Mirjam had experienced a loss related to sport herself. While it already was some years ago and she wasn't regretful about it anymore, Mirjam could recognise Anja's pain, and it was easy for her to show a genuine interest and to build a rapport with Anja.

As said before, we don't know what it was exactly that created this process of narrative development. Most importantly, Mirjam was there at that moment and listened. However, as Elliot Mishler states, although listening is an important and necessary condition for care giving, it is not sufficient: ‘someone [also] must be heard’ (Mishler, 1984, p. 181). Mishler stressed the importance of recognition ‘of the distinctive humanity of patients and respect for the contextual groundings of their problems in their life worlds’ (Mishler, 1984, p. 192) as the essential ingredient for humane care. The feeling of recognition and being heard, probably was given to Anja by the carefully phrased outsider reflection on her story through the member check account. Here Mirjam and the other researchers acknowledged her request by being both understanding and critical towards her independent and responsible attitudes by pointing out to her that her story, sense of self and actions seemed incongruent (Abrams, 1997).

According to Annemarie Mol (2008), ‘good care’ is about improving someone’s life, however, the question of how to do this is multifaceted and complicated; it needs ‘tinkering’, a process in which a patient and a healthcare professional try and explore what is suitable and what not (p. 88). Part of this is a local fine-tuning of healthcare standards that entails an adjustment to daily life. Therefore, healthcare professionals need to pay attention to life circumstances and their effects, but, ‘these are not [always] acceptable topics in healthcare settings’ (Mishler, 2005, p. 438).

Joan Tronto emphasises that care should be considered as a ‘relational practice’, which means that attention must be paid to purpose, power and particularity (Tronto, 2010). The ‘purpose’ of care, in general terms, is related to activities that repair and maintain a good life. ‘Power’ refers to good care being democratic, and not protective or paternalistic; care is an activity where decision-making power should be shared. ‘Particularity’ means that care needs to be adjusted to the personal needs of a unique person, at a particular moment in time and place. ‘Good care’ requires the moral virtues of being attentive, accepting moral responsibility, actually doing the caring work and being responsive, to evaluate whether caring activities meet needs (Tronto, 2010). This is exactly what Mirjam did in her engagement with Anja. She was attentive to the needs of Anja, felt a responsibility, and acted and checked to see if Anja’s needs were met. This enabled Anja to develop a polyphonic story and broaden her narrative habitus. Her narrative autonomy was engendered by the support she received from other people.

But, as political scientist Tronto alerts us, there is more to care than covering the intimate relations, because the institutional context in which care is provided is also of importance. It is in this context that approaches to purpose, power and particularity may be conflicting.[6] Tronto (2010) especially mentioned the danger of parochialism, which means that we preferably take care of those close to us. In a way, this is illustrated by the story we told in this chapter, because we privileged the story of Anja, a woman with a comparable social status position, more than others. But at the same time, by making this explicitly visible, we aimed to raise consciousness about these processes and underlying sociological concepts, like status positions and habitus. Ideally, in the context of healthcare, both the ill person and the healthcare professional are able to reflect on and if necessary adapt their 'narrative preferences' as part of a relational process (Frank, 1995, p. 77). This requires moral virtues like attentiveness, responsibility, doing care and responsiveness as well as trust and solidarity (Tronto, 2010).

Concluding remarks

The story of Anja shows that life sometimes is much more complex than the restitution story presupposes. Although she seemed to have all of the characteristics that favour 'restitution', Anja was not able to continue horse riding, which was an important part of her 'normal life' and also a means to keep control over her blood sugar level. This elaboration of a personal story reveals the necessity of other storylines besides the restitution story, or, in the case of a chronic illness, dominant storylines emphasising control and normality (Mazanderani & Paparini, 2015). People who are unable to live this type of story need an alternative 'corpus of stories' to draw on (Frank, 2010, p. 195), for example storylines which more explicitly incorporate quest and/or loss. Furthermore, it shows that changing a narrative habitus requires consciousness about the storylines someone applies and a (joint) search for alternatives.

When people need to reconstruct their story because of an illness, they benefit from being part of a relational process of co-construction or 'tinkering' (Mol, 2009). In the story of Anja, healthcare professionals were conspicuous by their absence, however, others—a researcher passing by, her yoga teacher—seemed to have offered help in this direction. Our case study illustrated how relational storytelling is important for narrative development, feelings of recognition and coping with, or managing, a chronic condition like diabetes in daily life. We argue that healthcare professionals can and should play a role in such relational, patient-centred processes to be able to provide better care for privileged people and even more for people belonging to underprivileged social groups.

Chapter notes

1. Actually, the voice of the editor of this volume directed us towards this focus and we noticed that it got our thinking moving in a helpful direction.
2. We did not use this storyline analysis during the member check procedure as the story we sent back to Anja was written in the third person. But we decided to use it in this chapter because it offered us a guideline to write a very dense I-person fragment that presents the core of a storyline. Following

Murray and Sools (pp. 140–143), we composed these ‘narrative summaries’ based on a combination of content and structural analysis, following these three steps: (1) the formulation of a storyline title to capture the essence of the storyline, (2) the identification and characterisation of five storyline elements, namely agent/character, acts/events, means and/or helpers, setting/scene, purpose/intention/desired or feared goal, and the breach, which refers to an imbalance between two storyline elements and makes clear how these elements are connected into a meaningful whole, and (3) the writing of a storyline summary in which the narrative causal connections between the parts are explicated.

3. This is the reason Anja is included as an author of this chapter. It emphasises the co-construction and co-authoring of this relational narrative, a process involving several voices. These voices each made their own contribution as we carefully described in this chapter.
4. This was later further specified as ‘LADA’, Latent Autoimmune Diabetes in Adults, a slow form of type 1 diabetes which is often mistakenly diagnosed as type 2.
5. Among these other voices is the voice of the Anja’s yoga teacher, a voice that I only know through Anja’s telling.
6. Tronto compared this to care in the context of the family, were the purpose, lines of power and particularities are unquestioned.

Chapter 8

Stepping outside the consultation room
On nurse-patient relationships and nursing responsibilities during a type 2 diabetes walking project

Mirjam Stuij, Agnes Elling & Tineke Abma

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What preceded Chapter 8

Challenge Diabetes

‘I played volleyball at the top level for another year and a half after my diagnosis of type 1 diabetes, so the role of sport did not change then. During my last game, about ten years ago, I was injured, and I had to recover from it for a while. I didn’t do anything for a month, and then my sugars went in all directions, I needed twice as much insulin when I was completely inactive. I wondered: what is going on here? And then you have to get that under control again. So, I slowly started to understand the role of sport and physical activity, because in that month I did no sport. After a month, I thought: ‘I’m going to put on my shorts again; run a bit.’ Well, that’s not for me, running, because I’m not a runner at all and I had no idea. Like ‘well, I’m going to run for an hour or so’, but yes, after ten, fifteen minutes, I was already fairly done with it. So, then I thought: ‘if I want to take that seriously, I just have to run a marathon in a year’, because then you have to train seriously. I noticed that as I started to walk, my blood sugars got better again, I needed less insulin. And that was more or less the point where I thought: ‘This is the role of exercise, and this ensures that I just have better sugars and that I can better calculate how much insulin I need.’ So, that was a crucial one. At the time, I also realised that the motivation to do sport always used to be performance, but now it was to have good sugars and feel good. And I still have that feeling.

Contrary to what many people may think, I do not automatically exercise a lot. I also have evenings when I prefer to sit on the couch and eat a bag of crisps, but yes, I know what it means when you achieve that training and eventually achieve the performance. That always gives a lot of motivation. But you have to have experienced this approach once, that you train for something, then achieve a good performance that you are proud of and that you know what it gives you. A challenge means that by putting something substantial in your schedule, you have that stick behind the door to start training, to get moving. And I hope that, because of that changed lifestyle for a few months, you realise what it does to your blood sugars and with your feelings, that you indeed lose a little fat, that you wake up fitter in the morning and that you need slightly less insulin and have more energy. The moment you know that, then, because a lot of people never have that experience, they never have, and they don’t know what it is like. They always, they just live, and at some point you get, yes, yes, a day older, have a little less energy, and that is the standard. But that does not have to be the standard; you have the opportunity to raise your standard slightly by being more active and therefore feeling fitter and thus weighing less and having better sugar regulation. Those are all, yes, arguments to get moving. By enabling people to experience that during such a project, perhaps it could mean that people write something into their schedule every year, or participate every year in the Four Days Walking Event or the Dam-to-Dam Run, you know. That is the trick, to get that done.’

Bas van de Goor
Olympic Gold, Atlanta 1996
Co-founder of the Bas van der Goor Foundation, sporty with diabetes
Narrated in autumn 2014

Abstract

Aims: To examine the care practices of nurses during the organisation of 20 weeks of walking sessions for people with type 2 diabetes and to reflect on implications for nurse–patient relationships and nursing responsibilities in the provision of physical activity care.
Design: Qualitative, ethnographic study.
Methods: Almost 70 hr of field work was completed by participant observations and informal conversations with nurses and participating patients of two different walking groups (April–October 2016). Analysis of field notes followed an inductive holistic-content approach, using both within-case and across-case analysis.
Results: The analysis revealed four main themes related to the nurses' care practices: (a) organisational efforts; (b) combining group and individual care; (c) stepping in- and outside the patient mode; and (d) implications back inside the consultation room. Underlying these themes was a process of relational development, both with and among patients.
Conclusion: Stepping outside the consultation room seems to offer more space for patients' lifeworld narratives and contribute to more continuous and person-centred care. However, it also raises new questions about the provision of physical activity care and nursing responsibilities in this.
Impact: Current nursing repertoires for physical activity counselling in type 2 diabetes care are insufficient and might be extended by organising walking sessions for patients. Related nursing care practices impacted relationships both with and among participating patients. These have consequences for boundaries of both nursing responsibilities and care provision.

Introduction

Worldwide, physical activity recommendations are part of clinical practice guidelines for the management of type 2 diabetes (IDF, 2017). However, previous studies indicate that physical activity is not an easy topic in diabetes care. While healthcare professionals consider it to be important, they mention uncertainty about the effectiveness of their counselling and uncomfortable feelings about providing detailed advice (Hébert et al., 2012). Their main repertoire inside the consultation room consists of education, offering advice and encouragement, or referral to exercise specialists, but this seems insufficient to support patients to adopt more active lifestyles (IDF, 2017; see Chapter 5).

To extent the professional 'physical activity care' repertoire, a Dutch project was initiated to facilitate healthcare professionals in the organisation of weekly walking sessions for patients with type 2 diabetes. This was scheduled for 20 weeks with participation in a Four Days Walking Event as a shared goal.

After small initiatives in 2014 and 2015, these walking sessions were organised as part of a yearly 'National Diabetes Challenge' (NDC) on 125 locations in 2016 and over 200 locations in 2018 (Bas van de Goor Foundation, 2016, 2018).

Many of these organising professionals are nurses, as they offer most of the practical type 2 diabetes care in the Netherlands. Over 85 per cent of Dutch people with type 2 diabetes is treated in primary care (Vektis, 2015), where general practitioners have the final responsibility, but generally most care is handed over to general practice nurses (*praktijkondersteuners somatiek*). These are registered nurses who, for instance, educate patients about diabetes and lifestyle (Freund et al., 2015). Patients in need of more complex care are referred to an internist in secondary care, where nurses specialised in diabetes can offer most of the practical care (Houweling et al., 2009).

Several studies point towards the potential of nurse-led interventions aimed at healthy lifestyle and chronic disease management (Sargent et al., 2012; Stephen et al., 2018). However, these might change existing practices and ask for professional, organisational and policy adaptations accordingly and challenge professional responsibilities (Stephen et al., 2018). Therefore, the aim of this study is to examine the care practices of nurses during the organisation of walking sessions and to reflect on implications for nurse–patient relationships and nursing responsibilities in the provision of physical activity care.

Background

Review studies show competing priorities and lack of time, training and reimbursement as the most important barriers to physical activity promotion practices for healthcare professionals, while good relationships with patients, knowledge about their personal lives and active lifestyles of professionals themselves are mentioned to be enhancing (Hébert et al., 2012; Huijg et al., 2015). Qualitative insights indicate ambivalent feelings of professionals about the understanding of inactive patient behaviour and regarding professional views related to individual and professional responsibilities for behaviour change (see Chapter 5). These findings illustrate the importance of the care context and the quality of relationships with patients, as well as the existence of morally ambivalent tensions in the provision of physical activity care (cf. Wiechula et al., 2016; Strandås & Bondas, 2018).

Overall, nurses seem to be mostly medically oriented, while patients experience little attention to personal, social and practical challenges to integrate illness into their daily life (Been-Dahmen et al., 2015; cf. Brundisini et al., 2015). This points towards a gap between system and lifeworld, proposed as a distinction between a scientific, bureaucratic and impersonal logic on the one hand and a logic based on values and narratively embedded face-to-face relations on the other hand (Habermas, 1984; Van den Ende & Kunneman, 2008; Kunneman, 2015). This distinction is considered a structural feature of care contexts, resulting in an ongoing tension. The course of a consultation, for instance, can be guided by blood sample results or the question ‘how are you?’.

Rather than dealing with a structural opposition between these logics, healthcare professionals can also operate in an in-between domain where both system and lifeworld are important; it depends on the situation which one prevails (Kunneman, 2015; Abma et al., 2017). Furthermore, it is argued that both logics generate morally ambivalent dilemma’s, for instance, related to solidarity, division of services and personal interests (Van den Ende & Kunneman, 2008). Therefore, professional care practices always involve moral choices about the provision and organisation of ‘good’ care.

Against this background, the NDC provides an interesting extension of the physical activity care repertoire, as nurses actually go walking with their patients instead of giving advice or a referral. It is initiated by the *Bas van de Goor Foundation*, a small non-profit organisation that promotes sport and physical activity for people with diabetes and aims to lower the threshold for patients to become more active. During the NDC, the foundation facilitates nurses in the organisation of weekly walking sessions; for instance, they provide communication materials and a project plan with training schedules, have a helpdesk and organise a final collective walking event (Bas van de Goor Foundation, 2015).

Several features of the nurses’ care practices in this project are different from their regular practices. Overall, these new practices seem to be more outside the system world and into the patients’ lifeworld than regular care practices. First, care is provided in a different context, because nurses and patients literally step outside the consultation room to walk outdoors. Second, instead of one-to-one care, nurses provide care to a group of people. These two features might impact nurse–patient relationships (Wiechula et al., 2016) and offer possibilities for patients to share experiences and learn from each other (Oftedal et al., 2010). Third, it is a bottom-up project without protocols about how to arrange care as only facilitation is offered and the organisation is left open to the nurses themselves—offering space for learning and adaptation along the way (Horstman & Houtepen, 2008).

Therefore, it is expected that these new care practices create opportunities to better meet the caring needs of patients, but also raise new moral questions about the provision and organisation of care. A study of the learning process and professional development of the organising nurses might offer a starting point for a reflection on nurse–patient relationships and nursing responsibilities in the provision of physical activity care.

The study

Aims

The aim of the study was to examine the care practices of nurses during the organisation of 20 weeks of walking sessions for people with type 2 diabetes and to reflect on implications for nurse–patient relationships and nursing responsibilities in the provision of physical activity care.

Design

This study was conducted from a social constructivist paradigm: we approached reality as multiple and socially constructed through lived experiences and interactions (Creswell & Poth, 2018). To examine the care practices carefully, an ethnographic study was carried out where the researcher (first author) participated in two walking groups. A comparison of two different locations enabled us to better understand these practices, as differences and similarities as well as specificities of the context emerged (Ayres et al., 2003). Furthermore, as we did not want to limit our observations, we did not define care practices in advance. Instead, we observed what was actually done in practice (Mol et al., 2010) what the nurses and others told the researcher and each other about it.

Participants

To understand what was new compared with regular care practices, the nurses in this study needed to take part in the project for the first time. Further inclusion criteria were pragmatic, namely feasibility for the researcher—e.g. walks not scheduled at the same time—and willingness of the nurses. One nurse, henceforth 'Ellen', presented herself after a presentation of the researcher at a general information meeting about the NDC. The second nurse, 'Nicole', was included after an e-mail sent by the *Bas van de Goor Foundation*. Relevant characteristics are listed in Table 8.1.

Table 8.1 Details of the organising nurses

Pseudonym	'Nicole' (location N)	'Ellen' (location E)
Position	Diabetes nurse	General practice nurse (*praktijkondersteuner somatiek* in Dutch)
Employed at	Hospital (secondary care)	Healthcare centre (primary care, a centre where general practitioners and several other (paramedic) healthcare professionals are located)
Gender	Female	Female
Years of working experience	Over 20 of which 15 years as diabetes nurse	12
Experiences with walking groups before	None	Already facilitated a small weekly walking group with her colleague for a few years

Data collection

The researcher was educated as a medical sociologist and had ten years of experience in qualitative research, including participant observations, with a focus on type 2 diabetes care and physical activity for the past 5 years. She participated in two walking groups from the onset until the final event and meetings (April–October 2016). She held informal conversations with the nurses and patients and made observations, both written down in field notes afterwards. In total, almost 70 hr of field work was completed.

As the researcher did not know the research setting beforehand, field notes were collected in an unstructured way, without specific questions or observation protocols (Hammersley & Atkinson, 2007). They were written in both first and third person. This was not a conscious decision, but reflected the researcher's presence as 'the lens through which one sees' as well as someone depicting others (Emerson et al., 2011, p. 101). As she was present from the beginning of the project onwards, she became part of the groups, in an undefined role mingling between observer, participating walker and scheduled as a walking guide at times. This enabled her to relate an 'insider' participant view to an 'outsider' academic view to make sense of the nurses' care practices (Green & Thorogood, 2018). She reflected on this in reflexive field notes.

