

Chapter 1

General introduction

The last decades the Dutch rehabilitation sector has been confronted with growing numbers of non-native patients. The process of rehabilitation in non-native patients is hampered by language and communication problems. Moreover, health professionals in clinical practice observed that non-native patients had more difficulties to understand the necessity of lifestyle changes and to achieve the treatment aims than native patients. This thesis addresses the process of rehabilitation care for non-native patients in The Netherlands by focussing on drop-out from rehabilitation treatment and potential solutions to improve the process of care for these patients.

Non-native citizens in The Netherlands

In The Netherlands, the status of origin is based on the country of birth of citizens and one or both of their parents. The definition of non-native origin is as follows: born outside The Netherlands and at least one parent born in the same country; or born in The Netherlands and both parents born outside The Netherlands. In The Netherlands, non-native citizens are divided in citizens of western non-native origin and non-western non-native origin. The status of a western non-native origin is given to citizens who are born (and one or both parents) in Europe (except The Netherlands and Turkey), North-America, Indonesia, Japan or Oceania. The status of a non-western non-native origin is given to citizens (and one or both parents) who are born in Turkey, a country in Africa, Asia (except Indonesia and Japan) or Latin America (www.cbs.nl). Because many citizens from Indonesia or former Dutch East Indies are from Dutch origin, these citizens are given the status of western non-native origin.

The general Dutch population contains 20% of non-native citizens and around 11% of these citizens have a non-western background. The percentage of non-native citizens in large cities such as Amsterdam is higher than in most of the smaller cities in The Netherlands (e.g., 49% in Amsterdam) (www.cbs.nl). Most citizens of western non-Dutch origin in The Netherlands are from Germany and the former Dutch colony Indonesia (1). Most non-native citizens of non-western origin have a Turkish or Moroccan background. These citizens came to The Netherlands as labour migrant around 1970 (2).

Health and healthcare use of non-native patients

Certain groups of patients of non-native origin in The Netherlands have disparities in their health status and healthcare use compared to native patients. The past years, many studies regarding the healthcare use and health disparities in non-native patients in The Netherlands have been conducted (3-7).

The incidence of diseases and the presence of risk factors differ between non-native and native citizens in The Netherlands. Cancer is less often present in non-native citizens (8), whereas diabetes (9;10) and chronic arthritis (11) are more prevalent in non-native citizens in The Netherlands. Overweight is more present in citizens of Moroccan, Turkish, Surinamese and Antillean origin (12;13) and non-native citizens practice sports less often (14). Schizophrenia is seen more often in non-native citizens of Surinamese, Antillean origin (15-17) and citizens, mainly males, of Moroccan origin (15), than in native Dutch citizens. In citizens of Turkish origin the prevalence of schizophrenia is comparable with native Dutch citizens (15-17). Thus, some somatic and mental diseases occur more frequent and some less frequent in specific non-native populations.

Citizens of Moroccan and Turkish origin in The Netherlands perceive their health status worse than native citizens, even after controlling for age, educational level, sex, marital status and employments status (18;19). However, these results must be interpreted cautiously because different ethnic groups attribute a different meaning to the concept of perceived health (20).

Non-native patients consult the general practitioner more often than native patients (18;21;22). Especially patients of Turkish origin consult their general practitioner more often (23). In contrast, the use of specialised health services by non-native patients has been reported to be lower, especially in patients of Turkish and Moroccan origin. Lower socioeconomic circumstances only partly explain this difference (24). Adult patients from Moroccan origin (25) and adults of 55 years and older of Turkish and Moroccan origin in The Netherlands less often consult a physical therapist (26). Furthermore, the use of inpatient nursing homes and homes for the elderly is limited among citizens of non-native origin in The Netherlands. However, the percentage of elderly of Surinamese origin in nursing homes is comparable with native Dutch elderly citizens (25). A potential cause for the low percentages of non-native citizens in homes for the elderly is that the atmosphere and daily routine in homes for the elderly are not tailored to the needs and culture of these persons (27), for instance adapted meals, being able to communicate in their own language and separate living rooms for male and female elderly (28). Furthermore, especially elderly citizens of Turkish and Moroccan origin in The Netherlands often receive more volunteer aid of family members or other persons in their network (29). The high level of consultations to the general practitioner and a relatively low use of specific healthcare services among patients of non-native origin potentially indicates that there are barriers in the access to health services and that the

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flow of patients from the general practitioner to specialised healthcare programmes is limited (22).

