Chapter 1

General Introduction

Introduction

This thesis aims to gain insight into factors that contribute to a strong workforce providing care to people with dementia in long-term-care facilities. A strong workforce is essential for the development of a comprehensive and high quality long-term-care system for this group. This has been emphasised by the World Health Organisation, policy makers, patients' associations and researchers.[1-4]

Gaining insight into factors that contribute to a strong workforce is particularly important given the challenges facing long-term care for people with dementia. First, the number of people with dementia is increasing rapidly[5] and the number of people of working age is declining at the same time.[6,7] Second, the job of healthcare workers in nursing homes is known to include high levels of workload.[8] Finally, the role of this workforce is increasingly important as the approach to long-term care is shifting from the traditional medical model towards a more person-centred policy in which the relationships and interactions between staff and residents are seen as crucial to residents' well-being. As a consequence, recruiting, retaining and training healthcare workers in long-term care facilities for people with dementia constitutes one of the main concerns of policy makers and employers in the coming years.

The thesis consists of two parts. The first part (Chapters 3 – 5) aims to obtain insight into factors that contribute to a healthy work environment in long-term care facilities for people with dementia. The second part (Chapters 6 – 7) focuses in more detail on the person-centred approach.

This general introduction first provides some background on the issues mentioned above. In addition, it describes both the model of occupational stress and the theory of person-centred care that have been used as a basis for this study. Finally, the research questions, the data collection used to answer these questions and the outline of this thesis are presented.

Dementia and the need for support and care

Symptoms of dementia may be caused by various conditions, such as Alzheimer's disease or vascular dementia. Unfortunately, these diseases are still not preventable. Symptoms include cognitive problems, such as difficulties with memory, language and reasoning, as well as mood and behavioural problems.[9,10] The nature of the increasing functional impairments and problems that arise makes it difficult for people with dementia to meet their own needs.[4,11] Therefore, the provision of support and care for people with dementia is indispensable.

Alzheimer's Disease International[5] stated that there are 46.8 million people with dementia worldwide in 2015, and this number is expected to increase to 74.7 million by 2030 and to 131.5 million by 2050. In the Netherlands, there are approximately 260,000 people living with dementia, a number which is expected to increase considerably in the next decades.[12] Most of the people with dementia live at home, often cared for and supported by family members or other informal caregivers. However, at a later stage of the disease or when informal care is absent or limited, or informal caregivers are overburdened, moving to a residential or nursing home often becomes inevitable. According to the most recent estimations, 36,934 people with dementia were living in long-term-care facilities in the Netherlands in 2008.[13]

Labour market challenges

In the years to come, long-term care will face two major related and simultaneous challenges[6] that threaten the number of available workers per person in need of long-term care: (1) a huge increase in demand given the tripling of the number of older people requiring long-term care from 2010 to 2060 according to Eurostat projections, including people with dementia[6]; and (2) a threat to the supply of healthcare workers in long-term care given the decline in the number of people of working age.[6,7] This means that recruiting, training and retaining an adequately qualified and skilled workforce constitutes one of the main concerns of policy makers and employers in long-term care for the coming years.[3] In addition to demographic changes, there are further reasons that explain the significance of this matter. First, budgetary constraints might limit the possibilities for improving the work environment and training.[1] Several countries such as Germany, Luxemburg, Japan, the Republic of Korea, and the Netherlands are reforming the long-term-care system to increase its financial sustainability[3]. Second, staff turnover rates in nursing homes are high[14] and some of the healthcare workers who leave their jobs indicate that this could have been prevented by, for example, a reduction of the workload.[15] Finally, the image of caring for older people and people with dementia is problematic[16,17]; healthcare workers in this field have a relatively low status compared with those in other healthcare work environments.[18]

Heavy workload

The job of healthcare workers is known to include high levels of perceived workload, particularly in nursing homes. In the Netherlands, it has been found that healthcare workers in nursing homes perceive a more demanding workload than those in other healthcare settings. Seventy-two percent of them feel they are subjected

to (too much) pressure in their job, and only 34% feel they have sufficient time to provide good care.[8] International studies also show that staff in nursing homes often feel rushed and are anxious about their ability to keep up with their work.[19,20] In line with these findings, combating workload[21], and ensuring adequate staffing[22] are important concerns of directors in nursing and residential homes. Finally, residents themselves in long-term care report that they are worried about healthcare workers' lack of time for them.[23]

Heavy workload and time pressure, both indicators of high job demands, have important implications for staff well-being and the quality of work in general.[24-27] It has been found that high job demands contribute to job strain, burnout and job dissatisfaction in long-term care[19,28,29], and are an important cause of staff turnover or even exit from the profession.[15,30] Having too much work to do and not having sufficient staff available have been found to be two of the most stressful working conditions for staff in nursing homes[31], while sufficient time for tasks is positively related to job satisfaction.[32] With regard to the impact of job demands on quality of work, it has been found that time pressure prevents staff from spending time socializing with and relating to residents and from providing opportunities for meaningful activities.[20,28]