Ethical considerations

This study was conducted as part of a larger project, which was waived requirement of full medical ethical approval by the university's medical research ethics committee and further discussed with its privacy officer. As a result, the organising nurses were informed by a letter explaining the aims, practical implications and benefits of the study and efforts to ensure confidentiality. This was talked about with each nurse and put down in an informed consent form. This form also ensured openness of the researcher about the study towards the participating patients to obtain oral informed consent. In practice, she introduced herself to the groups during the information meeting and first walk and then whenever necessary to ensure that everyone was informed. For privacy reasons, minimum information about the locations and people involved is provided.

Data analysis

Field notes were analysed using MaxQDA Version 12, following an inductive holistic–content approach (Lieblich et al., 1998): we interpreted practices in the context of other observations to connect these to each other, locate them in time and place and thereby explore the process and development of the nurses during the project (Lieblich et al., 1998; cf. Beal, 2013). We altered between (re-)reading field notes, open coding and further arrangements of codes (Elo & Kyngäs, 2008), which resulted in four major closely connected and more abstract themes. Moving between within-case and across-case analysis sensitised us towards critical reflections on these codes and themes and the preservation of the contextual richness of each case (Ayres et al., 2003). The analysis was carried out by the first author and frequently discussed with the others—a critical sport scholar and an interdisciplinary scholar in the fields of social sciences, humanities and medical sciences with a background in nursing.

Rigour

To enhance rigour, we used the following strategies (Polit & Beck, 2012): (a) prolonged engagement and persistent observation in the field by being present for the whole project; (b) space triangulation by collecting data on two locations; (c) informal member checks by discussion of the findings with nurses and patients during the walks and meetings; (d) reflexive journaling during data collection and analysis and in-depth discussions about this in the author team; and (e) thick description by providing rich and vivid descriptions.

Findings

The analysis resulted in four main themes related to the care practices of the nurses: (a) organisational efforts; (b) combining group and individual care; (c) stepping in- and outside the patient mode; and (d) implications back inside the consultation room. These themes were closely connected to each other; together they describe the context and process, especially related to developments of relations with and among patients.

Organisational efforts

Both nurses started with about 30 patients; included through consultations, information meetings and leaflets. These were not all their own patients, but also other people with type 2 diabetes living in the surrounding. Indeed, most participants in Ellen's group were not a patient of her. This indicates the nurses' responsibilities went beyond their own patient files from the beginning onwards.

The project demanded relatively considerable organisational efforts of the nurses. These comprised the practical work necessary for the realisation of the walks. Most of these efforts were calculated in beforehand, although the amount of necessary time was unforeseen, like the actual walking, tasks related to the recruitment of participating patients and 'walking guides', the planning of routes and the arrangement of devices and sweets to measure and, when necessary, increase blood glucose levels along the way. However, the nurses also needed to be flexible with respect to uncertain conditions, like the weather and number of people actually present during a walk. Although these efforts were necessary for both groups, Ellen's earlier experiences with a walking group seemed to help her. Especially the planning of routes seemed to cause less stress, as she already knew possible walking routes in the surrounding quite well.

Overall, three main organisational efforts were found: (a) organising support from colleagues; (b) personal investments; and (c) organising follow-up.

Organising support from colleagues

Both nurses made the decision to join the project themselves, because they were interested in this new approach. They got permission to do this and both were provided with about the same amount of time for the organisation. Moreover, they experienced most colleagues to be positive when they told them about this project. However, they equally struggled to find practical support from colleagues. Both had one or two colleagues helping them frequently and also found some others willing and able to guide a walk now and then. But this was not something easy and seemed to cause extra stress, especially because the nurses themselves could not be there every walk, for instance, because of other professional duties or their own summer holidays. This was illustrated by the inclusion of the researcher in the guidance schedule at location E.

For Nicole, especially the inclusion of doctors turned out to be difficult, despite the efforts she took to realise this:

> A lady asks why the walks are scheduled around diner time, because that is impractical with diabetes. Nicole tells her that it is more easy to empty the agenda of the internists at the end of the day. She does not tell about her own consultations. (location N, instruction meeting)
> Nicole tells the group she won't be there the next four weeks and still needs to fill the schedule with guides. But she will arrange for the doctors to be there, she says. The group thinks this won't work because the doctors always have excuses: too many consultations, meetings, or whatever. (location N, walk 8)

At the end of the project, Nicole said she was disappointed about the absence of the doctors. She thought they did not dare to walk along with their patients. This probably illustrates the dominance of the system world with a strict hierarchy between doctors and patients, something the patients seemed aware of. The doctors of the other location did not join either, something Ellen also noticed and tried to change, although it seemed to be less frustrating for her. This might indicate that the patients and nurse in the hospital experienced a larger distinction between the system—and related hierarchical positions—and lifeworld than those involved with the healthcare centre.

Personal investments

The organisational efforts were not all visible to others, as they were carried out whenever there was a spare moment. Moreover, these required the investment of the nurses' spare time, because working hours were not sufficient. Therefore, the project entered the lifeworld of the nurses themselves. The walks of Ellen, for instance, were scheduled in the evenings. At the other location, the walks were scheduled at the end of the working day with the first half planned inside 'consultation hours'. But this also meant Nicole often seemed to be in a hurry to be there in time for the walks, illustrating a tension with regular care practices.

Organising follow-up

The third main organisational effort had to do with follow-up. These were extra efforts the nurses went into, as they were not necessary for the project. First, part of the patients quit during the project. For instance, Ellen noticed that her 'slow group had disappeared' the second walk. Indeed, at both locations, the number of patients almost halved after the first walks. During the remainder of the project, some others quit as well. Both nurses called after them to convince them to continue participation and if they did not want to, to refer them to an exercise expert. Second, the nurses cared about follow-up after the project, to enable patients to continue to be active. Both searched in the neighbourhood for options, tried to create a social network with exercise coaches or the local walking club and organised a final meeting to inform their patients.

Combining individual and group care

The provision of care to a group of people was a new practice and brought along the intricacy of attentiveness towards individual needs, while, at the same time, having an eye for everyone. This was especially visible in the subthemes 'dealing with private matters' and 'taking care of both quick and slow walkers'. However, the group also provided opportunities for 'shared care', the third subtheme.

Dealing with private matters

Providing group care brought along issues about dealing with private matters. For instance, Nicole's group took part in a study on the effectiveness of the project and this required measurements beforehand:

> The scales are taken out. Nicole weighs everyone, measures their belly and waist circumference and notes the values down on a small piece of paper. This results in some funny remarks: 'Hey, don't hold your stomach!', or 'Plus ten kilos!' Most people do not know each other, this seems to evoke uncomfortable feelings. (location N, instruction meeting)

Here, the emphasis of the system world on measurements interfered with the intimacies from the lifeworld, which are normally discussed in the privacy of the consultation room. These issues were especially faced at the beginning of the project and sorted out along the way, because 'private' moments were created during the walks and the nurses got used to these matters. Both showed flexibility to handle these, illustrated by remarks like 'come by and see me tomorrow' and 'you can come in whenever my [consultation room] door is open'.

Taking care of both quick and slow walkers

From the first walk onwards, patients differed in their pace because of their different conditions. This resulted in 'quick' and 'slow' walkers, something the nurses had to adapt to. For example, one patient at location N was clearly slower than all others. After the first walk, he said he needed more pauses along the way. Therefore, Nicole took along a wheelchair for the second walk, which had implications for the others as well:

> Nicole is still not back [at the meeting point at the end of the walk] and the others are in doubt whether to go home or not. But then she arrives, together with her friend [a volunteer guide] and the man in the wheelchair. Nicole pushes the wheelchair and the three of them were behind the whole route. The other patients tell her they want someone walking with them in front as well, to guide them. They seem a bit annoyed. (location N, walk 2)

Nicole walked behind with this man for four walks, until he decided to quit because he could not carry on anymore. At the end of the project, Nicole indicated that she found it difficult to pay attention to everyone, especially because some demanded more than others.

Ellen used a different approach from the first walk onwards:

> The leading group is waiting beneath the crossover. Ellen says she wants everyone together to see how it goes. The very last walkers are still quite a way behind and Ellen suggests we walk back and get them. 'Vacuuming', she calls it. As not everyone sees the benefit, we go back with a small group. (location E, walk 1)

This was an approach she used throughout the project and matched her own sport biography; Ellen used to be a running coach and participated in marathons. Elements of performance were visible in her approach, as she measured and stressed the distance and number of steps for each walk.

These two approaches illustrate differences in the organisation of both nurses. This was probably dependent on many different factors—like the context, their patients with different conditions and care needs, their own preferences and Ellen's previous experiences with a walking group—and exemplifies the personal interpretation of both nurses in the provision of care. This interpretation was, many times, also a matter of improvisation because the context or needs of patients required last-minute adaptations. As the approach of Nicole illustrated, this also raised dilemmas.

Shared care

In the course of the project, patients also came to take care of each other. This 'shared care' was both practical and social and took some work off the nurses. For example, patients helped them to map out routes or distribute water bottles. Furthermore, they shared a lot of experiences and tips with each other, for instance, about what to do with high blood sugar levels, how to deal with insurance demands and where to buy good walking shoes.

Another form of shared care was a kind of social discipline that emerged: patients asked others about their absence and checked if everything was fine. In one of the groups, this social discipline continued after the project:

> Ellen's group is sharing phone numbers. They're starting a WhatsApp group and agree on walking every Saturday morning for two hours. (…) Ellen says she also joined the group, 'to keep an eye on them', she jokes. (location E, final meeting)

For these patients, shared care resulted in a self-organised follow-up of the project. It illustrates a shift in the responsibility of the nurse in organising physical activity care towards a delegation towards the patients themselves.

Stepping in- and outside the patient mode

Over the course of the project, relations between the nurses and patients changed. This was made explicit by one of the nurses near the end of the project:

> The leading group is waiting ahead. Ellen proposes a route to continue and tells the group she really has to leave [because of a scheduled consultation]. Up to three times she says: 'I need to get back into the patient mode now!' (location E, walk 20)

This remark implied another mode during the walks and another attitude towards the patients. At the other location, there were also hints towards being in a different mode:

> Nicole mapped out a route this time. She jokes we can walk by the ice-cream vendor and buy an ice-cream. (...) Indeed, we do and Nicole treats us. Some people pass, others pick the sugar free strawberry flavour. Her colleague does not want to, she seems to disagree. (location N, walk 8)

An ice-cream was something Nicole probably would not recommend inside the consultation room and it implied her being more outside the professional mode during the walks.

Related to this, the walks offered nurses and patients an opportunity to get to know each other beyond the biomedical. For instance, many informal talks about the surroundings resulted in personal talks about where one lived or daily pursuits. Furthermore, conversations were continued over the weeks and people talked about events in between the walks. In this process of getting acquainted, both nurses also exchanged personal information about themselves, something they told they hardly did before:

> Nicole wears a step counter as well. (...) She tells me she also joined the online community [they have] to make her data visible for everyone. She also added her body weight, so others can see it. She wants to lose some and she thought she'd better be fair about it in the group. (location N, walk 1)

This illustrates both an identification with patient issues and an example of shared care. Moreover, it indicates a shift where the nurse's lifeworld became part of the nurse–patient relations.

Implications back inside the consultation room

Near the end, both nurses narrated they noticed the conversations inside the consultation room changed; they experienced their patients to feel more free to ask questions and tell certain things, while they themselves asked other questions than before. Nicole, for instance, told she had an extensive conversation with someone about why he gained so much weight, while she usually asked patients only about their current dietary and exercise behaviour. Ellen experienced a patient that used to be stiff to talk more freely during consultations.

In addition, Nicole mentioned she became more interested in certain topics, because she heard much more about her patients' lifeworld experiences. An example of this was bariatric surgery, something several of her patients underwent, were on a waiting list for or thought about. One of her patients had such a surgery the week before the final walk:

> Nicole tells me everything went well; he sent her a WhatsApp message after surgery. He also texted that his nurse over there did not know how to deal with his high blood glucose levels. Nicole answered him by texting this was normal after surgery and should get better in time. He sent back a message with a thank you from the other nurse. Nicole says another patient had bariatrics recently. (...) She also talked about it with yet another one, but he does not dare to at the moment. She plans to relate these three to each other, so they can exchange experiences. (location N, final walk)

This excerpt demonstrates both new and creative care practices, more informal connections between the nurse and her patients and another example of the organisation of shared care. It illustrates how lifeworld experiences entered and impacted care relations.

Discussion

This study focussed on care practices of two nurses working in a new context; instead of protocol-based consultation room care, they provided 20 weeks of physical activity care outside by offering weekly walking sessions for people with type 2 diabetes. The organisation of these walks was facilitated, but without a fixed script; how to offer this care was left to the nurses—illustrated by differences in the two approaches. Furthermore, our focus on system and lifeworld dynamics provided detailed insights into innovations in physical activity care practices and especially the impact on relationships between those involved.

Overall, underlying the four main themes found in this study were two important processes of developments in relations with and among participating patients, namely in nurse-patient relationships and shared care. The aim of the discussion is to reflect on the value of these developments as well as on new questions that arise. Finally, these insights are used to reflect on implications for nursing responsibilities in the provision of physical activity care. Interestingly, although the starting point of the project was to help patients to become more active, the implications seemed to stretch beyond physical activity care and impact the provision of diabetes care more generally.

Nurse–patient relationships

Nurse–patient relationships are found to be shaped by the care context (Wiechula et al., 2016). The context in this particular study seemed to be more person-centred instead of patient-centred (Zhao et al., 2016), with a focus shifting from illness towards walking together and creating opportunities to exchange more extended narratives about life and illness (Frank, 2013) than the consultation room permits. Moreover, since nurses and patients saw each other weekly for a longer period, it offered an opportunity for what Zhao and colleagues (2016) call 'continuous care'. As a result, they got to know each other better—beyond the patient aspects.

Deeper insights into the patients' lifeworld experiences might contribute to a better professional understanding of patients' physical activity behaviour, including their difficulties in becoming more active (see Chapter 5; cf. Hinder & Greenhalgh, 2012). Furthermore, this might result in the development of a 'common story' about health enhancement that requires mutual commitment of both patient and nurse (Strandås & Bondas, 2018). In line with this, individual patient responsibility for physical activity behaviour became a form of shared responsibility because of the mutual commitment of everyone to this project.

In addition, the exchange between nurses and patients became more mutual during the project, as the nurses also shared information about themselves. Although the evidence is not unequivocal, this 'self-disclosure' has the potential to enhance relationships with patients (Arroll & Allen, 2015). However, it might also create new professional dilemmas, especially related to keeping a 'professional distance' (Hem & Heggen, 2003) and the nurses' own boundaries between their professional and personal life. For instance, they might face questions about what to share and whether they want to do this at all. Although the nurses in this study did not seem to face tensions related to this, it might also result in uncomfortable feelings.

Shared care

An important new feature of this project was offering care to a group of people. This brought new issues about how to care, for example, in dealing with private matters or caring for both quick and slow walkers. These questions were handled in practice. Moreover, group care brought new dynamics and offered the opportunity of shared care since patients came to take care of each other, as a form of social discipline (Huijer, 2013). This was also something the nurses learned to organise, for instance by connecting specific patients to each other. In this way, attention was refocused to what patients can learn from each other instead of from a nurse (Horstman & Houtepen, 2008).

However, care was not shared by everyone as a part of the patients quit during the project. Their reasons might be several, but, at a minimum, a fit with the walking project, the approach of the professional and preferably the pace and personalities of the others is required. This is something that cannot be controlled and thus, meet everyone's needs, as illustrated by the results. This creates new possible dilemma's, for instance, about how much extra effort to invest or when to let go of patients, especially when extra efforts require spare time. This might be even more complicated when behaviour change becomes a shared responsibility instead of an individual responsibility. In addition, colleagues of the organising nurses were difficult to include in the project, especially the doctors, despite the efforts taken. Their reasons might also be several, although it illustrates a system–lifeworld hierarchy that was not countered, at least not at these two locations.

Reflections on nursing responsibilities in the provision of physical activity care

Given the difficulties of healthcare professionals in physical activity promotion practices (Huijg et al., 2015; Hébert et al., 2012; see Chapter 5), physical activity care might benefit from more lifeworld-led forms of care (Dahlberg et al., 2009). Although the current study did not aim to measure effects of the project on actual physical activity behaviour, the findings offer a starting point for a reflection on nursing responsibilities in the provision of (physical activity) care.

Overall, this project seemed to have 'blurred' the boundaries of both nursing roles and care provision, by literally stepping outside the consultation room and leaving regular protocols behind. This was underlined by the professionals feeling 'outside the patient mode' during the walks. This different approach seemed to help nurses to enrich their generalised evidence-based knowledge of benefits of physical activity for their patients—most valued in the system world—with the concrete, local knowledge from their patients' lifeworld, more than they normally acquired inside their consultation room. This type of knowledge is considered a prerequisite for good care (Hamington, 2018) and might contribute to the nurses' tacit know-how (Salter & Kothari, 2016) in providing physical activity care.

Providing practical and social self-management support is found to be important in type 2 diabetes care (Oftedal et al., 2010).Taking patients by the hand might contribute to this, as it fosters the development of care attuned to personal needs and wishes through attentiveness and presence. As such, it fits with an ethics of care that directs nurses' attention to responsiveness in relationships (Abma & Baur, 2014). In this process, the nurses' responsibility shifted from expert education towards facilitation (Jacobs, 2011) of physical activity possibilities and shared care. Furthermore, participation in this project physical activity offer nurses a possibility to reflect on their own role and caring responsibilities in providing physical activity care and counselling (Jacobs, 2011).