In international studies it has been shown that disparities in the provision of care to ethnic minority patients are present. Some of these disparities are communication problems and different treatment decisions by physicians in ethnic minority patients with chronic pain (30).

Finally, the drop-out rate of non-native patients in some of the specialised healthcare sectors is high. In two international studies, conducted in mental healthcare programmes, the drop-out rates have been reported as 29% and 52% in ethnic minority patients compared to 19% and 30% in native patients, respectively (31;32). In healthcare programmes for drug addicts, the drop-out rate in patients of non-Dutch origin has been reported to be 60% compared to 50% in native Dutch patients (33). Although the subject of drop-out in non-native patients in The Netherlands is regularly debated in clinical practice, there is limited information available in the literature regarding drop-out rates in these patients.

Rehabilitation treatment of non-native patients

The ethnic background of patients is not registered systematically in the healthcare sector in The Netherlands, because this is prohibited by law. Consequently, it is unknown how many non-native patients receive rehabilitation treatment yearly. The Dutch branch union for the rehabilitation sector, 'Rehabilitation Netherlands' (Revalidatie Nederland), annually presents a branch report, which contains information regarding the use of rehabilitation care by all citizens in The Netherlands. In 2007, almost 61.000 patients received rehabilitation treatment. More than 7.700 patients were admitted to a rehabilitation institute and 56.800 patients received out-patient rehabilitation treatment (34).

There is limited knowledge regarding the use of rehabilitation care by non-native patients. An explorative study among non-native patients and their care providers in rehabilitation showed that several barriers are present (35). These barriers are: communication and language problems; differences in expectations regarding the content of rehabilitation treatment; patients having problems regarding complicated rules on (financial) support for, for instance, assistive devices for persons with disabilities. Non-native patients having other expectations regarding the content of treatment might be influenced by limited proto-professionalism (36). Proto-professionalism refers to the

process whereby patients gain information on causes and treatment of diseases and learn the origin and treatment of their health complaints from the perspective of health professionals (see theoretical framework). Furthermore, rehabilitation institutes have not adapted their programmes to the needs of the (culturally) diverse patient population and often do not use professional interpreters (35). A study by Van de Ven showed limited barriers in the use of rehabilitation care by patients of Turkish and Moroccan origin. However, health professionals did sometimes feel insecure in coping with non-native patients in treatment (37).

Drop-out rates from rehabilitation programmes in the general population, outside The Netherlands, range from 10%-42% in pain rehabilitation (38-40), 22-55% in cardiac rehabilitation (41-44), and 45% in osteoarthritis rehabilitation (45). To our knowledge, no studies have been conducted regarding drop-out from rehabilitation programmes in the general population as well as in non-native patients in The Netherlands.

Although limited research has been conducted regarding the use of rehabilitation care by non-native patients in The Netherlands, the subject is debated regularly in clinical practice. The impression is that the course of the treatment process in non-native patients is complicated. Furthermore, health professionals are not fully confident in providing rehabilitation services for non-native patients (35;37). In Reade, centre for rehabilitation and rheumatology, where the studies of this thesis were conducted, the clinical impression was that non-native patients with chronic non-specific low back pain more often dropped out of treatment than native patients did. In order to test this clinical impression, a retrospective medical file study aimed to determine the difference in drop-out rate between native and non-native patients with chronic non-specific low back pain participating in a rehabilitation programme in The Netherlands. The results of this study are presented in **chapter 2** of this thesis.

Theoretical framework

The use of healthcare programmes by patients depends on a broad range of factors (46). To understand the way patients cope with diseases and their treatment, Kleinman (1980) introduced the concept 'explanatory model'. Explanatory models are notions about illness events, the diagnosis, and treatment of the disease (47). In line with this concept, the concepts of 'disease' and 'illness' are used. The concept of 'disease' is used for the dysfunction of organs or organ systems, or the dysfunction of (neuro- or psycho) physiological processes in the body (48). This concept is part of the biomedical approach used in many western countries. It is focused on curing or controlling the disease. The

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concept of 'illness' refers to the individual experiences in relation to negative changes in the well being of a person in terms of organic, psychosocial, and cultural aspects. Illness is about the definition, experience, and explanation of a disorder by an ill person and his/her network (48).