Transition towards person-centred care

Enhancing well-being by meeting people's psychological needs is at the heart of the person-centred approach to dementia care.[33] Therefore, the relationships between healthcare workers and people with dementia are crucial for the provision of person-centred care.[2-4,34,35,36] A person-centred approach aims to improve the quality of care for people with dementia by acknowledging that the person and his or her psychological needs – and not the disease itself -, should be the focus of care delivery.[4,37] This is in contrast to more traditional approaches to dementia care based on a medical model, in which the disease is the focus of service delivery and involves only minimal interaction that is largely concentrated on personal care tasks.

There is an urgent need for action to improve the quality of care and services for people with dementia by making care more person-centred.[2,3,17,38] New care concepts that look and operate more like a home in which the staff aim to optimise residents' psychosocial well-being are receiving increasing attention in countries such as Japan, Sweden, the USA and the Netherlands.[39-43] In the Netherlands, for example, this has led to the concept of person-oriented small-scale care[43-45] which has been embraced by several care providers. This concept entails care being provided in a homelike environment in which residents and informal caregivers determine the organization of daily life together, which is analogous to a normal household.

Study aims

This thesis comprises two general parts. The first part is aimed at a better understanding of 'healthy working conditions' for the dementia workforce, how they are related to the quality of care, and how the changing care concept in long-term-care facilities influence them. This part is based on the Job Demand-Control-Support (DCS) Model.[46,47] The second part of this thesis addresses the relationship between person-centredness and staff and resident well-being. In this part, the theory of person-centred care[4,11] has been used as a starting point to gain insight into how person-centredness influences the well-being of both healthcare workers and residents.

Part 1: working conditions and staff well-being

Part 1: The Job Demand-Control-Support Model

The Job Demand-Control-Support (DCS) Model[47,48] will be used as a heuristic framework in the first part of this thesis (Chapters 3 – 5). The DCS Model is one of the most prominent models of occupational stress. Important characteristics of a healthy work environment in healthcare settings, such as perception of enough time and adequate staffing, job control, collegial/collaborative relationships and supportive manager relationships[49] are included in this model. The model has been frequently tested in healthcare research, but not often in long-term-care facilities for people with dementia specifically.

The DCS Model is an expansion of the Job Demand-Control (DC) Model of Karasek.[46] The original DC Model states that two core job characteristics – job demands and job control – influence employee health and well-being. The model refers to jobs with high demands and low control as *high strain jobs* in which adverse health outcomes and negative employee well-being are expected[46]. Furthermore, this model has two key assumptions, the so-called buffering hypothesis and the activation hypothesis. First, the buffering hypothesis in the DC Model assumes that the adverse effect of high job demands on employee health/well-being is moderated (i.e., buffered) when job control is high. Second, the activation hypothesis assumes that high job demands can also result in elevated levels of learning behaviour, motivation and feelings of competence when combined with (i.e., moderated by) high levels of job control. This is also referred to as a synergetic effect.[50]

In the present study, decision authority is used as a focused operationalization of job control. Decision authority refers to organizationally mediated possibilities for workers to make decisions about their work.[46,51] In previous studies on the DC Model, a broad conceptualisation of job control was often used, including not only decision authority but also skill discretion.[52] However, several researchers have argued that it is important to use a more focused measure of job control when studying the DC model because in most cases only then were the hypothesised buffering effects found.[53-55]

In 1988, Johnson and Hall[47] added a social dimension to the DC Model – workplace social support – which can be defined as helpful social interaction available on the job. This so-called Job Demand-Control-Support (DCS) Model assumes that the adverse effect of job demands on health and well-being is buffered most when both job control and social support are high (Johnson and Hall, 1988). The most adverse health outcomes are expected in jobs with both high levels of demands and low levels of both control and social support at the workplace. In addition, the expanded model proposes that employees are most activated in jobs in which demands, job control, and social support are high.[48,56]

The current study focuses on two distinct sources of work-related social support: coworker support and supervisor support. While studies regarding the DCS Model have often focused on a combined measure of social support, several authors have stated that it is worthwhile to focus research on distinct sources of social support.[26,57,58] This is especially important because the type of job and tasks could determine which source of social support is most salient, as is the case in healthcare[59].

Part 1: Research questions

The research questions from the first part of this thesis are schematically presented in Figure 1.