Participation of the two nurses in this project showed their intrinsic motivation to improve physical activity care and offered them a rich learning experience. However, being more outside the system world might also offer new risks and dilemmas, for instance, about maintaining a professional distance and the investment of time. Inside the consultation room, time is limited, or at least more or less. During this project, the requested investment of time was not limited in a similar way. Although the nurses probably did not know beforehand how much time was needed, it was not possible to (partly) withdraw during the project, because of their commitment towards patients. Especially the investment of their own spare time caused a dilemma between their own interest and solidarity with their patients (Van den Ende & Kunneman, 2008).

Therefore, professional innovations as illustrated in this study, also require organisational and policy adaptations (Stephen et al., 2018) to care for the nurses themselves. For instance, they need sufficient support to carry out the organisational efforts for such a project. Moreover, this project raises questions about the provision of physical activity care as part of self-management support. For instance, whether such a project should be part of nursing care at all. Given the results presented in this study, physical activity care might benefit from a more playful handling of the system and lifeworld balance and further exploration of creative elements in (physical activity) care for people with type 2 diabetes.

Limitations

A limitation of this study is that we did not talk to patients who quit or doctors who did not take part. Their insights might have added extra information, for instance, about whether doctors were unable or unwilling to join. Furthermore, the perspective of the patients was hardly included in this study. Finally, the two cases in this study were not indicative for all locations where the project was carried out. For instance, the learning process could have turned out differently, or failed.

Conclusion

This study provided a detailed examination of care practices of nurses organising weekly walks for people with type 2 diabetes. The focus on system and lifeworld dynamics offered in-depth insights into the potential of these new practices and especially revealed relational developments during the project. Stepping outside the consultation room seems to offer more space for patients' lifeworld narratives and contribute to more continuous and person-centred care. However, it also raises new questions about the provision of physical activity care and related nursing responsibilities. These questions need to be further discussed, for instance, by policy makers, healthcare professionals and researchers, to further develop the provision of 'good' physical activity care for people with type 2 diabetes.

Intermezzo IV

Physical activity care in motion

ZonMw offers an implementation grant for study results of Sport in Times of Illness. I like the idea of translating findings into practice, so I ask the ROHA, a care group in Amsterdam, if they are interested in such a project. They are, and they even remember the observation report I wrote about their training days (Chapter 4). What follows is an enthusiastic conversation, a proposal, the actual grant, and then a first meeting with the 'project group' consisting of two practice nurses, two dieticians, two general practitioners, and the project leader person-directed care, Willemien Rietman.

During this meeting, in January 2019, I first present myself and talk about the study results. I planned to speak about the study for about 20 minutes, but it takes more than an hour because of all the reactions – mostly recognition and exchanges of experiences. So, there is not much time left to talk about the 'what now?'. I ask them what they hope for, why they signed up to join the project, and the conversation easily goes to 'information to motivate patients to do more exercise', the lack of overviews of physical activity possibilities in the neighbourhood and options to organise actual offers. Hmm, the initial plan Willemien and I talked about was to focus on the topic of 'understanding patient behaviour', and frictions this might cause in patient–professional relationships. But I don't want to impose my ideas, so let's wait and see.

The next meeting is about six weeks later. By way of preparation, Willemien and I talk about our own 'sport and physical activity curriculum vitae'. We decide to ask everyone to write this down, including what activities meant in different phases of life. What follows during the meeting is an exchange of personal 'sport and physical activity stories' and a sort of collective reflection, something we follow up on during the third meeting. The discussions result in different kinds of reactions, like:

> 'I was not sport-minded at all, I did not grow up with this, and I was not allowed to cycle to school', while making defensive hand gestures.
>
> Surprises when some shared quite personal stories about physical impairments or serious diseases that affected sport and physical activity behaviour, and the impact on related meanings.
>
> An important eye-opener: 'I now see that I have more patience when it comes to diet during consultations, because I struggle with this myself too. Physical activity is something obvious to me, has always been, but I never realised this might be a source of frustration when I talk to patients who have difficulties in becoming (more) active.'

One important conclusion we arrive at is that the question about meaning is essential because it facilitates reflection and discussion. We decide to make a format for other healthcare professionals to write down their ‘physical activity CV’, including some questions to reflect on this (see Appendix). We discuss the ultimate goal of such ‘tool’, and this would be to increase work pleasure related to the topic of physical activity because it might be easier to see where certain frictions or frustrations in conversations with patients might come from. But it might also be helpful to talk with patients about their physical activity story in a different way.

In the period until the next meeting, two project members discuss this CV with a group of colleagues (*intervisie*). Others try to find moments to share it with colleagues or think about insights into their own behaviour and meanings while providing ‘physical activity care’. In the final meeting, we talk about their experiences. Sharing stories about physical activity, including meanings, provided them with insights into differences with others, and possible judgements based on their own meanings. This seems to bring about a better understanding, and the overall reactions are positive:

> ‘I found out I have prejudices. When a slim person walks into the consultation room, I think (s)he is sporty. With an overweight person, I think the opposite. Both judgements are not always true. I ask about it now.’
>
> ‘For me, physical activity has to be fun. I used this as an argument for my patients too. But I now see this has not to be the case for everyone, so I do not assume this any longer.’
>
> ‘The conversation in the consultation room about physical activity becomes a lot more fun.’

We discuss further implementation of this format and decide to write a short article for the upcoming newsletter, the professional magazine *De POH* (The Practice Nurse), and give a presentation during the internal training day for practice nurses and dieticians in October 2019. Although this is a small project and the result also seems small and simple, it seems to provide the project members with new insights and inspiration.

Chapter 9

General discussion

With this dissertation, I aim to provoke thought and discussion about the topic of physical activity in type 2 diabetes care in order to contribute to its further improvement. Based on several mostly qualitative studies conducted with others, my purpose is to offer a new and profound understanding of the intricacies people with type 2 diabetes and their healthcare professionals experience with 'physical activity care' within the broader socio-political, research and healthcare context in which this type of care is provided. Importantly, this understanding results from a critical narrative approach primarily placed within the social sciences on a topic that is predominantly influenced by (bio) medical and epidemiological research and understandings.

The previous chapters offered insight into the broader context relevant to the topic of this dissertation by presenting an analysis of sport policy documents and an account of observations during training days for healthcare professionals learning about a new way to look at (lifestyle) care provision. This was followed by in-depth insights into experiences of people with type 2 diabetes and healthcare professionals with physical activity and physical activity as an aspect of care. Detailed analyses of two out-of-the-box physical activity (care) practices that provide openings for further improvement of care were then presented. These were about extended talking and walking. In between these chapters, several intermezzos offered additional insights into the care context, experiences of people with type 2 diabetes with physical activity in- and outside the care context, and new thoughts on physical activity counselling created in partnership with a small group of healthcare professionals.

In this final chapter, I offer a narrative reflection on all findings taken together in order to answer the overall research questions of this dissertation. I do so guided by four theoretical lenses introduced in Chapter 1 that range from macro-theories critical of societal workings to micro-lenses aimed at narrative understandings. I also offer some reflections on my own research process that link to the topic of study. In the general introduction and order of the empirical chapters, I began with the broader political and care context to provide a background to the micro-level experiences and openings. In this general discussion, I start from the micro-level in-depth insights and end with suggestions of how the broader context can become more accommodating.

1) What can we learn about physical activity (care) experiences from people with type 2 diabetes and healthcare professionals?

The exploratory survey study presented in Chapter 2 provided a starting point for the qualitative studies that followed by indicating a mismatch between the care experiences and needs of people with diabetes related to physical activity. To gain more profound insights into this mismatch, I conducted in-depth interviews with people with type 2 diabetes and healthcare professionals providing physical activity counselling (like practice nurses) or training (physiotherapists) about their experiences with physical activity (care), as presented in Chapters 5 and 6. During the analysis, I paid attention to their complete story, or better, the story they co-constructed with the interviewer (mostly me) in a certain (official) context. With this, I aimed to better understand how the interviewees made sense of their experiences within the broader social and institutional context in which they live and work.

These studies started from the prominent place of physical activity in type 2 diabetes care: aiming for an increase in physical activity is a basis of treatment and remains important throughout the entire period of illness (NHG, 2013, p. 6; see also IDF, 2012). This prominence is based on a large body of (bio)medical and epidemiological research among large numbers of anonymous individuals, resulting in detached and disembodied perceptions about the benefits of physical activity for health in general and type 2 diabetes control specifically. These perceptions are further translated into (medical) guidelines on the required (minimum) amount and intensity of physical activity for diabetes control *and* into widely accepted understandings on the importance of physical activity for health and type 2 diabetes control.

My aim here is to formulate several points of interest based on the experiences presented in Chapter 5 and 6 to provide input for further thought and discussion on the topic of physical activity (care) for people with type 2 diabetes. To do so, I now use the theoretical lenses of a narrative habitus (Frank, 2010) and healthism (Crawford, 1980) as tools to 'think with' (Jackson & Mazzei, 2013). People make sense of their experiences by storytelling, but they do so in a certain social context that provides them with norms or rules about what stories or storylines are appropriate as part of an inner library they can draw from—their 'narrative habitus' (Frank, 2010; see also Riessman, 2008; Gubrium & Holstein, 2009). Healthism adds a critical focus on the societal emphasis on individual choice and responsibility for behaviour (and health) as a storyline that often goes without saying and is clearly traceable in current policy, research and social norms as introduced in Chapter 1.

As illustrated by the findings presented throughout this dissertation, this societal emphasis is also clearly present in the experiences of people with type 2 diabetes and healthcare professionals, which is something I did not ask about during the interviews. The lenses of narrative habitus and healthism combined now bring my focus to how storytellers relate to the powerful storyline of the benefits of physical activity for type 2 diabetes ('exercise as medicine') and related understandings about (individual) choice and responsibility for behaviour. More importantly, I reflect on what this storyline means to the storytellers and how it affects their daily lives or working practices related to physical activity, because in practice both people with type 2 diabetes and healthcare professionals have to search for a translation of this storyline that fits with their own experiences in a way that preferably also matches how they want to or feel they should relate to it.

Experiences of people with type 2 diabetes

The perception of exercise as 'medicine' permeated all stories told by people with type 2 diabetes, albeit in different ways. Some embraced it or had experiences that matched it. Others were disappointed because it did not match their embodied experiences, were annoyed because it was something they heard so often or felt they had to defend themselves during the interview for not being active (enough). Furthermore, there were also respondents who acknowledged the general perception but did not need this 'medicine' themselves or did not know how to integrate it in daily life.

Overall, almost all considered physical activity a useful means to manage blood glucose levels and postpone possible complications, including those who did not want to be (more) active despite healthcare advice. In other words, although the latter seemed to subscribe to the message on a general level, it did not correspond to their own daily life-informed understandings, experiences and wishes (Wiest et al., 2015; Malcolm, 2017). Since the promise of exercise is strongly related to control over diabetes and thus feeling well, at least in theory, it might be questionable whether it is possible to resist this in an interview setting or in a consultation with a healthcare professional. However, this might make the translation of healthcare advice into daily life understandings and practices even more difficult and an even more individual search. Therefore, I argue that more attention is needed to the mismatch between theory and embodied experiences, feelings of stigmatisation and negative care experiences by not being seen as a person.

Mismatch between theory and embodied experiences

The storylines presented in Chapter 6 showed that some of the respondents were more convinced of their approach than others—for instance, because the immediate results of their lifestyle were positive and matched with how they wanted to live (Ms Borst, Mr Postma), or they found another (religious) moral claim on how to live more important (Mr Tahiri). Other storylines illustrated difficulties with the translation of exercise as 'medicine' into (matching) daily life experiences and were accompanied by emotions, insecurities, incongruencies, despair, annoyance, chaos in chronology and tenses or unease during the interview (see Research reflection 9.1).

Importantly, these stories were about embodied experiences; many respondents described a time after diagnosis in which they searched for the right type and amount of medication in combination with lifestyle adjustments as a phase of adjusting to bodily experiences or measurable blood glucose levels, resulting in a new balance where diabetes was always there but not as a real impediment (i.e., liveable and incorporated in daily life). However, others did not find this balance or experienced a disruption of an earlier found balance. These experiences impacted their stories and how they related to the dominant discourse at the moment of storytelling. This was clearly illustrated by the different stories of Ms Borst (Intermezzo II) and Ms Hoekstra (Intermezzo III).

Interestingly, by being directly measurable, diabetes lends itself to this embodied storytelling. It offers a numbered, embodied result of physical activity combined with dietary actions and medication in a different combination for each person, as the variety in stories illustrates. However, the result of physical activity on blood glucose levels was not always as expected based on the general messages illustrated in the prologue of this dissertation and several experiences presented in Chapter 6. For instance, Ms Borst needed a specific type of workout, as did Ms Hoekstra, who was already active all day during her work as a caregiver and mentioned that 'sitting is out of the question'. Ms Mulder had times when she did not experience effects of physical activity at all, and Mr Jansen resigned himself to the idea of losing his health and pancreatic function despite being very sporty. As such, the embodied results did not necessarily match the promise of exercise. This realisation, which clearly counters mainstream ideas, seemed to leave these storytellers with (extra) feelings of loneliness because they could not fulfil the ideal of self-management by being (more) active and doubted this ideal. In the experience of Mr Jansen, ‘in the end, nobody knows’ how active he should or could be, meaning he had to sort this out for himself.

Research reflection 9.1
As a researcher, I not only noticed these difficulties during the conversation but also, or maybe especially, when I wrote an account to return to the respondent. This account served as a ‘member check’, but also to provide the respondent with insight into how I understood his or her story and offer an outsider reflection on this. In this account, I tried to retell the story in a way that reflected the story told but was also respectful towards and readable for the teller based on my judgement as a researcher and individual living in the same society (but with a different social location). I found this more difficult or paid more attention to careful phrasing and reflection as well as deliberation with my supervisor(s) for people who encountered difficulties in their life with diabetes (see also Chapter 7).

Feelings of stigmatisation
Moreover, in these individual experiences, another more hidden implication of the perception that exercise is a ‘medicine’ was present, namely the translation into the idea that a lack of physical activity (whether or not combined with certain dietary habits) was the cause of the type 2 diagnosis. This also had to do with differences between type 1 and type 2 diabetes and the difficulty that these are not always easy to distinguish, as Anja’s story in Chapter 7 illustrates. This was something I also encountered more than once when I presented my work to healthcare professionals. For instance, when I presented the story of Ms Mulder, who could not (self-)control her diabetes during her period despite being sporty and eating healthy, their immediate reaction was to say that she must have type 1 diabetes. When I said that she was diagnosed with type 2 diabetes, they countered that it must be LADA, which is a slow form of type 1 diabetes that develops later in adulthood and might be mistakenly diagnosed as type 2.

Although these reactions based on professional experiences and clinical eyes might be accurate, they also reinforce a dominant and difficult image of people with type 2 diabetes, which is something that Mr Jansen in particular was quite angry about. By attributing the diagnosis to an inactive or unhealthy lifestyle, personal responsibility and blame of being diagnosed in the first place resound; this is an image type 1 diabetes and LADA do not have. Moreover, this image also suggests that lifestyle is the preferable 'medicine' for type 2 diabetes. As the annoyance, defence or vagueness about actual behaviour during the interviews illustrated, this is something the respondents were probably aware of, hence their subscription to the general perception of 'exercise as medicine' on a general level.

In addition, this image leaves little room for (bad) luck, such as that related to differences in upbringing and living circumstances that impact sport and physical activity behaviour (e.g., Kraaykamp et al., 2012; Oude Groeninger et al., 2019; van Stam & van den Dool, 2020) or what health means to individuals (Stronks et al., 2018). It also does not include individual differences in metabolic processes of dealing with blood glucose underlying type 2 diabetes (Zeevi et al., 2015; Mendes-Soares et al., 2019) or the amounts and workings of body fat underlying body weight (Boon & van Rossum, 2019). Moreover, this image does not take into account the intersections of multiple inequalities within this complex whole (e.g., Stuij et al., 2020a).

The (taken for granted) emphasis on individual responsibility for behaviour in the evidence-based understanding of 'exercise as medicine' makes underlying differences in physical, social and economic conditions 'fade into the background as cultural noise (...) outside the practitioners' scope of practice' because it is considered a 'non-modifiable risk factor' (Cairney et al., 2018, p. 392; see also Wiest et al., 2015). Several storylines presented in Chapter 6 countered this ideal of the individual ability to take responsibility and resulted in exercise as a necessity impossible to integrate in daily life (Ms Hoekstra, Mr Martens) or not working as promised (Ms Mulder). These experiences even further emphasised the storytellers' own responsibility, because they did not experience adequate professional support and seemed to feel left to their own devices.

Negative care experiences: (not) being seen as a person

Most respondents told about rather negative care experiences related to physical activity counselling and treatment. As argued in Chapter 6, these might result from the organisation of the diabetes medical environment with its focus on protocols, measurable parameters and self-management support, as well as the limited time and financial frames. For instance, Ms Hoekstra (Intermezzo III) did not dare ask for help from her internist in including more exercise in her stressful life, because she experienced the 10 or 15 minutes consultations four times a year as too little to address her daily life struggles. Additionally, Mr Martens' health insurance did not cover his need for long-term dietary support, and Mr Evers pointed to the need of support in the gym but seemed unsure about where to get this.