Kleinman makes a distinction between different sectors in the provision of (health) care. The 'Popular' sector is the sector that contains individual persons and their families and networks. The 'Folk' sector is the sector that contains 'Healers'. These healers, for example Winti healers, do not have an official position in the Dutch healthcare system. The third sector is the 'Professional' sector. This sector contains doctors, nurses, allied health professionals, etc. Each sector has its own knowledge and ideas about illness and health (47;49). The distinction between the different sectors is relevant for the studies in this thesis because patients may use all the sectors in their process of finding a solution for their disease or disease symptoms. In this thesis, we focus on the views of the Popular and Professional sector.

The theory regarding explanatory models is based on the notion that people experience illness and health differently because of differences in their social and cultural background. For instance, pain complaints in some social and cultural groups are deliberately kept private (46). Each person attributes an individual meaning to an episode of illness (35;47). In each new illness episode, new explanations arise or previous illness experiences are reinterpreted (48). These explanations are derived from available knowledge or beliefs in the healthcare sector, but are differently interpreted by each person. Explanatory models are dynamic and change in new situations and in contact with other persons or health providers.

Patients may explain health problems differently than physicians and other health professionals do. Understanding of these differences potentially improves the provision of care to patients. Health providers should be aware of the emotional, social, behavioural, and religious dimensions of a person's illness experience (46). Patients use information from different models in finding solutions for their health problem (46). It is important that healthcare providers create possibilities to manage the differences in explanatory models of patients and providers. Concordance between the patient's explanatory model and that of the health professional will lead to patient satisfaction regarding the treatment (50). This is only possible with good communication between patients and their care providers.

Unequal power relations between patients and care providers influence the negotiation process that occurs during the course of diagnosing disease complaints (51). Power differences between patients and health providers exist due to differences in education, social class, and the location (healthcare institute) where the care is provided (46). Furthermore, prejudices and stereotypes regarding differences between native and non-native patients influence the process of diagnosing a disease. For instance, physicians sometimes unjustly expect that non-native patients more often than native patients ask for medication as treatment option for their health problem (52).

As mentioned above, an explanatory model of health and disease is dynamic in nature (46). Proto-professionalism is the process whereby patients learn to perceive the origin and treatment of diseases from the perspective of health professionals. Among other options, this process enables patients to adjust their explanatory model to that of the care providers. By this process of proto-professionalism, patients gain more information on causes and treatment of diseases and develop a view on cause and treatment of symptoms (36). This process of proto-professionalism is enhanced by education, easily accessible popular medical information by television, internet, and books, and taking part in healthcare programmes. The process of proto-professionalism has been reported to be different in patients of non-native origin in The Netherlands (35;53). Potentially this is influenced by a lack of proficiency in the Dutch language and being brought up in a different (cultural) context and with another healthcare system. As a result of this different process, patients potentially are less informed about the possibilities of the healthcare programmes or have a different view on the origin and treatment of their complaints than their care providers. When patients demonstrate proto-professionalism and perceive their health situation from the perspective of their care provider, they will more easily take part in healthcare programmes and adhere to treatment given by health professionals (54). To improve the adherence to, and the use of, rehabilitation treatment, the explanatory model of the patient and health providers need to match or at least show some similarity with each other. However, when patients and physicians in the end can not agree on the origin of the disease and the specific treatment of the chronic non-specific low back pain, patients potentially drop out of treatment.

In this thesis, we focused on the interpretation and explanations of patients regarding the origin and treatment of their illness. Patients and care providers in the pain rehabilitation sector potentially have different ideas and knowledge of the origin and treatment of chronic non-specific low back pain. Patients might have the impression that chronic pain is solely caused by a medical problem such as a lumbar radiculopathy. This view is in

contrast with the view of physicians and health professionals who explain chronic pain by a multifactorial model, in which physical, psychological, and social-environmental factors interact (55).