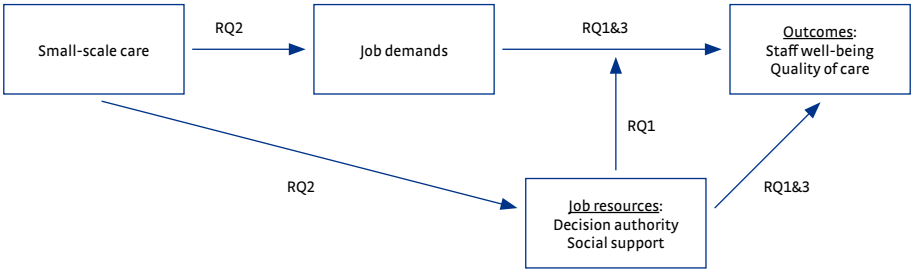

Figure 1. Schematic presentation of research questions from the first part of this thesis.

1. *Do job resources (i.e. decision authority and workplace social support) moderate (i.e. buffer) the adverse effect of high job demands on staff well-being, and moderate (i.e. activate) the positive effects of high job demands on staff's feelings of competence? (Chapter 3)*
   Healthcare workers in long-term-care facilities are faced with relatively high job demands that can have a detrimental impact on job-related well-being. The DCS Model assumes that the detrimental impact of (too) high job demands can be reduced or *buffered* when job resources – decision authority and social support – are high in a working environment. Additionally, the model assumes that jobs in which both job demands and resources are high can have positive consequences for staff in terms of creativity, learning, motivation and competence.

2. *In what way is small-scale care related to staff's job characteristics – job demands, decision authority, co-worker support, and supervisor support? (Chapter 4)*
   Chapter 4 addresses the effect of a new, more person-oriented and homelike care concept on the job characteristics of healthcare workers in dementia care. This concept of care is often referred to in the Netherlands as small-scale or group living home care. The job characteristics included in this study are those specified in the DCS Model – job demands, decision authority and workplace social support.

3. *What is the relationship between job characteristics and the prescription of physical restraints and psychotropic drugs? (Chapter 5)*
   Research shows that long-term-care facilities differ to a large extent in the use of psychotropic drugs and physical restraints. One explanation might lie in differences in the healthcare staff's work environment. Chapter 5 describes whether characteristics of an unhealthy work environment (i.e. (too) high job demands, low decision authority, and low workplace social support) in long-term-care facilities care are associated with greater prescription of psychotropic drugs and physical restraints.

Part 1: Methods

To answer the research questions in part one of this thesis, cross-sectional data from the first measurement cycle of the Living Arrangements[a] for people with Dementia study (LAD-study) were used. Box 1 briefly presents the design of the LAD-study for the part that is included in this thesis. Chapter 2 of this introduction section describes the complete study protocol.

To study the research questions addressed in Chapter 3, data from surveys filled out by healthcare workers about their job characteristics and job-related well-being were used. For Chapter 4, we used data on the characteristics of the long-term-care facilities assessed in an interview with the manager, observational questionnaires about residents' functioning and healthcare workers' surveys about their job characteristics.

Box 1. Short overview of the design of the first measurement cycle of the LAD-study.

Key characteristics of the *Living Arrangements for people with Dementia study (LAD-study)*:

- an ongoing monitoring study of the developments and variety in Dutch long-term-care facilities for people with dementia;
- the first measurement cycle took place from November 2008 – May 2009;
- 136 long-term-care facilities participated;
- all participating long-term-care facilities had dementia-specific care wards or dementia-specific homes providing nursing home care and were non-private, receiving state reimbursement dependent on the referral status of the resident;
- in all long-term-care facilities:
  - surveys were filled out by healthcare workers on their job characteristics and job-related well-being (n=1,147);
  - observational questionnaires were filled out by healthcare workers about residents' functioning and quality of life (n=1,327);
  - a manager was interviewed on staff ratio and characteristics of the long-term-care facility, such as small-scale care characteristics; and
  - registrations on the use of physical restraints and psychotropic drugs were obtained.

[a] Living arrangements and long-term-care facilities are used interchangeably in this thesis.

Part 2: person-centredness and well-being of staff and residents

Part 2: Theory of person-centred care

For part two of this thesis, the concept of personhood described by Kitwood[4] forms an important basis. In his work, Kitwood pleads for a person-centred approach to people with dementia in which the point of reference should no longer be person-with-DEMENTIA, but PERSON-with-dementia. The aim of this approach is to maintain the personhood of people with dementia by meeting their psychological needs. Personhood was defined by Kitwood[4] (page 8) as follows: "It is a standing or status that is bestowed upon one human being, by others, in the context of relationship and social being. It implies recognition, respect and trust. Both the according of personhood, and the failure to do so, have consequences that are empirically testable".