However, there is another layer in these experiences summarised by the experience of Mr Cohen of being 'just another person with diabetes' for his healthcare professionals. This refers to a certain image of ‘persons with diabetes’ and illustrates a wish to be seen as an individual person. For instance, in the conversations Ms Borst and Ms Mulder held with their professionals, physical activity was not a topic, although both wanted it to be. The annoyance and irritation of Ms Sital and Mr Hendriks about physical activity as a topic of healthcare counselling also illustrates that they did not experience this counselling as matching their wishes. Furthermore, Ms Dekker (Anja in Chapter 7) gave up on asking for help because she had overall negative experiences.

I remember two respondents being positive about their healthcare professionals’ help despite their feeling they were not able to gain control over their diabetes at that moment. These experiences were not presented in Chapter 6, because they were not about physical activity—a topic that was not needed or fitting as part of their conversations in care. When I met Ms Vonk, she had a great deal of stress because her health problems led to troubles with her employer, which impacted her diabetes again. Although her internist was not able to help her with this, Ms Vonk experienced him listening to her and acknowledging her difficulties. Similarly, Ms Mohan was satisfied with her healthcare professionals, because they paid attention to all her troubles: no job, many health problems and an ill mother. Both also had significant others (partner, family members) who offered them a listening ear.

These positive experiences point towards the importance of listening as an aspect in itself. However, listening and paying attention to individual experiences requires time, which is not necessarily easy to realise inside the framework of type 2 diabetes care. In addition, it also requires genuine attention, empathy and curiosity to learn what is ‘behind’ someone’s diabetes (and body weight, see Stuij et al., 2020b) and get to know and understand a person. I return to these elements later in this chapter.

Experiences of healthcare professionals

Most of the professionals in Chapter 5 experienced physical activity as a ‘tricky’ foundation of type 2 diabetes care, which is a tension that illustrates both the importance and the difficulties professionals experience in providing physical activity counselling or treatment. Two underlying tensions came to the fore in these professionals’ stories. The first were difficulties in understanding patients’ lifestyle behaviour or choices, especially when these did not match the prescribed lifestyles. The second encompassed professional views on responsibilities of both patients and themselves when it comes to the topic of behaviour change. These resulted in dilemmas related to questions like who is responsible for behaviour and behaviour change, what are and are not professionals’ responsibilities and how far do these responsibilities go? Professionals expressed different and ambivalent feelings about these dilemmas.

Professionals experience their own task of counselling patients so they become more active as unrealistic: it is ‘an utopian dream to think you have it fixed in twelve weeks’, a physiotherapist mentioned. This was also related to the organisation of care with a low frequency of appointments, limited timeframes, an emphasis on protocols and administration or high demands of insurance companies. The internist stated, ‘I’ve only ten minutes and more to discuss.’ This is where the mismatch between the system world underlying the organisation of care and the lifeworld of their patients’ needs and difficulties became palpable to professionals since they have a one-to-one relation with each patient, resulting in doubts or ideas about when it is time ‘to let someone go’ and leave the responsibility for physical activity behaviour to the patient because counselling does not work out.

As a result, while professionals considered behavioural change a patient responsibility in the end, they also experienced it as an unrealistic expectation (cf. Jallinoja et al., 2007). Certain professional experiences made patients’ understanding and questions about responsibilities more difficult. Below, I argue that these are also related to professionals’ own (personal) health-related ideas, experiences and behaviours. Moreover, the complex professional experiences with physical activity as an aspect of type 2 diabetes care might lead to categorisation of patients, a complicated professional legitimisation for physiotherapists and a loss of professional motivation.

Recognition of the presence of professionals’ personal experiences in care provision

Professionals’ own experiences with and ideas about physical activity represented elements like intrinsic motivation in being active (fun), participation in specific sports and activities that are taken for granted. They also mentioned embodied experiences, such as effects of physical activity on the body (fatigue, relaxation), missing these effects when not active because of injuries or other priorities or effects of getting used to new activities (muscle aches). Since some of these experiences made understanding patient difficulties more or less easy, these experiences might make physical activity a more personal topic in healthcare than others such as use of medication.

As argued in Chapter 5, professionals’ experienced tensions related to responsibilities and understanding of patient behaviour seemed greater when the professionals’ own physical activity behaviour and opinions on healthy living differed more from those of their patients. This was especially related to ‘priority’; professionals’ perceived patients to give low priorities to being active by choosing for ‘drinking coffee with the neighbour instead of being at a training’ or ‘buying a large flat screen television instead of paying for sport’. While professionals realised that considering these choices as a ‘low’ priority was their own point of view (‘what is a legitimate reason?’), it was clear that they would have prioritised things differently. Although professionals also mentioned different living circumstances from many of their patients, these differences in priorities seemed to hinder professionals in understanding the lifeworld of their patients.

Risk of professional categorisation

Healthcare professionals discussed their work experiences in a more general way, namely based on comparable stories they hear from many patients and how they as professionals act upon and think about these. This also resulted in generalisations. Sarah (practice nurse) described 'two categories of people', separating those who 'sit behind the wheel, who want to have control over their life, and [take] their own responsibility' from those 'who sit in the back of the bus and let themselves be driven, who let it happen'.

Others divided those 'in the back of the bus' into two groups: people who could not become more active because of other (health-related, economic or social) circumstances and people who did not want to be more active, which even after years of conversations about the topic and with the patient incentive of maintaining a certain quality of life, is something Willem (internist) found 'very special', which seemed to be a polite way of saying that he did not understand it. This distinction between 'could not' and 'want not' is based on an estimation a professional makes founded on the conversations with a single patient. However, it is also based on conversations the professional has with other patients, such as those with what seem to be similar living circumstances and whose storylines echo in the story a patient tells.

In addition, this distinction is probably based on the dominant societal emphasis on individual responsibility for (physical activity) behaviour, because this is a storyline that results in a group of people who take this responsibility and a group who do not—as a rational and autonomous choice. Although this categorisation might be helpful and accurate at times, there is a great risk of bias and quick judgement that can lead to an illusion of understanding and selective listening (Murphy, 2020). Hearing the same storylines over and over again of people who cannot or do not want to be more active might make it difficult to be open to (new) patient stories and to stay curious about what is behind each of them.

Moreover, ideas about health are found to differ between socioeconomic status groups and are related to the actual circumstances in which people live, including higher risks of health problems (Stronks et al., 2018). The study by Stronks and colleagues (2018) highlights different attitudes towards health, with those from the higher social strata having a more pro-active attitude while people from the intermediate or lower strata having a more accepting attitude towards life and what it brings. These different attitudes were also felt and acknowledged by healthcare professionals (Chapter 5) and people with type 2 diabetes (Chapter 6). It seems important to make those intersections and inequalities more explicit in discussions about how to provide ‘good’ physical activity care, which is care adjusted to each particular situation (Mol, 2006).

Complicated professional legitimisation for physiotherapists

Another important distinction to make is between professionals who provide physical activity counselling by discussing the topic with their patients and physiotherapists who offer actual training. The latter seemed to experience more difficulties in understanding their (inactive) patients as illustrated by their bold statements about ‘those people [who] have a totally different approach on how to keep your body healthy’. Some possible explanations were already provided in Chapter 5, such as their personal interest in sport and physical activity, the temporary care they offer with a sole focus on physical activity, the exercise ‘bubble’ of the treatment context versus the invisible ‘battle’ patients experience at home (Danielsen et al., 2015) and a professional shift in the past decades from ‘fixing’ patients to guiding them in a process of behaviour change.

However, the concept of narrative habitus adds another layer to this. Physiotherapists have a strategic interest in the ‘exercise is medicine’ storyline, because it offers them an extra legitimation of their profession, especially to enhance their position as paramedics in their difficult negotiations with healthcare insurers about contracts, costs and reimbursements (NZa, 2019; KNGF, 2018a; see also KNGF, 2018b). Moreover, they have to position themselves in a field with all kinds of sports providers, interventions, voluntary walking initiatives, subsidised exercise programmes and the recently entered lifestyle coaches. As such, physiotherapists have more to gain with a story about successful physical activity care for people with type 2 diabetes compared to other healthcare professionals who also have other topics to turn to. A successful story on exercise as a ‘medicine’ offers physiotherapists a possibility to reunite themselves as a group of professionals and create more negotiating space on a policy level. However, their experiences with ‘administering’ exercise as a ‘medicine’ in practice—both in contact with their patients as within defined time and financial frames—do not seem to match. The interview setting for this study might have been a place for them to vent their frustration about this tension (see Research reflection 9.2).

Research reflection 9.2
My relative 'outsider' position as an interviewer (see Chapter 1) offered me certain advantages during the conversations with both healthcare professionals and people with diabetes. I only met them once and promised not to use their name or other reducible characteristics in accounts or reports. Except for some general topics I asked about, I had no specific interests (e.g., regarding the answers) and asked open-ended questions. I was just curious about their experiences, which I let them know and which they wanted to discuss. I also told them I had the time to listen by having no other appointments afterwards. I used different ways to ask questions (see Chapters 5 and 6), which offered the respondent the possibility to reflect on the topic in different ways, which many of them appreciated.

Loss of professional motivation: fatigue

Although low patient motivation for the uptake of (more) physical activity is a frequent topic of worry and discussion, the findings presented in this dissertation also point towards a risk of decreasing professional motivation for physical activity counselling. The phrase 'flogging a dead horse' ('*trekken aan een dood paard'* in Dutch) was one I frequently heard professionals say in this context. Other studies also indicated a lack of reimbursement—that is, seeing actual results of professional efforts to increase patient physical activity—as an important barrier for lifestyle counselling (Jansink et al., 2010; Hébert et al., 2012; Rushfort et al., 2016).

The difficulties described in this chapter so far, as well as those described in Chapters 5 and 6, make physical activity a difficult topic in type 2 diabetes care for both professionals and their patients. In particular, the professionals with more years of work experience like Sarah, Marjolein, Willem and Krista described their learning process over time: they learned that patient behaviour was not their responsibility. This indicates that they approached this differently before, and they now experience a certain 'fatigue'. Willem mentioned the importance of 'what's in it for me?' as a professional as something important to stay motivated.

Therefore, more attention to professional wellbeing is needed to improve professionals' working lives. Similar to 'self-perceived' patient health, it would be interesting to explore 'self-perceived working health' for professionals, at least related to the topic of physical activity care or broader lifestyle counselling. Does better experienced working health result in more pleasure in work or less absence? How can this working health be improved? In the remainder of this chapter, I provide some suggestions for further exploration and discussion.

Concluding comments

As the empirical studies illustrated, both people with diabetes and healthcare professionals have to relate to a general perception of exercise as ‘medicine’ that they do not necessarily experience as working in practice. Professionals see it working for some of their patients, but not all. The stories of people with diabetes display a wide variation in effects of physical activity, adding nuances and resistance to the general message. Overall, the dominant underlying storyline on responsibility and choice for physical activity behaviour as having a prominent place in the narrative habitus or inner library of all respondents clearly affected their living and working experiences. As such, while the perception of exercise as ‘medicine’ provides attention to physical activity as an important aspect of type 2 diabetes care, it also might have unintended negative effects and lead to a further stigmatisation of people with diabetes.

Within this dominant storyline, physical activity has an instrumental purpose, namely as a means to establish and maintain control over diabetes. However, this does not do justice to the experiences of those involved at this micro-level. Not only people with type 2 diabetes apply a broader range of meanings but also professionals cannot approach physical activity only from an instrumental point of view because of what they hear from their patients and because of their own experiences and opinions. Since this is something patients and professionals now have to deal with themselves, a broader recognition of these difficulties is needed to improve (working) lives.

The current physical activity care repertoire mainly consists of information provision, discussion of the topic and temporary training. When this type of care does not work, the organisation of type 2 diabetes care seems insufficient to offer another approach. The findings in this study illustrate that both people with diabetes and healthcare professionals experience that knowing *what* to do does not necessarily equal knowing *how* to do it in this given context (see also WRR, 2017). Since self-management practices are proposed to be ‘contextual, unlimited, and changeable’ (Rosenbek Minet et al., 2011), care practice should also have those characteristics. It is therefore interesting to now focus on what a change of context and boundaries might bring.

2) What can <u>openings</u> created by extended talking and walking practices add to an improvement of physical activity care?

Chapters 7 and 8 presented two examples of a change of context (and people), providing room and more time for talking and walking. Chapter 7 is about extended talking practices, and presents an analysis of my prolonged interaction with Anja, one of the interview respondents. She was diagnosed with type 2 diabetes twelve years earlier, and wanted to take part in the interview study because she had just decided to quit horseback riding. We kept in touch over a period of more than five years, resulting in her involvement in writing Chapter 7. Chapter 8 presents an analysis of extended walking practices of two nurses who organised walking groups for their patients over a period of 20 weeks. I participated in both groups and observed what happened.

In the empirical chapters, we analysed the implications of these examples separately. Here I consider them together to focus on common underlying elements. To see what these examples might add to a further improvement of physical activity care practices, I use logic of care as a lens. This brings a focus on understanding and formulating important underlying specifics of care practices, especially those that improve care (Mol, 2006). Moreover, this logic has a focus on 'good' care, which has a normative perspective in defining what is 'good' as dependent on the situation and people involved. In this logic, the aim is to improve the lives of patients.

Needs to improve care

These two extended talking and walking practices were prompted by a need to improve care as provided until then, and both illustrated shortcomings of a logic of choice as a common underlying way of thinking. In this logic, the patient is considered the one responsible for choices, such as those related to physical activity behaviour and illness management (Mol, 2006).

This feeling of responsibility was clearly visible in the experiences Anja related during the first interview (Chapter 7); she collected and read all information available, made her own decisions (to switch to insulin, for instance) and measured the impact of her actions on her blood glucose in a systematic way. However, at that moment, there was a mismatch between the diabetes requirements and her main aim to live a 'good' life, which she defined as an active life, with pleasure and sufficient freedom to do what she wanted. Throughout her story, feelings of loss of several elements, like loss of fun, physical abilities and feelings of youth, indicated that her actions to take responsibility were no longer sufficient to meet this aim.

Similarly, the care repertoire of the nurses in Chapter 8 before they took part in the walking challenge mostly consisted of providing their patients with information or discussing the possibilities to integrate more physical activity in their life. Although one of the nurses already facilitated a small walking group, they both felt the need to do something more for their patients and were interested in this new approach. They seemed to have an intrinsic motivation to participate in this walking challenge, because the project demanded substantial organisational efforts from the nurses in getting and keeping patients involved, doing practical work for the realisation of the walks, organising support from colleagues and making large personal spare time investments.

Care in motion

The aim of an articulation of a logic of care is to give words to or specify what ‘good’ care practices entail (Mol, 2006). Interestingly, both examples brought about an element of movement that seemed important—at this point, the Dutch word for physical activity, *bewegen*, would have captured what happened. This movement was brought about by (accidentally) providing space for storytelling and the introduction of new or other stories. The example of extended talking brought movement in a story, and the example of extended walking brought not only physical movement but also movement in relationships and responsibilities. There seemed to be several underlying elements in both cases, like the availability of time and attention, a change of context and (partly) people. These provided a context to foreground dynamics and relationality in care practices.

A core element of what happened might be a shift in responsibility because of commitments those involved took on. Anja attached much importance to her own responsibility in living a good life with diabetes, an attitude she was not really aware of, but did not work well at the moment of the first interview. Her request for help in the unusual setting the interview provided, the emotional appeal she made and my commitment to try to offer her something more than an opportunity to tell her story resulted in a relational process in which Anja felt heard. In this process, I did not share my personal story, but used stories or narratives from research on how people may act or respond when they are ill (Frank, 1995), including a more critical reflection on these, to exchange with Anja’s story. I committed to this process because I felt a responsibility to respond to her request (see Research reflection 9.3).

The two nurses who started a walking group also committed themselves to a process, and they probably experienced this commitment differently than they did in ‘normal’ care—for instance, because they were enthusiastic and motivated at the beginning, got to know their patients in a different way over time (‘outside the patient mode’) and noticed social and physical effects of the walking groups for their patients. In this process of weekly walking together, individual patient responsibility for physical activity became a responsibility shared with the nurse and other participants. The mutual exchange of stories during the walks and getting to know each other better beyond the patient-professional divide further enhanced their commitment—for instance, by bringing elements of fun (in being active, in providing care), challenge (to keep coming, to keep organising) and newness (a new activity, including different people and a new professional role).

In both practices, the promise of physical activity as something valuable was present, offering encouraging openings for existing practices. In Anja’s story, this resulted from recognising her feelings of loss and pain and providing another view on her yoga practices—something she initially did not like but learned to value differently over time. Importantly, this was not a predetermined purpose of our conversations. In the walking groups, becoming active was the starting point, but the social discipline the participants created together became an important motivation to keep coming. This was best illustrated by a small group continuing the walks after the project, which they still did at least till two years later. Additionally, both nurses were still involved in organising walking groups then, albeit more in cooperation with other professionals in the neighbourhood. In this sense, they also learned to share their professional responsibility.

Research reflection 9.3

Overall, the stories I found most moving or poignant were those in which the teller did not feel well and there seemed to be nobody around to help or just listen in either the private or the healthcare setting. These stories left me with an impression of loneliness. For some respondents (like Ms Hoekstra, Ms Mulder and Anja in Chapter 7), the interview setting seemed to offer them an opportunity to be listened to, albeit by an unknown person. This might also have resulted in an even stronger emphasis I placed on the importance of storytelling, listening and social support throughout this study.