Reasons for drop-out from rehabilitation

There is limited knowledge regarding reasons for drop-out from low back pain rehabilitation programmes. More days of sick leave (38;56;57), higher pain severity (57;58), being less active in sports (38), a lower age (57), and the idea that exercise did not help or aggravated pain (59) have been identified as predictors of drop-out in low back pain rehabilitation programmes. However, these predictors do not explain the exact reasons why patients drop out from (rehabilitation) treatment. A systematic review of qualitative and quantitative studies in patients with low back pain regarding their expectations of and satisfaction with treatment (60) showed that patients in general (i.e., not specifically selected for a non-native background) have a number of reasons to be dissatisfied with low back pain treatment, including: not obtaining a specific diagnosis of the pain; pain relief not being the main aim of treatment; lack of physical examination and diagnostic tests; lack of referrals to other therapy or specialists for further treatment; and no possibility for sickness certification. This review study seems to show that patients with low back pain often have different expectations regarding the content of treatment. Other sources of dissatisfaction reported in this review are limited information and instructions by the health workers, and care providers lacking the ability to listen, show respect, and include the patient in decision making. These sources of dissatisfaction potentially are reasons for refusal of or withdrawal from the prescribed rehabilitation treatment.

A review study provided an overview of different barriers on patient, provider and organisation level, which influence the treatment process and might lead to drop-out (61). The patient level refers to patient related characteristics (e.g. education and income), which determine how people make use of the healthcare system. The provider level refers to provider characteristics (e.g. skills and attitudes), which determine how health care is provided by professionals. The system level represents the system characteristics (e.g. policy and organizational factors), which determine how the care is organized around the patient.

The information in the literature regarding the reasons for drop-out in (non-native) patients is limited to a broad range of potential drop-out factors. Studies with more precise evidence on reasons for drop-out in patient with chronic non-specific low back

pain were lacking. Therefore the aim of this thesis was to determine differences in reasons for drop-out between native patients and non-native patients with chronic non-specific low back pain who dropped out from rehabilitation treatment in The Netherlands. The results of this medical file study are reported in **chapter 3**. Because there was limited information regarding the course of the treatment process in non-native patients, a qualitative study determined sources of tension in the interaction between Dutch rehabilitation physicians and non-native patients of Turkish and Moroccan origin during the first consultation, which might lead to future drop-out (**chapter 4**). Because the knowledge regarding the reasons for drop-out from the perspective of non-native patients is limited, the following research aim has been formulated: to determine reasons for drop-out, by semi-structured interviews, in patients of Turkish and Moroccan origin who dropped out from rehabilitation treatment. The results of this study are provided in **chapter 5**.

Interventions and strategies to improve healthcare for non-native patients

Patients of diverse ethnic and cultural backgrounds take part in healthcare programmes in The Netherlands. In 2000, the RVZ ('The Board for Public Health and Care') reported that healthcare for non-native patients in The Netherlands is not sufficiently adjusted to the needs of these patients (62). The Board has chosen the approach 'Zorg op maat' (Tailor-made care) to care for patients of non-native origin. This approach is based on the view that the healthcare system has to be differentiated in order to improve the accessibility and quality of the care for certain groups, such as non-native patients. This approach means that the healthcare system should be adapted to patients with different ethnic and cultural backgrounds, because people experience and explain health and illness in various ways (47). This adaptation process is called the 'interculturalisation of the healthcare system'.

A concept related to interculturalisation is culturally competent services. Culturally competent services are defined as: 'the ability to adequately understand and respond to the needs and concerns of individuals with disability and their families from ethnic and minority communities, with responses based on an accurate understanding of their specific cultural practices' (63). By creating culturally competent services health professionals are able to reduce the gap between the explanatory model of patient and the health professional. Whereas patients by the process of proto-professionalism increasingly perceive their health problem from the perspective of health professionals. Culturally competent services facilitate the process of proto-professionalism in patients, by helping them to gain knowledge on their illness and how to cope with it. Various

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interventions or strategies are available for health professionals to overcome the reported barriers in the accessibility and quality of healthcare in non-native patients. Among others these are: a health adviser with the same cultural background, adapted health education, professional interpreters, and cultural competence training (64-67). Furthermore, several Dutch educational publications aim to create cultural competence in medical students and healthcare providers (68;69).

In the rehabilitation sector, there is very limited experience with creating culturally competent services. In face of the fact that a prior study a decade ago already observed barriers in treatment (35) it is difficult to understand why so little knowledge on improving rehabilitation care currently is available. Many questions need to be answered in order to understand this gap in the literature and clinical practice. It might be that health professionals working at institutes without adaptations do not sufficiently evaluate their daily working methods in treating patients with a different cultural or ethnic background (70). Another option is that management policies of institutes function as a barrier for health professionals to overcome disparities in the use of rehabilitation care. Moreover, health professionals may experience a lack of knowledge or resources, which prohibits them to initiate cultural competent services.