Kitwood described five needs which are assumed to be present in all human beings: comfort, attachment, inclusion, occupation and identity, and which come together in the central need for love. However, he stated that these needs are more obvious in people with dementia, who are far more vulnerable and usually less able to take the initiatives that would lead to their needs being met. This gives primacy to the role of the social environment and interpersonal interactions in meeting psychological needs and influencing well-being.[4,33,60] Social interactions which meet the needs of people with dementia are referred to as 'personal enhancers' (PEs)[61] and these comprise 'positive person work'.[4] Those which undermine needs are referred to as 'personal detractions' (PDs) which comprise a 'malignant social psychology'.[4]

In line with Kitwood's remark that both the according of personhood (personal enhancers), and the failure to do so (personal detractions), have consequences that are empirically testable, the Bradford Dementia Group developed Dementia Care Mapping.[61] Dementia Care Mapping is an observational tool which yields both quantitative and qualitative data about the experience of care from the perspective of the person with dementia. This is used in chapter 7.

Chapter 6 combines Kitwood's theory of personhood and person-centred care, and the DCS Model. With regard to person-centred care, staff's person-centredness, or in other words the recognition of the personhood of people with dementia plays a central role. To measure staff's person-centredness in this study, the operationalization of 'recognition of personhood' of Lintern and colleagues[35,62] – the recognition of people with dementia as sentient beings – was used. This operationalization is strongly inspired by Kitwood's work.

Part 2: Research questions

The research questions from the second part of this thesis are schematically presented in Figure 2.

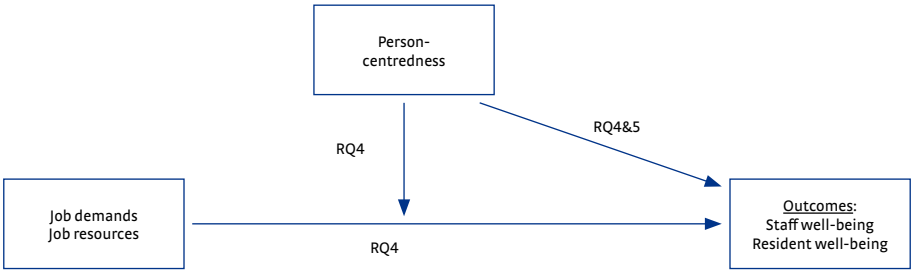

Figure 2. Schematic presentation of conceptual model studied in the second part of this thesis.

4. *What is the role of staff's person-centredness towards people with dementia in relation to characteristics of their work environment and staff's job-related well-being? (Chapter 6)*
   Chapter 6 expands on earlier research not only by studying how a person-centred attitude influences job-related well-being, but also by examining whether there are particular job characteristics that staff with a strong person-centred attitude require and benefit from. This is in line with occupational stress research which suggests that employees' personal characteristics, such as person-centredness, can influence (i.e. moderate) the impact that particular job characteristics have on their job-related well-being. Accordingly, both the direct and moderating effects of person-centredness are studied.

5. *To what extent do staff address or undermine the psychological needs of residents with dementia through their interactions, and how is this associated with residents' well-being? (Chapter 7)*
   Previous research demonstrates that person-centred staff-resident interactions are still limited, although these interactions have a positive impact on residents' well-being. They do not tell us to what extent different psychological needs, such as the need for occupation and attachment, are addressed or undermined by staff-resident interactions that occur. Furthermore, it is unclear if certain interactions are more or less likely to influence residents' well-being in a positive or negative way. Chapter 7 provides some insight into this issue.

Part 2: Methods

To answer the research questions from part two of this thesis, both cross-sectional data from the first measurement cycle of the LAD-study (Box 1), and Dementia Care Mapping (DCM) data from the in-depth study of the LAD-study were used. Box 2 briefly presents the design of the in-depth study which is described in more detail in Chapter 2. In Chapter 6, data from the surveys filled out by healthcare workers were used. In Chapter 7, DCM data from the in-depth study were used.

Box 2. Short overview of the design of the in-depth study of the LAD-study using Dementia Care Mapping.

The in-depth study of the Living Arrangements for people with Dementia study (LAD-study) was conducted:

- in ten of the participating long-term-care facilities – both relatively high and low scoring facilities on the primary LAD-study outcomes;
- to gain more insight into facilitators and barriers of high-quality dementia care;
- between December 2009 – March 2010;
- using Dementia Care Mapping to gain insight into the impact of care on the residents' well-being.

Outline

This thesis consists of eight chapters, including the introduction chapter. Chapter 2 presents the study protocol of the LAD-study. Next, Chapters 3, 4 and 5 contain the empirical studies of the first part of this thesis that focuses on the working conditions of healthcare workers in long-term-care facilities for people with dementia. Chapters 6 and 7 together form part two of this thesis, addressing staff's person-centredness. Finally, Chapter 8 presents an overview of the main findings, and contains a general discussion of methodological issues, as well as practical implications going forward. It concludes with recommendations for future research.

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