Concluding comments

The extended walking and talking practices presented in this dissertation offer space for more spontaneous and informal interaction, resulting in more time for listening and sharing stories. This was something the nurses organising the walking groups enjoyed and valued for their professional development. Inside the consultation room, the type 2 diabetes care framework is generally very much defined in terms of protocols, time, hierarchy and a division of roles. These are acknowledged by both professionals and patients and are useful when they work. However, breaking through those structures might be necessary when care practices ‘get stuck’ and when those involved do not know what to do next or how to do it.

The underlying elements in these two examples were related to a change in responsibility and in commitment, namely a commitment to something new, providing space to ‘let stories breathe’ (Frank, 2010). Those elements also brought more room for a better understanding of daily difficulties of living with diabetes. In sum, both examples showed that physical activity care might benefit from a more playful handling of system and lifeworld dynamics. Additionally, they indicate that professional motivation and feelings of responsibility are important driving forces for a further improvement of physical activity care—something that should be recognised by providing professionals with (paid) time, autonomy and confidence.

These extended talking and walking practices are not *the* answers to improve physical activity care, because they do not match the needs of *all* patients and possibilities or wishes of *all* professionals. However, they do provide valuable options to broaden the prevailing care repertoire and the available narrative maps. Nonetheless, these openings are still located at the level of patient-professional relations and practices, which means that the responsibility for physical activity (care) still remains a patient-professional responsibility, albeit somewhat differently shared. While meaningful, this also implies more responsibility for the professional, and this is still very difficult when the broader context does not change. This is why I now offer a more critical reflection on the context.

3) How can the broader socio-political, research and healthcare context further support an improvement of physical activity care for people with type 2 diabetes?

Although the institutional context—the organisation of type 2 diabetes care—and the broader socio-political and research context are interdependent, I reflect on the implications of the study findings for these contexts separately.

Organisation of type 2 diabetes care

In Intermezzo I, I presented some observations and reflections on tensions in current type 2 diabetes consultations. These mainly centred on a focus on numbers versus a focus on the human beings behind these numbers. For instance, these tensions were visible in difficult translations of abstract medical terms (‘HbA1c’) into practical daily life consequences, contradictions between (positive) lab results and (negative) physical complaints and the sometimes difficult task of professionals to estimate whether a patient understands the information received about type 2 diabetes or is actually as active as he or she indicates.

Exactly this tension and the resulting difficulties to help or motivate patients to change their lifestyle behaviour within the current care framework seemed the main motivation for a group of practice nurses and the care group to which they belonged to organise training days on a new approach in care provision in late 2015, as described in Chapter 4. This encompassed a shift from care oriented towards illness and care (or *Ziekte en Zorg*, ZZ, in Dutch) towards care more focussed on health and behaviour (*Gezondheid en Gedrag*, GG). By applying this new approach in practice through asking other questions, leaving ‘the solution’ to the patient and taking patient experiences as a starting point for care, these practice nurses would be better equipped to help their patients function well in their daily lives.

Although this GG approach was received with enthusiasm, it was also met with questions and objections (see also Bendien & van Dorp, 2018). These mainly had to do with a clash between the system world aimed at objective numbers that underlies type 2 diabetes care protocols and the wish to better adapt care to the lifeworld experiences of patients—a clash that has already emerged in this general discussion. To focus on implications of the studies in this dissertation for the organisation of type 2 diabetes care, I now use the lens of system and lifeworld (Habermas, 1984). This lens especially urges one to make contrasts: healthcare versus daily life, ZZ versus GG and objectivity of numbers versus subjectivity of experiences. Although these are simplifications of complex realities, they are helpful to understand why these contrasting worlds might not work well together, such as when it comes to the presence of a lifeworld topic of physical activity in a system world like type 2 diabetes care (see Research reflection 9.4). I now provide some reflections on possibilities for mixing those worlds, including three starting points interesting for future exploration and discussion.

Research reflection 9.4

I constructed certain contrasts as well, such as by providing people with diabetes with last names as a pseudonym but professionals with first names. This was something I only really noticed afterwards, and it probably illustrates a distance I felt between myself as a professional presenting others' personal life experiences or others' professional working experiences.

Moreover, I created a contrast by emphasising social class differences between people with diabetes and healthcare professionals throughout this dissertation. In individual patient-professional relations, these differences are not always present, nor do they have to be problematic. In addition, differences (and resulting power relations) between patients and professionals are also important for (many) other aspects of identity, such as gender, ethnicity and age.

However, social class differences are generally considered more uncomfortable and difficult to discuss or acknowledge in the Netherlands compared to other aspects of identity (e.g., van Eijk, 2013), or these differences are enlarged by the use of names like '*Henk & Ingrid*' or '*Tokkies*', who are proposed to exemplify certain social strata. Although concepts representing socioeconomic status like educational and income level are very common in policy, media and research, these are only a small operationalisation of social class and ignore how and to what extent people experience, construct and reproduce social class differences in relation to others (van Eijk, 2013). As illustrated throughout this dissertation, a broader and more in-depth understanding of social class in relation to lifestyle differences, might help to further improve physical activity care for people with type 2 diabetes.

Bringing lifeworlds into physical activity care: on better listening

As argued in Chapter 1, the general introduction, the focus on physical activity in (type 2 diabetes) care is a form of medicalisation of an everyday activity, which is made very explicit in the 'exercise is medicine' slogan. As a result, physical activity has a predominantly instrumental purpose in type 2 diabetes care. Consequently, it is stripped of other possible meanings, at least in the intention of making it a healthcare topic (cf. Chapter 3). This is illustrated by the required check in the patient file after a professional assessment of whether or not a patient conforms to the physical activity guidelines (see Intermezzo I).

This check in the patient file makes physical activity also a required and repeated topic of care, in terms of how much someone does and how intensive this is. As such, both professionals and patients acknowledge these questions as legitimate to ask. However, this approach also results in behaviour for which patients feel they are being held accountable, as the experiences of Ms Sital, Mr Hendriks and Mr Evers in Chapter 6 illustrated. The latter was unsure if he was active enough despite the reassurance of his diabetes nurse. The other two were clearly annoyed or irritated by the steady stream of messages on physical activity and other lifestyle behaviours from their healthcare professionals, and the questions of the interviewer.

To include lifeworld aspects in physical activity care requires a move beyond the biomedical aspects of physical activity in relation to type 2 diabetes (Gillet et al., 2002) towards genuine attention to all kinds of meanings attached to and experiences with physical activity. The storylines in Chapter 6 already revealed some other meanings, including related emotions such as pleasure and enjoyment because of performance or taking part in competition or pain because of loss of former activities and physical abilities. To pay genuine attention requires listening, and this is something more than asking questions and hearing the answers.

Good listening is about determining why a person—a patient—is saying certain things, which is something he or she might not even know (Murphy, 2020). According to Murphy (2020) in her book on (not) listening, to understand this, a listener not only needs to pay attention to what someone says but also to how and in what context it is said. This resonates with the ingredients of the narrative approach applied in this dissertation and with the research reflections provided in this final chapter. Murphy also added that it is important to pay attention to how a story resonates with oneself as a listener, because that has much to do with how one responds and one's ability to 'crystallise [one's] own thoughts' (Murphy, 2020).

To take listening more seriously inside the care framework requires changes, as was also illustrated during the training days of practice nurses (Chapter 4). First, paying more attention to how to listen requires sufficient attention in professional education about how to listen. Second, to provide professionals with more room for listening, they need more time in consultations as well as the feeling that listening is important to spent time on. Third, to give room for the actual outcomes of listening requires an even greater change. Since these outcomes might be different than those matching treatment advice or protocols, listening might be a tense activity and create tension with the demands of the system world. Therefore, space is needed, with more trust in professional capacities and better outcomes aimed at improvement of patients' lives.

Dealing with the system world in lifeworld-led care: towards context-based practice

Although this is a plea for more lifeworld-led physical activity care for people with type 2 diabetes, it is important to mention that the system world is not a bad thing by definition. On the contrary, because of the current organisation of type 2 diabetes care, it is found to be of very high quality (Garrrofé et al., 2014) or 'the best care in the world' according to the experienced internist quoted in Intermezzo I. Moreover, since the extended walking practices described in Chapter 8 required much (private) effort from the nurses, the boundaries of the consultation room also offer professionals protection, especially in terms of time expenditure, but possibly also in terms of keeping a personal-professional distance.

This organisation of care is great when it works well for a patient. I remember a respondent telling me that he had to get used to his internist who filled the 10-minute consultations by stating the lab results and focussing on adjustments in medication while only looking at his computer screen. After a while, the respondent was accustomed to this and knew what he would and would not 'get' from these consultations, and he was fine with it, because it worked for him and he was able to find other support—for instance, related to how to practice sport—in his social network. However, when it does not work, as the stories of Ms Hoekstra (Intermezzo III) and others illustrate, the system world leaves very little time and room for other approaches.

One such other approach is the organisation of walking groups led by (healthcare) professionals. Although this is not a completely new form of care, it is now facilitated and organised on a more national scale by the National Diabetes Challenge with almost 4,700 people walking in 2019 from 216 locations and promising effects on the wellbeing of participants (Regeer et al., 2018; VZinfo, 2020). This large scale illustrates a need of healthcare professionals to offer another type of (physical activity) care. However, this is a project that also challenges diabetes care—both its provision and providers—and was (and still is) difficult to integrate in the system world organisation to provide healthcare professionals with (paid) time for the organisation.

To better integrate this project in the healthcare context, the *Bas van de Goor Foundation* puts in much efforts to comply with the system world requirements regarding evidence and effectivity. They conduct large scale research with validated surveys, physical measurements and step counters, managed to get the label ‘well described’ in a national database, but still aim to get the label most valuable in the system world, namely ‘effective’— something they experience to be very difficult, because the walking groups are organised at more than 200 locations and adapted to the local context (Bas van de Goor Foundation, 2019; personal communication with the Bas van de Goor Foundation).

As the Council of Public Health & Society already noticed, the high requirements on evidence are often not compatible with the reality of healthcare practice (RVS, 2017). As a result, the organisation of walking groups is now very much dependent on (single) professionals who have extra drive and energy to improve care on top of their usual workload, as is the collection of evidence on its effectiveness. To better integrate lifeworld-led care in the organisation of type 2 diabetes care requires a more general revaluation of what counts as evidence and what is considered ‘good’ care. Since ‘good’ care is by definition context-dependent, context-based practice might be an interesting starting point for discussion (RVS, 2017; see Research reflection 9.5).

Research reflection 9.5

Similarly, as a researcher I also felt confronted with tensions between the lifeworld and system world at times. From a narrative perspective, my aim was to pay attention to each individual story and to do justice towards each story in the presentation. However, this was not easy to combine with the existing frames—for instance, the word limit or the prescribed structure of a journal paper—and more general expectations on what research produces and what ‘good’ research is.

Regarding those expectations, I felt those tensions between the lifeworld and system world both within and outside the research setting. For example, within the academic setting, one of the peer reviewers of Chapter 6 considered our sample of 18 people ‘quite small for a major qualitative study’. This seems to resonate with general perceptions about qualitative research with ‘small’ sample sizes being ‘exploratory’ or ‘pilot’ studies instead of studies on their own. Indeed, from our narrative and lifeworld point of view we considered our sample quite large to present in one paper, searching for a balance between presenting respondents’ individual daily life complexities within a limited number of overall storylines. Moreover, the time consuming process of data collection, writing a storied account to send back to each respondent and the in-depth analysis both on the level of the individual stories and all stories together seems easily overlooked in such a remark.

Outside the academic setting, I was frequently asked for ‘concrete’ answers, themes or outcomes, and especially a ‘what to do now’ with those answers—for instance, in practice. As such, I often felt considered to be an expert who, from an instrumental point of view, helps to fix things or make problems manageable. For me, this exemplifies

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a general tension between a wish to make daily life experiences as simple and compact as possible and hence manageable in care (and research) versus providing room for all kinds of ins and outs, difficulties, and subtleties. This was summarised well by a journalist writing about my study saying that all those nuances I wanted to add were not easy to read.

Dynamics in the in-between: towards normative professionalisation

Until this point, I used the system and lifeworld lens to reflect on tensions between the 'objective' healthcare system and the 'subjective' patient lifeworlds. However, the findings in Chapters 5, 6 and 8 also highlighted the presence of the professional lifeworld in physical activity care, at least the part containing 'personal' sport and physical activity biographies and ideas on healthy living and corresponding responsibilities. Sometimes these lifeworld experiences were made explicit in care relations, as nicely illustrated by Nicole's action of sharing her body weight and step counter data with the participants of her walking group (Chapter 8).

These professional lifeworld experiences seemed helpful when they resembled patient difficulties (cf. Fox et al., 2009 on doctors who have been patients themselves). However, they seemed more frustrating when they opposed patient experiences. An extreme illustration was provided by the irritation of two physiotherapists in Chapter 5, but other healthcare professionals had difficulties really understanding the (inactive) behaviour of their patients. This provided the starting point for a small implementation project described in Intermezzo IV. During this project, I regularly met with a group of healthcare professionals, and we reflected on and exchanged our own sport and physical activity biographies, explicitly including the meanings of those activities. This resulted in very open and sometimes eye-opening conversations and realisations about the possible impact of these experiences on professionals' attitudes towards and conversations with patients.

Using professional sport and physical activity biographies does not imply that professionals need to make these meanings explicit to their patients. However, awareness of their own assumptions might help professionals gain more insight into frictions and possible prejudices. Because of the dominance of 'exercise is medicine' or 'sport is good for health' perceptions and the emphasis on individual responsibility, it might take some effort to critically question personal assumptions and to understand (different) patient positions. As such, this requires professionals to reflect on their own (embodied) experiences, ideas, values and interests related to physical activity and health, including the contexts in which they grew up and currently live.

In line with this, normative professionalisation might be worthwhile for further exploration. While too comprehensive to explain here, this discourse builds on the normativity that is inherent in professional practices and shaped in each practice again (van Ewijk, 2013). This resonates with the premises of ‘good’ care (Mol, 2006) and is clearly illustrated by the tensions and dilemmas healthcare professionals experience in providing physical activity care (Chapter 5). The system world leads to a de-personalisation and de-professionalisation of those involved by means of control and being held accountable for actions—something both professionals and patients experience due to the focus on numbers and protocols. A better acknowledgement of and continual reflection on the normativity of physical activity care practices, including a focus on further development through dialogue, might add to better care and do more justice to professional experience and expertise (van Ewijk, 2013; see also Jacobs et al., 2008; Kunneman, 2013; van Ewijk & Kunneman, 2013).

Navigation between those worlds: towards broader recognition and discussion

The most complicated part seems to be a confrontation between expectations of physical activity regarding control and manageability from a macro- or meso-level (especially research and (care) policy) and practical difficulties encompassing the complexity of daily life experiences at a micro-level. This confrontation is most visible in healthcare practices, which on paper follow the system world but in practice need to adapt to lifeworld difficulties. In between, there is the professional’s personal lifeworld, often hidden or forgotten because of the evidence-based and ‘objective’ world in which the professional works. To connect these different worlds and navigate between them is now mainly the task of a healthcare professional and each individual patient. To further improve physical activity care for people with type 2 diabetes, it is necessary to include other societal levels in a recognition of these difficulties and a discussion of how to better connect and navigate through these worlds.

Broader reflections on the socio-political and research context

I started writing this discussion in May 2020 when some measures of the Dutch ‘intelligent lockdown’ because of COVID-19 were eased. In the past few months, the main topics of this dissertation—healthcare and physical activity—have frequently been emphasised as ‘crucial’ for our society and for individual wellbeing. The first, obviously, belonged to one of the vital sectors continued during the lockdown. Regarding the second, the prime minister stated during a national press conference that ‘sport evidently [is] extremely important for our health, for all of us’, and the sport sector was one of the first to be partly opened again (Rijksoverheid, 2020).

This message was highlighted by several organisations or experts in the past months, stressing the importance of paying more attention to the benefits and effects of sport and physical activity for health as part of broader lifestyle behaviour (NILG, 2020; Trouw, 19 May 2020; Tweede Kamer, 25 June 2020; FD, 4 July 2020). A group of prominent people, mostly with a background in elite sport, garnered much attention in the media with their pamphlet entitled ‘Physical activity. The New Normal’ in which they stressed the importance of ‘seeing physical activity as a medicine’ and urged the government and ‘all other Dutchmen’ to use physical activity as a means to make our society more resilient, including against COVID-19 (De Volkskrant, 23 May 2020; see also Hall et al., 2020). In addition, people with type 2 diabetes as well as extremely overweight people are considered more at risk of becoming seriously ill when infected with COVID-19, including intensive care admission and death (RIVM, 2020). Therefore, there seems to be momentum for physical activity to be even more integrated in care for people with type 2 diabetes.

At the same time, COVID-19 increased certain tensions related to those topics of physical activity and healthcare. For instance, a recent survey of 3,000 nurses and caregivers gained much media attention because it showed the professionals’ frustration and disappointment with political support in terms of both salary and more general appreciation and it indicated that 39 per cent were considering a job outside the healthcare sector (NU’91, 26 June 2020). Furthermore, the SER, which is the most important governmental advisory board on socioeconomic issues, wrote an alarming report on the future durability of the Dutch care system given the increasing demands, especially because of a growing number of people with one or more chronic illnesses combined with an increasing shortage of healthcare professionals, which results in high workload and absence (SER, 2020). Moreover, social and economic inequalities, especially related to working and living circumstances, seem to have increased, with a yet-unknown long-term impact on health outcomes and sport participation, among other things (e.g., Douglas et al., 2020; Evans et al., 2020).