The pain rehabilitation sector might benefit from available knowledge from other rehabilitation programmes regarding interventions and strategies that aim for improvement of rehabilitation treatment in non-native patients. In a Dutch rehabilitation institute in Amsterdam, an adapted multidisciplinary cardiac programme containing six adapted treatment modules and additional strategies for non-native patients was instigated. The programme was developed because non-native patients' physical complaints did not decrease and the methods to manage cardiac risk factors such as regular physical exercise and the consumption of healthy food were not applied after completion of the regular rehabilitation programme. The aim of the adapted programme was to improve patient participation in treatment, reduce physical complaints, and improve the maintenance of healthy living habits after completion of the programme. There was no knowledge regarding the effect of the adapted cardiac rehabilitation programme on the experiences of patients who took part in this programme. A qualitative study that aimed to explore the treatment experiences in patients of Moroccan and Turkish origin and their rehabilitation therapists regarding this adapted cardiac rehabilitation programme is presented in **chapter 6**.

As mentioned above, there is knowledge of interventions and strategies to improve the accessibility and quality of healthcare programmes for non-native patients. It was, however, unknown which interventions and strategies are implemented in the clinical practice of rehabilitation treatment. Furthermore, there was no knowledge whether institutes characteristics (e.g., a high percentage of non-native citizens in the service area of the institute) are related to having implemented adaptations for non-native patients. Therefore, the aim was to determine whether adaptations for non-native patients have been implemented in pain rehabilitation programmes by rehabilitation institutes and to determine whether characteristics of the rehabilitation institute are related to having adaptations for non-native patients in place. **(Chapter 7).**

Methodology

Various methods have been used in the studies which were conducted for this thesis. The drop-out rate and reported reasons for drop-out of native and non-native patients have been determined by a retrospective medical file study. This method has been chosen to verify whether there was indeed a higher drop-out among non-native patients and to determine the reported reasons for drop-out. Because there was limited knowledge of the reasons for drop-out in non-native patients, as well as in the general population, we used an explorative method (patient interviews) to create knowledge from the patient perspective of reasons for drop-out from a rehabilitation programme in patients with chronic non-specific low back pain. Patients were interviewed in their home situation in most cases with the use of a professional interpreter. Due to a lack of knowledge regarding the applicability of an adapted cardiac programme, the patients' experiences regarding this adapted programme have been explored by interviews. Lastly, a questionnaire was used to determine how often adaptations for non-native patients were implemented by rehabilitation institutions that offer rehabilitation programmes for patients with chronic pain. This method was chosen because this offered the opportunity to obtain quantitative data.

Specific setting: Rehabilitation in chronic low back pain patients and patients with cardiac diseases

The majority of the studies conducted for this thesis focused on patients with chronic non-specific low back pain who dropped out from rehabilitation treatment. Chronic non-specific low back pain is defined as low back pain that exists for longer than twelve weeks and cannot be ascribed to a specific pathology. Chronic non-specific low back pain is a major health problem and a cause of disability, medical expenses, and absenteeism (71). There is no evidence that the prevalence of chronic (low back) pain in ethnic minorities is

higher than in native patients (23;30). The aim of rehabilitation programmes for patients with chronic non-specific low back pain, which are based on physical training and cognitive behavioural training, is to improve the health-related quality of life of patients by coaching them to cope with their pain and its consequences (72).

The study presented in **chapter 6**, in contrast with the other studies in this thesis, deals with patients who have been through a coronary event, such as an acute myocardial infarction. These patients can benefit from a multidisciplinary cardiac rehabilitation programme (42;73), aimed at physical and psychological recovery and secondary prevention. This study was conducted because the cardiac rehabilitation programme has been adjusted with separate modules and strategies for non-native patients. This study offered the opportunity to explore the patients' experiences with this adapted rehabilitation programme. Knowledge regarding adaptations of rehabilitation programmes can be used to find solutions for the barriers in the accessibility and quality of rehabilitation programmes for patients with chronic pain. Cardiac rehabilitation is comparable with rehabilitation in patients with chronic pain because both programmes aim for lifestyle changes in health behaviour. An important difference between pain and cardiac rehabilitation is that in the latter type of rehabilitation treatment patients receive a specific medical diagnosis of their symptoms, which is lacking in patients with chronic pain.