While these developments and issues are too recent to reflect on in this dissertation, it is important to have these developments in mind in a reflection on the socio-political and research context and foreground the critical approach of this study even more. I do so using the lens of healthism (Crawford, 1980) again. Importantly and as elaborated on in Chapter 6 and at the beginning of the current chapter, from this perspective, physical activity as ‘medicine’ is not merely a neutral and evidence-based message but an inherently normative one that results in ‘good’ and ‘bad’ physical activity behaviour as an individual responsibility (Wiest et al., 2015).

New policy developments: separating sport from physical activity

The study presented in Chapter 3 started from the observation that physical activity had been given a very prominent place in Dutch governmental health policy in 2012 as an important means to contribute to a more healthy society (Ministry of Health, Welfare and Sport, 2012). A close analysis of sport policy documents since the 1950s indicated how the further integration of health arguments in national sport policy had intended and unintended effects for the Dutch sport sector as well as for the definition of sport and sport participation—a process health researches also played a role in. This illustrated a move from policy aimed at an improvement of lifeworld-based sport experiences towards a more system world-fitting legible, simplified and rationalised approach to sport and especially physical activity.

Interestingly, in the *Nationaal Sportakkoord,* the current national sport agreement describing the ambitions until 2021, health only seems a minor argument for governmental interference in sport (VWS, 2018; Pulles et al., 2020). Sport and physical activity in relation to health now have a place in the *National Prevention Agreement,* the current prevention policy, especially within the focus on obesity (Ministry of Health, Welfare and Sport, 2019). Given the contemporary societal intertwinement of sport, physical activity and health, this is an interesting move and might be more difficult to relate to meso- and micro-level experiences.

Individual versus societal interests

With this prevention agreement, the current government made a shift from ‘lifestyle politics’ emphasising individual responsibility for health to a focus on ‘healthier people making healthier choices in a healthy environment’ (Ministry of Health, Welfare and Sport, 2019, p. 5). Although this is definitely a change of tone and a stronger focus on the condition and impact of the living environment instead of individual behaviour, traces of healthism are still there, albeit more hidden. Even if the ‘healthy’ choice is made the ‘easy’ choice as the current political climate favours, behaviour is still a matter of choice—something you ‘opt’ for. This is not necessarily problematic unless people are called to account for their choice of behaviour. This is something that happens as recently illustrated by a widely and fiercely debated quote from a Dutch journalist and presenter stating that the COVID-19 lockdown measures were too strict in order to save ‘a small group of old people who are too fat and smoked’, resulting in a great economic crisis (Omrôp Fryslan, 2020).

This debate illustrates a shortcoming of the still-dominant neoliberal emphasis and focus on individual behaviour, because it illustrates where individual choice conflicts with societal interests. While the latter are especially aimed at economic wellbeing, productivity and lowering healthcare costs, ‘individual choice’ presupposes ‘living a good life’ from an individual perspective and the freedom to fill this in accordingly. Therefore, it seems complicated to address people towards their individual responsibility when the actual interests underlying policy are societal ones (see Research reflection 9.6).

The broad variation in storylines on physical activity from people with type 2 diabetes presented in this dissertation also includes a broad variety of interpretations of a ‘good life’. Ms Borst and Ms Dekker wanted to be active and able to do the things they wanted with an emphasis on pleasure. Ms Hoekstra, Mr Martens and Ms Mohan hoped for balance in their life with diabetes and other stressful circumstances. Mr Jansen’s interpretation included elements of performance now aimed at health promotion instead of sportive achievements. Mr Tahiri’s ‘good’ life was primarily prescribed by his religion, and Mr Postma preferred insulin injections to being more active because it matched the way he wanted to live now.

Research reflection 9.6

As mentioned in the general introduction (Chapter 1), as a critical narrative researcher in the field of type 2 diabetes care and physical activity research, I often reflected on how to relate myself to the prevailing and powerful evidence-based research framework. Based on my fieldwork experiences and discussions with other researchers, I noticed that it makes a difference whether the topic of physical activity for people with type 2 diabetes is approached from a health perspective or a care perspective. Although these two perspectives might seem similar, for me, they are not. From a health perspective, and especially a public health perspective, physical activity is primarily aimed at diabetes control and reduction of body weight, and therefore a wise thing to do. This results in a more narrow and instrumental meaning of physical activity, while other aspects, like social contacts, are extras or conditions to start with physical activity. From a care perspective, physical activity can (and should) be an important topic of care for people with diabetes, but primarily because participation in physical activity might add to someone’s overall health and wellbeing. This also means that a broader range of meanings might need attention. Moreover, physical activity does not have to be a topic for everyone every consultation, it is something a professional and individual with diabetes have to tinker out themselves, time and time again. Instead of the individual autonomy and overall control the health perspective strives for, the care perspective departs from interdependencies between those involved inside care practices and their experiences.

This difference is also reflected in the study on the walking groups conducted in 2016 (Chapter 8). Initially, and according to our research proposal, my aim was to focus on what this type of physical activity meant to people with diabetes. However, based on the in-depth interviews I had already held with healthcare professionals (Chapter 5), my overall study focus shifted from a strong ‘patient’ perspective towards professional dilemmas in providing physical activity care. As such, I joined the walking groups with an open and general interest in what these groups meant to those involved and to the provision of (physical activity) care. I wrote down my fieldnotes as soon as possible after each walk, and wrote extensively about what I saw and what I remembered of the conversations I held or heard. During the overall analysis, I noticed that while physical activity provided the starting point for this study, my fieldnotes were more about the relationships between professionals and their patients, the efforts of the nurses to provide this new type of care, and the implications for their responsibilities. As such, the focus was more on what these walking groups brought those involved from a care perspective, than from a health perspective.

Towards broader recognition

In the end, people involved at macro- and meso-levels like policymakers and researchers have their own micro-level experiences, and these do not necessarily match those at which the policy is aimed (Täuber, 2018), nor are they often acknowledged. This became particularly clear to me during an expert meeting related to the topic of my study, in which participants—policymakers, researchers and other professionals—repeatedly spoke about citizens as others at whom to aim certain actions. These citizens seemed not to include themselves as part of (one) society. This example also illustrates a distance between people involved at different levels that is also felt at all levels, although this distance was not acknowledged at the expert meeting. To decrease this distance, more attention towards and acknowledgement of the actual difficulties and tensions at the micro-level is needed. This also requires a more critical reflection on how the system world can be more accommodating.

A risk of the current (extra) emphasis on the importance of lifestyle might be an even further distance between the macro- and micro-levels, because this might lead to more stigmatisation and a greater social divide (Täuber, 2018). This is especially a risk if this emphasis is only accompanied by positive numbers on the impact of lifestyle on health and success stories of those who experienced this. While success stories have an important inspirational function, researchers now estimate that approximately 40 per cent of people with type 2 diabetes can get rid of their medication with lifestyle changes (NILG, 2019). This is a large number of people, but it is less than half—and it does not show the amount of work invested at the micro-level. Presenting only positive stories, with ‘simple’ solutions, means there is a risk that lifestyle, including active behaviour, ends up being portrayed as the only ‘good’ medicine. This is a promise that is not realistic, as is illustrated by the mismatch with actual embodied experiences (Chapter 6), and might only contribute to further blame frames at the level of individual responsibility for behaviour (Saguy, 2013). Therefore, a broader repertoire of experiences is needed.

The plea to consider physical activity the new normal in times of COVID-19 and beyond was not accompanied by a ‘how to do so’ except for an emphasis on ‘working together’. The latter was only proposed as a ‘structural, interdepartmental, and preferably evidence-based national programme’ at the governmental level (Scherder, 2020). Although presented as a simple message, the studies in this dissertation highlight the importance of more ‘practice-based’ thought and discussion on the ‘how to do so’ at the micro-level. ‘Good’ physical activity care for those who need this requires a great deal of work at this micro-level from all involved; it constantly requires time, attention, creativity, curiosity, energy, tinkering, motivation and reflection as a ‘balancing act’ between person-directed care and evidence-based guidelines (Holmen et al., 2020). This needs to be more acknowledged at other levels as well.

Concluding comments

The central tension presented in this dissertation between a described, objective and desired macro-level reality and an experienced and complex micro-level reality is not new or limited to the topic of physical activity care for people with type 2 diabetes. Indeed, it seems especially palpable today in relation to some urgent societal issues, such as COVID-19-related restrictions of visiting people living in care homes (Trouw, 27 June 2020) or worldwide experiences with racism in sport (Hylton, 2020). It might be interesting to compare those developments, including the impact of storytelling in terms of action and support.

This tension is not avoidable and does not necessarily have to be avoided. However, it seems important for it to be seen, recognised and discussed in order to bring physical activity care for people with type 2 diabetes further. To better connect different relevant levels, the conversation on physical activity must also be held outside the consultation room and include the easily obscured normative aspects related to responsibilities, the contradictory (individual and societal) interests that are at stake and intersecting social inequalities.

Who defines how to live a good life or how to live life with diabetes? How to include (physical, economic and social) 'bad luck' and social inequalities? How to include more lifeworld-based meanings of physical activity *and* sport in care? How to improve professional working health? How to share responsibilities differently? Where do individual interests (not) meet societal and political ones? A better connection between daily life/work experiences and the policy/societal and research level, between the concrete and abstract and between empiricism and theory might be helpful. This dissertation hopefully provides an impulse for such conversations.

Epilogue

To think with stories

Mr Cohen, who is quoted in Intermezzo I and Chapter 6 and who felt he 'entered the diabetes world' after diagnosis still did not feel at home there when I met him 18 months later. In the reflection on his story I sent him afterwards, I wrote that it seemed to me that he had to sort everything out for himself, something he agreed to. This does not mean that his healthcare professionals did not try or mean well, but from his perspective, they did not succeed in providing him with good care.

He did find an approach that worked for him after a while, and by completely refraining from sugars, having a 'good' conversation with a new diabetes nurse and self-measuring his glucose all the time to learn how his body reacted to food, he managed to lower his blood glucose level and experienced more energy. As a central element in his story, he mentioned the importance of 'quality of life', which for him means 'to become 96 years old with two legs and good eyes'. Interestingly, his focus on dietary restrictions seemed to match his belief about what a 'good' life entails, because he had already been a vegetarian for 30 years and was moving towards veganism. As such, what a 'good' life entails for a particular person might be an important starting point for the provision of 'good' care for that particular person.

Similar feelings about a mismatch between life and care experiences were expressed by others whose story (or numbers) provided valuable input for this dissertation. Needless to say, these stories only represent a part of daily life or working life experiences, only come from a small group of people and might have changed between the moment they were told, when I wrote about them, or when you as a reader read about them. However, these experiences represent important parts of daily life and work, especially in light of dominant perceptions and current developments on micro-, meso- and macro-levels of society as it comes to an emphasis on physical activity as 'medicine'. Therefore, in addition to Jackson and Mazzei (2013), I argue that it is not only important to think with theory but also, or maybe especially, with stories.

On topics as complex and intricately interwoven in all aspects of our life such as physical activity and health(care), stories of those (most) involved provide us with an opportunity to be taken by surprise, to have our own professional-personal story contradicted, to be argued with, to be provided with confirmation or to interrogate what might easily be taken for granted. To make room for these stories in care, policy, research and beyond, it is necessary to hear these stories and think along with them. Above all, it requires us to accept contradicting and complex experiences, or even better, to actively search for stories that challenge mainstream thoughts and to embrace these as opportunities to try to further improve personal and professional lives.

Appendix

Physical activity CV for healthcare professionals

Developed with the ROHA as part of the implementation project ‘Physical activity in type 2 diabetes care’, supported by ZonMw. Translated from https://www.rohamsterdam.nl/document/format-beweegverhaal-aug-2019/, version July 2019

The role of physical activity in my life

Below are my experiences with physical activity in my life: what I did, divided over different life phases, and what this meant to me and means to me now. With physical activity, I mean everything that takes effort: from daily mobility to sport.

Life phase	**Physical activity**	**Meaning**
Child		
Adolescent		
Young adult		
…[fill in yourself]…		

Physical activity CV—Instructions for healthcare professionals

Background

The reason for this document is the (increasing) emphasis on the importance of physical activity for patients. As we work in an increasingly patient-directed way, it is important to let the patient be in charge and fit in with what the patient considers of value.

The aim of thinking about and writing down your own 'physical activity story' (or 'CV') is to be conscious of the role and meaning(s) of physical activity in your life and the value you attach to it. This might help to gain insight into differences with others, and in possible judgements about patients' physical activity behaviour. This might contribute to better understanding your patients. You can also talk about a patient's story about physical activity with this format, or exchange stories with colleagues to see whether this results in new insights.

When filling in this form

Some life phases are stated, but please feel free to change them. Remember that important life events, like moving house, starting work, becoming a parent, or an illness, might have a considerable impact on physical activity and participation in sport.

When you filled in your own story

- Does this bring you new insights?
- Are you aware of your own experiences in the course of your work, for instance when talking about physical activity with a patient?
- Does your story sometimes have a negative impact during a conversation with a patient? How come? Was this something you were aware of?
- Do you think it is useful to be aware of your own experiences in the course of your work?

When you filled in a patient's story together

- What was the reason to use this format?
- How do you think the patient experienced this?
- Did it bring him/her new insights?
- Did it bring you new insights?
- What are differences with your own story? Were you aware of these?
- How did the conversation go?
- What are you going to do next?

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About the author

Sport and physical activity biography

‘When I was four years old, I joined the local gymnastics club in Aalten, where I grew up. Although I was not very talented, gymnastics became an important part of my (social) life. From the age of 12 to 18, I went there at least four times a week; for my own weekly training sessions, as an assistant trainer for younger girls, and during training sessions of both the acrobatics and springing teams. As part of an acrobatics trio I even took part in the Dutch Championships once.

At primary school, I also joined a tennis club, together with my parents, sister and brother. I had lessons once a week and took part in small tournaments at the weekend. I stopped because I no longer got on with the trainer and, with my best friend, joined badminton training at high school. Although sport was a ‘normal’ activity during my childhood and youth, I was frequently hindered by my hypermobile joints. I especially remember the sprained ankles, because of playing tag or ‘scissors’ in the school playground. This also meant I was somewhat ambivalent about the physical education lessons at school, for fear of picking up injuries.

When I was 18 years of age, I moved to Amsterdam and joined the student badminton club to play twice a week. However, because of the continuing strain on my joints, I stopped about five years later. This was not an easy decision, as, again, this had become an important part of my (social) life. Moreover, I did not know what to do next. I tried swimming, fitness and group lessons at a fitness club, but did not really like any of these activities and did not persevere. My focus shifted from sport towards physical activity, and especially towards active transport. In Summer 2016, I took part in the National Diabetes Challenge at two locations and joined the walks once or twice a week over a period of twenty weeks. From May 2013 to December 2016, I lived 10 km from my main workplace, a distance I enjoyed cycling; and something I missed very much after moving to Hoofddorp.

Over time, I learned to integrate active transport in my daily routines, more than enough to meet the physical activity guidelines (most weeks). However, because of a severe hernia in my lower back in early 2019, I was seriously impeded from physical activity for about six months. This was a personal experience with ‘exercise as medicine’, as I was advised to remain active—something the medical guidelines also state. I started an intensive course of physiotherapy, and joined a weekly training group at the physiotherapists’ gym from October onwards. I was also able to pick up my ‘normal’ walking and cycling activities again. However, the Dutch measures in relation to COVID-19 from March 2020 onwards, including working from home and the temporary closure of the gym, disrupted these activities, something I still not have completely recovered since. But the weekly training at the physiotherapists’ gym is something I picked up again.’

Professional biography

'I obtained a Bachelor's degree in Medical Biology (cum laude) and a Master's degree in Medical Anthropology and Sociology at the University of Amsterdam. My Master's thesis was on how children with different socio-economic backgrounds think about sport, physical activity, body ideals and health. This was supervised by sport sociologist Dr Ruud Stokvis, and meant my introduction to the work of Bourdieu and Elias, sport sociology, and qualitative research. In 2007, I became a researcher at the Mulier Institute on a historical sociological study about notions of physical activity, health and body ideals. In addition, I worked on several other research projects, for instance about children's sport behaviour at school, monitoring of government sport policy, and development of youth interventions.

From 2012 onwards, I was involved in the pilot studies leading to the research proposal and project Sport in Times of Illness, together with Dr Agnes Elling and Professor Tineke Abma. To conduct this study, I was also appointed at the department of Medical Humanities of the Amsterdam UMC (location VUmc) from May 2013 until May 2020. To better combine narrative and scientific writing, I followed an intensive course on science journalism. In 2017, I wrote a series of columns on 'physical activity as a topic in the consultation room' for Diabetes Pro, a Dutch professional magazine for diabetes professionals. These columns were based on the interviews I held with healthcare professionals.

From 2014 until 2017, I was a member of the Quality Committee of the (then) EMGO+ research institute of the VUmc, for internal audits and quality measures. In that capacity, I revised the guidelines for qualitative research with the input of key experts, which were published in October 2017. In addition, I conducted an interview study among children who were receiving healthcare because of their body weight, to explore their perspectives on the words healthcare professionals use when discussing weight. Moreover, together with colleagues, I developed a practical guide for qualitative researchers to conduct a secondary analysis using an intersectionality perspective. Such an analysis aims to gain insight into how different aspects of identity like gender, class, age, and ethnicity interact with each other and influence daily experiences of people. This perspective is helpful to understand how identity is of importance in social inequality.

Currently, I work at the Mulier Institute on several qualitative research projects. My main theme's include combining physical activity and healthcare, and applying life-course and social network perspectives to understand why people stop (or start) with sport after a major life transition. I am also involved in a recently started research project on social inequality in sport because of COVID-19. Using qualitative and narrative methodology, I will focus on the experiences of people who are probably most affected by COVID-19 and its measures in terms of health and socio-economic position, and on how professionals, like local sport professionals and policy makers, can add to a more 'inclusive' sport.'

Mirjam Stuij
September 2020

Summary

Physical activity in type 2 diabetes care

A critical narrative study

Based on numerous biomedical and epidemiological studies, physical activity (including exercise) is considered a ‘corner stone’ in type 2 diabetes care, and, as such, one of the starting points for and an important topic throughout medical treatment. Type 2 diabetes is a chronic condition, characterised by disrupted blood glucose regulation. Both its origin and management are strongly linked to physical (in)activity and extreme overweight. This means that healthcare professionals are instructed to stimulate physical activity among people who generally are not inclined to be active.

The central aim of this dissertation is to provide in-depth insights into experiences with physical activity (as an aspect of care) and openings for ‘physical activity care’ for people with type 2 diabetes. These insights stem from several empirical studies using a qualitative narrative approach, which implies an explicit inclusion of the broader socio-political, research, and healthcare context to understand how these contexts affect the experiences of healthcare professionals and people with type 2 diabetes. As indicated in the subtitle, this dissertation is critical towards (im)possibilities and understandings offered by the broader context. As such, the purpose is to provoke thought and discussion on the topic of physical activity in healthcare to contribute to further improvements in care for people with type 2 diabetes.

Introduction

Chapter 1, the general introduction, provides information relevant to the overall background and theoretical frame of the empirical work conducted for this dissertation. This chapter starts with an introduction on how physical activity and health have become increasingly and intensively intertwined in health research, governmental health policy, and broader societal notions over the past few decades, resulting in a general perception of 'exercise as medicine', especially for people with type 2 diabetes. Also, a short explanation of the organisation of type 2 diabetes healthcare in the Netherlands, the country in which this study is situated, is provided. The main aim of type 2 diabetes healthcare is to prevent and treat symptoms and complications of diabetes and maintain blood glucose levels within 'normal' ranges. Overall, type 2 diabetes care is organised very efficiently and implements evidence-based protocols.

Regarding physical activity, healthcare professionals are instructed to provide information, advice, encouragement and ongoing counselling to their patients. Previous studies on related topics often focused on barriers and enablers from a healthcare and patient perspective, following epidemiological evidence that stresses the importance of physical activity for people with diabetes. In the studies in this dissertation, I, the author and main executing researcher, take a different perspective: one that is critical towards the 'top-down' presentation of this epidemiological evidence and instead aims to elicit what this evidence means to people with diabetes and healthcare professionals and how it affects their daily lives or working practices.

To do so, I primarily used a narrative methodological approach to collect and analyse data as well as in the writing process. I conducted in-depth interviews with people diagnosed with type 2 diabetes and healthcare professionals, and observed them in different healthcare settings. During the analysis, the focus was on both the content ('what') and form ('how') of the data. Overall, four main theoretical lenses, ranging from critical macro-levels to narrative micro-levels, guided me throughout this study. These lenses are reflected by the questions I asked during different phases of fieldwork, analysis and writing, and that I used to develop an understanding of physical activity as an aspect of care for people with type 2 diabetes.

Chapter 2 is part of the introduction, and is based on an exploratory online questionnaire completed by 181 people with diabetes. The aim was to explore how they experienced physical activity counselling, a topic most respondents were critical about. This indicated a 'mismatch' between physical activity counselling experiences and needs of people with diabetes, as a starting point to further unravel in the qualitative in-depth studies. The introduction ends with **Intermezzo I**, a presentation of observations and reflections that highlight some elements of the ‘diabetes world’, which is how one of the respondents referred to the Dutch type 2 diabetes care.

This dissertation is then further divided into three parts that present empirical studies on the policy and healthcare context, individual experiences, and openings to improve physical activity counselling and treatment, respectively. Most of these chapters are written together with other authors. Each part ends with an intermezzo to offer additional insights into experiences of people with type 2 diabetes with physical activity in- and outside the care context, and new thoughts on physical activity counselling, created in partnership with a small group of healthcare professionals.

Context: changing understandings in policy and care

This part is about relevant developments in the broader context in which physical activity is provided as form of care. In **Chapter 3**, the focus is on health arguments in sport policy from the 1950s onwards. A close analysis of sport policy documents and sport participation surveys indicated how different stakeholders used health arguments as a major legitimation for governmental interference in the Dutch sport sector. This process also had implications for the governmental focus; over time, the emphasis in sport policy shifted from sport-related elements, like well-being and recreation, towards health-related elements of sport such as frequency, intensity, and the broader term physical activity. This chapter highlights changing and interdependent power relations between the fields of policy, research and societal interest groups, resulting in a further intermingling of sport and physical activity in relation to health.

Chapter 4 is an account of participant observations I made during training days for nurses working in general practice (*praktijkondersteuners* in Dutch). In the Netherlands, these nurses care for a large share of people with type 2 diabetes. During this training, they were introduced to a new approach of how to provide care to people with a chronic condition. This approach, focussed on ‘health and behaviour’ instead of ‘illness and care’, aims to increase health instead of decreasing illness and implies a change in which the professional follows the patient’s values and needs instead of instructing the patient what to do. Although the nurses seemed enthusiastic about this new approach, they also had a lot of discussion about how to integrate the approach into the existing organisation of care. With this, Chapter 4 provides insights into a more general turning point in current chronic care provision, stemming from dissatisfactions of healthcare professionals (and patients) about the way this care is currently organised.

Intermezzo II presents the experiences of Ms Borst, who wanted to ‘use’ exercise as a ‘medicine’, but experienced that she needed another type of exercise than generally prescribed.

Experiences: healthcare dilemmas and daily life narratives

The following two chapters provide insight into experiences with physical activity in daily life and work. **Chapter 5** presents experiences of healthcare professionals in delivering physical activity counselling to people with type 2 diabetes. Based on interviews with 24 professionals, such as nurses working in primary care practices, diabetes nurses, and physiotherapists, this chapter provides insights into the dilemma they experience between the importance of the topic of physical activity as a 'foundation' of care and the 'trickiness' of this topic. This trickiness is illustrated by two main fields of tension the professionals discussed: (1) understanding patient behaviour and (2) professionals' views on responsibilities, including their responsibilities as professionals and their ideas on who is responsible for behaviour change. Within the broader socio-political context, which emphasises individual responsibility for behaviour, professionals have to navigate between (im)possibilities the diabetes care framework offers, options for finding connections to embed physical activity in the patient's life, and the professionals' own opinions on and experiences with physical activity and healthy living.

Chapter 6 focuses on how people diagnosed with type 2 diabetes translate the perception that exercise is a 'medicine' into their daily life, and how they experience physical activity as an aspect of care. A critical narrative analysis of stories told by 18 people diagnosed with type 2 diabetes revealed a range of meanings given to sport and physical activity. These different meanings were not all acknowledged by their healthcare professionals. Indeed, most participants talked about negative experiences with care and support regarding the uptake or continuation of sport or physical activity participation after diagnosis. In addition, although almost all participants seemed to subscribe to the idea of exercise as 'medicine' on a general level, they employed different strategies to negotiate with this idea in their daily life. These strategies ranged from (almost) total acceptance to resistance.

Intermezzo III is a narrative summary of the story told by Ms Hoekstra. She experienced positive effects of an intensive exercise programme on her diabetes, but found this type of exercise too demanding to implement permanently into her stressful life. As such, she experienced exercise as an impossible necessity.

Openings: extended talking and walking practices

The third part presents two initiatives that might provide valuable openings for change in physical activity counselling and treatment. **Chapter 7** is about extended talking practices, and presents an analysis of my prolonged interaction with Anja, one of the interview respondents. She was diagnosed with type 2 diabetes twelve years earlier, and signed up for the study at the moment she decided to quit horseback riding; an activity she very much enjoyed, but could not do anymore because she had too much pain in her legs as a consequence of diabetes. This decision caused her pain, and she did not know how to 'start over again'—which was her normal approach to problem solving. At the end of the interview, she asked me for my thoughts on her story, which I provided by an account and reflection I sent her afterwards. This resulted in an ongoing interaction by e-mail, in person conversation, and her involvement in writing Chapter 7. Over time, by exchanging stories, she changed her own story and attitude which made it easier for her to deal with her diabetes. In this chapter, we provide a detailed analysis of this co-constructed narrative, with listening, recognition, and local finetuning as important ingredients; and useful elements for healthcare interactions.

Chapter 8 presents extended walking practices of two healthcare professionals and their patients over a period of 20 weeks. In 2016, I participated in two different walking groups, organised by a nurse working in general practice and a diabetes nurse working in secondary care, respectively. Based on fieldnotes written shortly afterwards, the aim was to study the care practices of these nurses and the implications for nurse-patient relationships and nursing responsibilities in the provision of (physical activity) care. Both nurses put a lot of effort into the organisation of these groups, and needed to learn to provide care to (individuals in) a group. Over time, both nurses also experienced they stepped 'outside the patient mode' during the walks, learned more about their patients' lives, and shared elements of their own lifeworld with their patients. The nurses also noted the implications of stepping outside the patient mode for conversations in the consultation room. For example, the nurses noticed patients felt freer to ask questions or share certain things. As such, this walking project seemed to offer more space for patients' lifeworld narratives and contributed to more continuous and person-centred care. However, the organisation of such walking groups also raises new questions about the provision of physical activity in healthcare and related nursing responsibilities. These questions point towards the importance of further discussion on physical activity in healthcare, not only by healthcare professionals and patients, but also by policymakers and researchers.

Intermezzo IV provides an account of a small implementation project, in which healthcare professionals and I talked about the added value of discussing and reflecting on their own experiences with sport and physical activity, the meaning of sport and physical activity, and the impact these may have on their care provision.

General discussion

In the final chapter, **Chapter 9**, I offer a narrative reflection on all findings from previous chapters to provide input for further thought and discussion on the topic of physical activity in type 2 diabetes care to contribute to its further improvement.

First, I reflected on what can be learned about physical activity (care) ***experiences*** from people with type 2 diabetes and healthcare professionals. I focussed especially on how the powerful storyline on the benefits of physical activity for type 2 diabetes ('exercise is medicine') and the strong and related emphasis on individual choice and responsibility for behaviour affects daily life experiences and working practices of those involved at the micro level. The storylines of people with type 2 diabetes (Chapter 6) pointed towards the importance of recognition of (1) the possible mismatch between theory and embodied experiences, (2) feelings of stigmatisation, and (3) negative care experiences resulting from not being seen as a person. The tensions experienced by healthcare professionals (Chapter 5) ask more attention for (1) hindrances professionals' experience by the organisation of care, (2) recognition of the presence of professionals' personal physical activity experiences and opinions in care provision, (3) risks of professional categorisation of patients, (4) the complicated professional legitimation that 'exercise as medicine' offers physiotherapists, and (5) the loss of professional motivation in physical activity counselling and treatment. As such, while the perception of exercise as 'medicine' provides attention to physical activity as an important aspect of type 2 diabetes care, it also has unintended negative effects and leads to a further stigmatisation of people with diabetes. In addition, when physical activity care does not work out for an individual patient, the current organisation of care seems unable to offer another approach.

Second, I reflected on what ***openings*** created by extended talking and walking practices can add to improving physical activity care. Interestingly, both examples presented in this dissertation (Chapter 7 and 8) brought about an element of movement that seemed important; they offered space for more spontaneous and informal interaction, resulting in more time for listening and sharing stories. The underlying elements seemed to be related to a change of responsibility and commitment of those involved; a commitment to something new, which offered a sort of fresh air to let stories breathe. Those elements allowed for more room for understanding the difficulties of living with diabetes. In sum, both examples showed that physical activity care might benefit from a more playful handling of system and lifeworld dynamics. They also point to professional motivation and responsibilities as important driving forces for a further improvement of care, something that should be more recognised in the broader context in which care is organised.

Third, I reflect on how the broader socio-political, research and care ***context*** can further support the improvement of physical activity care for people with type 2 diabetes. As illustrated by many stories and observations presented in this dissertation, the current type 2 diabetes care context centres on a tension between a focus on numbers versus a focus on the human beings behind these numbers. This tension is difficult with an everyday practice as physical activity. To better integrate physical activity in care, I reflect on the importance of (1) better listening to bring lived experiences into physical activity care, (2) a stronger focus on context-based practice instead of evidence-based protocols to better deal with the system world in lifeworld led care, and (3) professional reflection on the normative aspects of physical activity care. However, the most complicated part of physical activity as an aspect of care seems to be the confrontation between expectations of physical activity regarding control and manageability from a macro research and (care) policy level and the practical difficulties encompassing the complexity of daily life experiences at a micro level. Therefore, the conversation on physical activity must also be held outside the consultation room—for instance, by (care) policy makers, researchers, and groups with an interest in exercise or lifestyle as 'medicine'—and better include the now often obscured normative aspects related to responsibilities and diverging individual and societal interests. The emphasis on physical activity as 'medicine' in general and for people with type 2 diabetes in particular, is even stronger now because of COVID-19, while the dissatisfaction with the workload and political valuation of healthcare professionals seems to be increasing.

To conclude, I argue that it is important 'to think with' stories. With topics as complex and intricately interwoven in all aspects of our life such as physical activity and health(care), stories of those (most) involved provide us with an opportunity to be taken by surprise, to have our own (professional-personal) story contradicted, to be argued with, to be provided with confirmation or to interrogate what might easily be taken for granted. To make room for these stories in care, policy, research and beyond, it is necessary to hear these stories and think along with them. Above all, it requires us to accept contradicting and complex experiences, or even better, to actively search for stories that challenge mainstream thoughts and to embrace these as opportunities to try to further improve personal and professional lives.

Samenvatting

Beweging in de type 2-diabeteszorg

Een kritische narratieve studie

Dit proefschrift gaat over het onderwerp bewegen, inclusief sport, als onderdeel van de zorg voor mensen met type 2 diabetes. Gebaseerd op vele (bio)medische en epidemiologische studies wordt lichaamsbeweging als 'hoeksteen' van de type 2-diabeteszorg beschouwd en is het in de medische richtlijnen opgenomen als een van de uitgangspunten voor en een belangrijk onderwerp tijdens de behandeling. Type 2 diabetes is een chronische aandoening die wordt gekenmerkt door een verstoorde bloedglucoseregulatie. Zowel het ontstaan als de behandeling ervan is sterk gerelateerd aan lichamelijke (in)activiteit en extreem overgewicht. Dit betekent dat zorgverleners de instructie krijgen om mensen die over het algemeen niet of minder geneigd zijn om fysiek actief te zijn, te stimuleren om (meer) te gaan bewegen.

Het centrale doel van dit proefschrift is om verdiepende inzichten te bieden in ervaringen met beweging als onderdeel van zorg voor mensen met type 2 diabetes, alsmede in openingen voor veranderingen in 'beweegzorg'. Daarvoor zijn verschillende empirische studies uitgevoerd die een kwalitatieve narratieve benadering kennen, wat inhoudt dat de bredere sociaal-politieke, onderzoeks- en gezondheidszorgcontexten expliciet zijn meegenomen om te begrijpen hoe deze contexten inwerken op de ervaringen van zorgverleners en mensen met type 2 diabetes. Zoals de ondertitel aangeeft, is in dit proefschrift een kritisch perspectief gehanteerd ten aanzien van (on)mogelijkheden en opvattingen die de bredere context biedt. Het doel daarvan is om input te geven voor het nadenken over en bediscussiëren van het onderwerp beweging in de gezondheidszorg om bij te dragen aan een verdere verbetering van de zorg voor mensen met type 2 diabetes.

Introductie

Hoofdstuk 1, de algemene inleiding, schetst de achtergronden en het theoretisch kader die ten grondslag liggen aan de empirische studies die voor dit proefschrift zijn uitgevoerd. Dit hoofdstuk begint met een korte uiteenzetting over hoe lichaamsbeweging en gezondheid in de afgelopen decennia steeds intensiever met elkaar verweven zijn geraakt in gezondheidsonderzoek, het gezondheidsbeleid van de overheid en in algemene maatschappelijke opvatting. Dit komt tot uiting in de heersende opvatting van 'bewegen als medicijn', zeker voor mensen met type 2 diabetes. Dan volgt een korte uitleg over de organisatie van de diabeteszorg in Nederland. Het belangrijkste doel van deze zorg is het voorkomen en behandelen van symptomen en complicaties van diabetes en de bloedglucosespiegel binnen de 'normale' waarden brengen en behouden. In het algemeen is de diabeteszorg in Nederland zeer efficiënt georganiseerd en gebaseerd op *evidence-based* protocollen.

Als het gaat om het onderwerp lichaamsbeweging krijgen zorgverleners de instructie om hun patiënten informatie en advies te geven, te stimuleren en voortdurende begeleiding te bieden. Eerdere studies naar dit onderwerp zijn veelal gericht op belemmeringen en stimulansen vanuit een gezondheidszorg- en patiëntenperspectief en volgen het epidemiologisch bewijs dat het belang van lichaamsbeweging voor mensen met diabetes benadrukt. In dit proefschrift neem ik, de auteur en uitvoerend onderzoeker, een ander perspectief in: een dat kritisch is ten aanzien van de 'top-down' presentatie van dit epidemiologisch bewijs en dat, in plaats van dat te volgen, probeert te achterhalen wat dit bewijs betekent voor mensen met diabetes en zorgverleners en hoe dit bewijs op hun ervaringen in hun dagelijks leven of werk inwerkt.