Patients of Turkish and Moroccan origin

The studies in this thesis focused on patients of Turkish and Moroccan origin. These patients belong to the largest groups of non-native patients of non-western origin in The Netherlands. Although there are cultural differences between the two subgroups of patients, the groups in this thesis were too small to be presented separately. Despite the cultural differences between the two subgroups, there are also many similarities between the groups regarding their socioeconomic circumstances and migration history. Persons from Turkish and Moroccan background in The Netherlands who belong to the first generation labour migrants or migrated due to family reunification frequently received limited education, have a comparable position on the Dutch labour market (2;74), and live in the more deprived areas of larger cities such as Amsterdam and Utrecht where these studies were conducted.

Aim of this thesis

This thesis addresses the process of rehabilitation care for non-native patients in The Netherlands by focussing on drop-out from rehabilitation treatment and potential solutions to improve the process of care for these patients.

The overall research goals addressed in this thesis are:

- To describe the drop-out rate in native and non-native patients with chronic non-specific low back pain.
- To explore which factors could contribute to the premature ending of the rehabilitation treatment for non-medical reasons in native and non-native patients with chronic non-specific low back pain.
- To explore solutions for the limited accessibility of a cardiac rehabilitation programme for non-native patients.
- To describe the implementation of potential solutions for the limited accessibility of care in the pain rehabilitation sector.

More specifically, the following research aims were established:

- To determine the difference in drop-out rate between native and non-native patients with chronic non-specific low back pain participating in a rehabilitation programme in The Netherlands. **(Chapter 2)**
- To determine differences in reasons for drop-out (according to the medical patient file) between native patients and non-native patients with chronic non-specific low back pain participating in a rehabilitation programme. **(Chapter 3)**
- To explore which factors lead to tension in the patient-physician interaction in the first consultation by rehabilitation physicians of patients with chronic non-specific low back pain of Turkish and Moroccan origin. **(Chapter 4)**
- To explore which factors led to drop-out in patients with chronic non-specific low back pain of Turkish and Moroccan origin who participated in a rehabilitation programme. **(Chapter 5)**
- To explore the treatment experiences in patients of Moroccan and Turkish origin and their rehabilitation therapists regarding an adapted cardiac rehabilitation programme. **(Chapter 6)**

- To determine (i) whether adaptations for non-native patients have been implemented in pain rehabilitation programmes, and (ii) whether characteristics of the rehabilitation institute are related to having adaptations for non-native patients in place. **(Chapter 7)**

A schematic summary of the different studies conducted for this thesis is presented beneath, showing the participants in the different studies.

Chapter	Title	Participants
2	Higher drop-out rate in non-native patients than in native patients in rehabilitation in The Netherlands	Native (N=344) and non-native (N=185) men and women aged 15-90
3	Reasons for drop-out in rehabilitation treatment of native patients and non-native patients with chronic low back pain in The Netherlands: A medical file study	Native (N=11) and non-native (N=88) men and women aged 16-80
4	First rehabilitation consultation in patients of non-native origin: Factors that lead to tension in the patient physician interaction	Men and women of Turkish and Moroccan origin aged 24-45 (N=12)
5	Reasons for drop-out from rehabilitation in patients from Turkish and Moroccan origin with chronic low back pain in The Netherlands: A qualitative study	Men and women of Turkish and Moroccan origin aged 29-57 (N=23)
6	Adapted cardiac rehabilitation programme to improve uptake in patients of Moroccan and Turkish origin in The Netherlands: A qualitative study	Men and women of Turkish and Moroccan and Dutch origin aged 38-69 (N=11)
7	Adaptations to pain rehabilitation programmes for non-native patients with chronic pain	Rehabilitation centres and rehabilitation departments of general hospitals (N=27)

An overall discussion of the findings in this thesis is provided in **Chapter 8**.

Chapters 2-7 were originally written as separate articles for publication in international scientific journals. Therefore, there is some overlap between the different chapters. The introduction and the general discussion offer a link between the different chapters and an overview of the findings from this thesis.

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