Om dat te doen heb ik grotendeels een narratieve methodologische benadering gebruikt bij het verzamelen en analyseren van gegevens en bij het schrijven daarover. Ik heb diepte-interviews afgenomen met mensen met type 2 diabetes en zorgverleners en geobserveerd bij verschillende 'zorgpraktijken'. Tijdens de analyse lag de focus zowel op de inhoud (het 'wat') als de vorm (het 'hoe') van deze gegevens. Vier verschillende theoretische lenzen, variërend van kritisch op macroniveau tot verhalend op microniveau, gidsten me tijdens de studies. Deze lenzen komen terug in de vragen die ik stelde gedurende verschillende fasen van veldwerk, analyse en schrijven, en hielpen me om een perspectief te bieden op lichaamsbeweging als onderdeel van zorg voor mensen met type 2 diabetes.

Hoofdstuk 2 is deel van de introductie en gebaseerd op een verkennende digitale vragenlijst ingevuld door 181 mensen met diabetes. Het doel was om na te gaan hoe zij vanuit de zorg begeleiding bij bewegen hebben ervaren; een onderwerp waar de meeste respondenten kritisch over waren. Dit wees op een ‘mismatch’ tussen ervaringen en behoeften van mensen met diabetes en vormde een startpunt voor verdere uitdieping in kwalitatieve studies. De introductie eindigt met **Intermezzo I**, een presentatie van enkele observaties en reflecties die elementen uitlichten uit de ‘diabeteswereld’, zoals een van de respondenten de diabeteszorg omschreef.

Dan volgen drie delen die empirische studies presenteren over respectievelijk de politieke en gezondheidszorgcontext, individuele ervaringen en openingen om beweegzorg te verbeteren. De meeste van deze hoofdstukken heb ik samen met andere auteurs geschreven. Elk deel eindigt met een intermezzo waarin ervaringen van mensen met type 2 diabetes met bewegen worden uitgelicht en nieuwe ideeën over ‘beweegbegeleiding’ naar voren komen die samen met een kleine groep zorgverleners zijn uitgedacht.

Context: veranderende opvattingen in beleid en zorg

Dit deel gaat over relevante ontwikkelingen in de bredere context waarin bewegen als onderdeel van zorg wordt verleend. In **hoofdstuk 3** ligt de focus op gezondheidsargumenten in het Nederlandse sportbeleid sinds de jaren vijftig van de vorige eeuw. Een nauwkeurige analyse van sportbeleidsdocumenten en studies naar sportparticipatie van de bevolking toont hoe verschillende belanghebbenden, zoals vertegenwoordigers vanuit de sportsector, gezondheidsargumenten gebruikten als legitimering van overheidsbemoeienis met de Nederlandse sportsector. De daaraan gerelateerde ontwikkelingen hadden ook gevolgen voor de focus van de overheid; in de loop van de tijd verschoof het accent in het sportbeleid van sportgerelateerde elementen, zoals welzijn en recreatie, naar gezondheidsgerelateerde elementen van sport, zoals de frequentie, intensiteit en de bredere term bewegen. Dit hoofdstuk belicht veranderende en onderling van elkaar afhankelijke machtsverhoudingen tussen de ‘velden’ van beleid, onderzoek en maatschappelijke belangengroepen, resulterend in een verdere vermenging van sport en bewegen in relatie tot gezondheid.

Hoofdstuk 4 bevat een verslag van observaties van trainingsdagen voor een groep praktijkondersteuners (POH-ers) waar ik aan deelnam. Praktijkondersteuners nemen in Nederland een groot deel van de zorg voor mensen met type 2 diabetes op zich. Tijdens deze training maakten zij kennis met een nieuwe benadering van zorgverlening aan mensen met een chronische aandoening. Deze benadering, gericht 'gezondheid en gedrag' in plaats 'ziekte en zorg', beoogt gezondheid te verbeteren in plaats van ziekte te verminderen. Hiervoor volgt de zorgverlener de waarden en behoeften van een patiënt in plaats van instructies te geven aan de patiënt over wat te doen. Hoewel de praktijkondersteuners enthousiast waren over deze nieuwe aanpak, voerden ze ook veel discussie over hoe deze aanpak te integreren in de wijze waarop de zorg is georganiseerd. Hiermee geeft hoofdstuk 4 inzicht in een meer algemeen keerpunt in de huidige zorg voor mensen met een chronische aandoening, voortkomend uit onvrede van zorgverleners (en patiënten) over de manier waarop deze zorg momenteel is georganiseerd.

Intermezzo II gaat over de ervaringen van mevrouw Borst, die lichaamsbeweging zelf graag als 'medicijn' wilde inzetten, maar merkte dat ze een andere vorm van beweging nodig had dan over het algemeen wordt voorgeschreven.

Ervaringen: dilemma's uit de zorg en verhalen uit het dagelijks leven

De volgende twee hoofdstukken bieden inzichten in ervaringen met beweging in het dagelijks leven en als onderwerp van zorg. **Hoofdstuk 5** gaat over ervaringen van zorgverleners met het begeleiden van mensen met type 2 diabetes op het gebied van beweging. Op basis van interviews met 24 professionals—zoals praktijkondersteuners werkzaam in de eerste lijn, diabetesverpleegkundigen uit de tweede lijn en fysiotherapeuten—geeft dit hoofdstuk inzicht in het dilemma dat zij ervaren tussen het belang dat zij aan beweging toekennen als 'basis' van de zorg en de ervaring dat het een 'heikel' onderwerp in de zorg is. Dit dilemma wordt geïllustreerd door twee belangrijke spanningsvelden die in de interviews naar voren kwamen: (1) begrip opbrengen voor het gedrag van patiënten en (2) opvattingen en ideeën van zorgverleners over verantwoordelijkheden, zowel hun verantwoordelijkheden als professional als ideeën over wie (uiteindelijk) verantwoordelijk is voor gedragsverandering. Binnen de bredere sociaal-politieke context, die een sterke nadruk legt op individuele verantwoordelijkheid voor leefstijlgedrag, moeten zorgverleners navigeren tussen (on)mogelijkheden die de kaders van de diabeteszorg ze biedt, mogelijkheden om verbindingen te leggen om beweging in het leven van de patiënt in te bedden en de eigen meningen en ervaringen die zorgverleners hebben als het gaat om lichaamsbeweging en gezond leven.

Hoofdstuk 6 gaat in op hoe mensen die gediagnosticeerd zijn met type 2 diabetes de opvatting dat bewegen een 'medicijn' is vertalen naar hun dagelijks leven en op hoe zij bewegen als onderwerp van zorg ervaren. Een kritisch narratieve analyse van verhalen verteld door achttien mensen geeft een reeks aan betekenissen die zij aan sport en bewegen toekennen. Deze betekenissen werden niet allemaal erkend door hun zorgverleners. De meeste mensen vertelden over negatieve ervaringen met zorg en ondersteuning als het gaat om het voortzetten of (weer) oppakken van bewegen of sport na de diagnose. Hoewel bijna alle respondenten het algemene idee van bewegen als ‘medicijn’ leken te onderschrijven, gebruikten ze verschillende strategieën om daar in het dagelijks leven mee om te gaan. Deze varieerden van (vrijwel) totale acceptatie tot verzet.

Intermezzo III geeft een verhalende samenvatting van het verhaal van mevrouw Hoekstra. Zij ervaarde positieve effecten op haar diabetes tijdens haar deelname aan een intensief trainingsprogramma, maar vond dit programma te veeleisend om blijvend in haar stressvolle leven te integreren. Daardoor ervaarde ze lichaamsbeweging als een onmogelijke noodzaak.

Openingen: verlengde praat- en wandelpraktijken

Het derde deel van dit proefschrift presenteert uitwerkingen van twee initiatieven die waardevolle openingen kunnen bieden voor veranderingen in beweegzorg. **Hoofdstuk 7** gaat over ‘verlengde praatpraktijken’ en geeft een analyse van mijn langdurige interactie met Anja, een van de interviewrespondenten uit hoofdstuk 6. Twaalf jaar eerder werd bij haar type 2 diabetes vastgesteld. Ze meldde zich aan voor mijn onderzoek op het moment dat ze besloot dat ze moest stoppen met paardrijden; een activiteit die veel voor haar betekende, maar die ze niet meer kon volhouden omdat ze te veel pijn in haar benen had als gevolg van haar diabetes. Deze beslissing deed haar pijn en ze wist niet hoe ze ‘opnieuw moest beginnen’, wat haar normale benadering van problemen was. Aan het eind van het interview vroeg ze mij naar mijn mening over haar verhaal. Ik gaf haar deze mening in een verslag van het gesprek, inclusief een uitgebreide reflectie vanuit mijn onderzoeksperspectief, dat ik naderhand aan haar stuurde. Dit resulteerde in een langere periode van interactie via telefoongesprekken, e-mail, nog een interview en haar betrokkenheid bij het schrijven van hoofdstuk 7. Door het wederzijds uitwisselen van verhalen veranderde haar eigen verhaal en houding in de loop van de tijd, waardoor ze gemakkelijker met haar diabetes kon omgaan. Dit hoofdstuk geeft een gedetailleerde analyse van dit gezamenlijk geconstrueerde verhaal, waarbij luisteren, (h)erkenning en afstemming of kalibratie belangrijke ingrediënten vormen, en biedt daarmee nuttige elementen voor interacties in de zorg.

In **hoofdstuk 8** komen ‘verlengde wandelpraktijken’ van twee zorgverleners en hun patiënten aan bod. In 2016 nam ik deel aan twee wandelgroepen, die gedurende twintig weken werden georganiseerd door respectievelijk een praktijkondersteuner en een diabetesverpleegkundige. Op basis van observaties die ik kort na elke wandeling opschreef, was het doel van deze studie om de zorgpraktijken van deze zorgverleners te bestuderen en implicaties te benoemen voor hun relaties met patiënten en hun verantwoordelijkheden in het verlenen van (beweeg)zorg. Beide zorgverleners staken veel energie in de organisatie van de wandelgroepen en moesten leren om zorg te verlenen aan (individuen in) een groep. In de loop van deze twintig weken hebben beide zorgverleners ook ervaren dat ze tijdens de wandelingen 'uit de patiëntenmodus' stapten, meer leerden over de leefwerelden van hun patiënten en elementen uit hun eigen leven met hun patiënten deelden. Daarnaast ervaarden ze gevolgen voor de gesprekken in de spreekkamer. Zo merkten ze dat hun patiënten zich in de spreekkamer vrijer voelden om vragen te stellen of bepaalde dingen te delen. Als zodanig bood dit wandelproject meer ruimte van leefwereldverhalen van patiënten en droeg het bij aan meer continue en persoonsgerichte zorg. De organisatie van dergelijke wandelgroepen riep echter ook nieuwe vragen op over het verlenen van beweegzorg en daaraan gerelateerde verantwoordelijkheden van zorgverleners. Deze vragen tonen het belang van verdere discussie over bewegen als onderwerp van zorg, niet alleen door zorgverleners en patiënten, maar ook door beleidsmakers en onderzoekers.

Intermezzo IV geeft een verslag van een klein implementatieproject waarin ik met een groep zorgverleners sprak over de meerwaarde van gesprekken over en reflectie op hun eigen ervaringen met en betekenissen van sport en bewegen, en de impact die deze ervaringen kunnen hebben op de manier waarop ze zorg verlenen.

Algemene discussie

In het laatste hoofdstuk, **hoofdstuk 9**, bied ik een narratieve (verhalende) reflectie op alle bevindingen tezamen om input te geven voor verder nadenken en discussiëren over bewegen als onderwerp in de type 2-diabeteszorg, om bij te dragen aan verbetering ervan.

Als eerste reflecteer ik op wat we kunnen leren van ***ervaringen*** met bewegen en beweegzorg van mensen met type 2 diabetes en zorgverleners. Ik richtte me daarbij vooral op hoe de krachtige verhaallijn over de voordelen van fysieke activiteit op type 2 diabetes ('bewegen als medicijn') en de sterke en daaraan gerelateerde nadruk op individuele keuze en verantwoordelijkheid voor gedrag inwerkt op de ervaringen in het dagelijks leven en werk van degenen die hier op microniveau mee te maken hebben. De verhaallijnen van mensen met diabetes (hoofdstuk 6) wezen op het belang van erkenning van (1) een mogelijke 'mismatch' tussen theorie en belichaamde ervaringen, (2) gevoelens van stigmatisering en (3) negatieve zorgervaringen door niet als persoon gezien te worden. De spanningsvelden die zorgverleners ervaren (hoofdstuk 5) vragen om meer aandacht voor (1) moeilijkheden die zorgverleners ervaren in de wijze waarop de diabeteszorg georganiseerd is, (2) erkenning van de aanwezigheid van de eigen ervaringen met en opvattingen over bewegen van zorgverleners, (3) het risico van het categoriseren van patiënten, (4) de ingewikkelde professionele legitimatie die ‘bewegen als medicijn’ fysiotherapeuten biedt, en (5) het verlies van motivatie om beweegzorg te blijven bieden. Hoewel de opvatting ‘bewegen als medicijn’ aandacht geeft aan bewegen als belangrijk onderdeel van zorg voor mensen met type 2 diabetes, heeft deze opvatting ook onbedoelde negatieve effecten en leidt deze tot verdere stigmatisering van mensen met diabetes. In aanvulling daarop lijkt de huidige wijze waarop de zorg is georganiseerd geen andere benadering van beweegzorg te kunnen bieden als de manier waarop het nu wordt ingevuld niet werkt voor een individuele patiënt.

Als tweede reflecteer ik op wat ***openingen*** gecreëerd door verlengde praat- en wandelpraktijken kunnen bijdragen aan een verbetering van beweegzorg. Interessant is dat beide voorbeelden die in dit proefschrift zijn gepresenteerd (hoofdstuk 7 en 8) een belangrijk element van beweging brachten: ze boden ruimte voor meer spontane en informele interacties dan in de spreekkamer, met als gevolg meer tijd voor luisteren en het uitwisselen van verhalen. De onderliggende elementen leken te zijn gerelateerd aan een verandering van verantwoordelijkheid en toewijding van degenen die betrokken waren; een toewijding aan iets nieuws, die, in de woorden van Arthur Frank, frisse lucht bood om verhalen te laten ademen. Deze elementen gaven meer ruimte voor begrip voor de moeilijkheden in het dagelijks leven met diabetes. Samenvattend laten beide voorbeelden zien dat beweegzorg profijt kan hebben van een meer speelse benadering van systeem- en leefwerelddynamieken. Ook wijzen ze op professionele motivatie en verantwoordelijkheden als belangrijke krachten voor een verdere verbetering van zorg, iets dat meer erkent zou moeten worden door de bredere context waarin de zorg is georganiseerd.

Als derde reflecteer ik op hoe die bredere sociaalpolitieke, onderzoeks- en gezondheidszorg***context*** een verdere verbetering van beweegzorg voor mensen met type 2 diabetes kan ondersteunen. Zoals geïllustreerd door de vele verhalen en observaties die in dit proefschrift zijn gepresenteerd, is er in de huidige type 2 diabeteszorg een spanning tussen een focus op ‘cijfers’, zoals laboratoriumuitslagen, en een focus op de personen achter deze cijfers. Deze spanning is lastig te combineren met een onderdeel uit het dagelijks leven, zoals fysieke activiteit. Om beweging beter in de zorg te integreren, reflecteer ik op het belang van (1) beter luisteren om beleefde ervaringen in beweegzorg te brengen, (2) een sterkere focus op *context-based* in plaats van *evidence-based* protocollen om beter om te gaan met de systeemwereld in zorg gericht op de leefwereld, en (3) professionele reflectie op de normatieve aspecten van beweegzorg. Het meest ingewikkeld van bewegen als onderwerp van zorg lijkt echter een confrontatie tussen verwachtingen van bewegen als het gaat om controle en beheersbaarheid op een macro onderzoeks- en beleidsniveau en de praktische moeilijkheden die gaan over de complexiteit van ervaringen in het dagelijks leven op microniveau. Het gesprek over bewegen moet daarom ook meer gevoerd worden buiten de spreekkamer, bijvoorbeeld door beleidsmakers, onderzoekers, en belangengroepen met een interesse in bewegen of leefstijl als 'medicijn'. Dit gesprek moet meer gaan over de nu vaak verborgen normatieve aspecten gerelateerd aan verantwoordelijkheden en uiteenlopende individuele en maatschappelijke belangen. De nadruk op bewegen als 'medicijn' in het algemeen en voor mensen met type 2 diabetes in het bijzonder, is momenteel nog sterker door COVID-19, terwijl de onvrede met de werkdruk en politieke waardering van zorgverleners lijkt toe te nemen.

Tot slot beargumenteer ik dat het belangrijk is om 'na te denken met verhalen'. Met onderwerpen die zo complex en ontzettend verweven zijn met alle aspecten van ons leven als bewegen en gezondheid(szorg), kunnen verhalen van degenen die het meest betrokken zijn ons verrassen, ons eigen professionele en/of persoonlijke verhaal tegenspreken, ons helpen om te discussiëren, ons bevestigen of juist helpen bevragen wat gemakkelijk als vanzelfsprekend zou kunnen worden beschouwd. Om ruimte te maken voor deze verhalen in zorg, beleid, onderzoek en daarbuiten, is het nodig om deze verhalen te horen en ermee na te denken. Bovenal vraagt het van ons dat we tegenstrijdige en complexe ervaringen accepteren, of beter nog, actief zoeken naar verhalen die gangbare opvattingen bevragen en deze omarmen als mogelijkheden om persoonlijke en professionele levens verder helpen te verbeteren.

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