

KADI LUBI

The role of information search and
interpretation in living with chronic illness.
The case of Estonian Parkinson's
disease patients



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32

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interpretation in living with chronic illness.
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Institute of Social Studies, University of Tartu, Estonia

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LIST OF ORIGINAL PUBLICATIONS

This dissertation is based on the following original publications, which are listed according to the order of publication and will be referred to in the dissertation by the listed Roman numerals.

- I **Lubi, K.**, Vihalemm, T., Krikmann, Ü., Paju, T. & Taba, P. (2013). “There is no need to tell me too much”: chronically ill patients’ strategies of controlling information inflow. *The International Journal of Communication and Health*, 1, 24–30.
- II **Lubi, K.**, Vihalemm, T. & Taba, P. (2014). Illness-related information seeking: the case of Parkinson’s disease patients. In: Lee, G. (Ed). 2014 2nd International Conference on Social Science and Health (ICSSH 2014). Book Series: *Advances in Education Research*, 59 (98–111). Delaware: Information Engineering Research Institute.
- III **Lubi, K.**, Vihalemm, T. & Taba, P. (2016). Patients’ interpretation of CAM-related information: manoeuvring between patient and consumer positionings. In: Marinescu, V. & Mitu, B. (Eds.) *The Power of the Media in Health Communication* (73–90). Oxon, UK: Routledge.
- IV **Lubi, K.** The adaptation of everyday practices in the adoption of chronic illness. *Health: (Accepted for publication)*.

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AUTHOR’S CONTRIBUTION

Study I: The author was responsible for all aspects of this study (including the secondary analysis of the data, and writing the theoretical, empirical and discussion parts), except for the data collection, as data was collected during the InfoPark study.

Study II: The author contributed to all aspects of the study: the development of the study questionnaire, data collection, data analysis and writing all parts of the article in cooperation with the co-authors.

Study III: The author contributed to all aspects of the study: conducting in-depth interviews, analysing data and writing all parts of the article, in cooperation with the co-authors.

Study IV: The author was solely responsible for defining the research problems, conducting research, interpreting results and drawing conclusions.

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1. INTRODUCTION

“Problems are solved, not by providing new information, but by arranging what we have known for a long time” (Wittgenstein, 1953).

This quotation by Wittgenstein, after more than 60 years, illustrates and summarises the core of this thesis, which deals with the role of information seeking¹ in the formation of the experience of living with a chronic illness. In the context of today’s information society, the quotation from Wittgenstein might seem unconventional: we expect new information about different areas of life to be continuously available. Technical means that make the information available have created new opportunities for personal modification of the time, content and forms of information received, and new forms of recycling information across channels and generating interactions. These opportunities also shape what we define as new or useful information. However, there is scientific evidence in the area of health communication showing that people subjectively perceive a lack of information (e.g. Kutner et al., 1999; Clayman et al., 2008). If information is available and there are a lot of ways to gather it, then what is the problem? The problem might lie in the meaning expressed in the quote above: it’s about more than information provision. The formation of the experience of living with a chronic illness is a complex process, where information needs vary and information seeking – both in terms of the search for sources and the interpretation of content – is both a means and a result of the adaptation to a chronic disease. There are many forms of illness-related information, from the general meaning-making of illness, health and healing to instructive treatment information. All of these forms of information are significant when dealing with an incurable progressive disease, which is the focus of this study.

The question of how information provision can be used to help ill people to adapt physically, psychologically and socially is crucial, both from the personal and institutional points of view. Chronic diseases are connected with the advancement of medicine and ageing societies. In addition to the biomedical aspect, the social aspects of assistance become crucial: how is it possible to support chronically ill people to maintain their ordinary ways of life and social relations as much as possible? How can we support their self-management abilities to continue living with the disease by rearranging their daily practices while preserving as much as possible of their subjective quality of life, social relations and independence in undertaking activities?

This thesis is interdisciplinary in nature, linking areas of medical sociology and (health) communication, and contributes to the scholarly discussions of information-seeking and interpreting practices. I have investigated people diagnosed with chronic incurable Parkinson’s disease (PD). The aim of the thesis is **to explain the role of information search and interpretation in their management of being ill (i.e. physical, psychological and social challenges)**. As a

¹ The terms *information search(ing)*, *information seek(ing)* and *information-seeking behaviour* are used interchangeably, not as in the conceptual model provided by Wilson (1999).

practical implication, I propose solutions to improve institutional arrangements of information provision in order to support their self-management. This approach differs from the individual- or interaction-centred approaches to the information needs of patients (e.g. Kutner et al., 1999, Guo et al., 2013, Ackerman et al., 2015). Various forms of communication, including its material, embodied forms, are analysed in order to conceptualize the chronic illness experience. For this thesis, I have analysed in-depth interviews with PD patients from the InfoPark study (collected in 2003, **Study I**), questionnaires (**Study II**) and in-depth interviews with PD patients (performed in 2013–2014; **Studies III and IV** and additional analysis).

Theoretically this thesis approaches the issue from the sociological concept of (patients’) agency by investigating the role of information seeking or rejection of information in the management of illness as important means of maintaining social resources and skills. The thesis discusses general structural constraints that shape the current public understanding of chronic illness and what problems arise in the context of today’s media society. The theoretical inspiration for the thesis came from Bourdieu’s (1984) views on structure and agency in the course of illness, as well as from the writings of Cockerham (2005), who is critical of individualistic approaches to illness-related social changes.

Besides the overview article, this thesis consists of four studies. **Study I** analyses the role of information in different stages of the disease and explains different strategies used by chronically ill people to control information inflow, in terms of content and the amount of information, to fit their emotional and social resources. **Study II** explains the links between people’s previous habits of news media use and their illness-related information-seeking activity, and the re-establishing of social relations while ill. Both studies empirically explain different strategies of illness-related information search and interpretation, and changing expectations regarding the mode of information provision from medical professionals and institutional communicative support.

Study III goes further in explaining the information-seeking practices of chronically ill people in regard to complementary and alternative methods of treatment (CAM)², which usually are regarded as “alien” in the field of biomedicine and are not supported by primary caregivers. The investigation of how the CAM-related information is obtained, interpreted and situationally hidden from other people (including doctors) explains how ill people have learned to operate as patients in the medical field by considering its rules, authorities and

² In the context of the current thesis, the definition of the term *CAM* is used as provided by Eisenberg et al. (1993: 246): (CAM is) “everything that is not evidence-based medicine”. The thesis excludes complementary methods that have been accepted as part of treatment, relief, physiotherapy etc. (e.g. massage). Thus, here CAM covers energetic or “magic” healing, i.e. all kinds of treatments by alternative non-medical practitioners, non-evidence-based “natural” or “herbal” products etc.

values, and how they operate as consumers. **Study III** explains the social (power) relations that shape perceptions of accepted behaviours.

Study IV examines the development of illness self-management as a process of negotiations over the maintenance, modification or termination of everyday habits and the role of information seeking in this process. The argument is raised that the maintenance of everyday practices is related to self-dignity and, therefore, the possibility of maintaining or slightly modifying the habitual lifestyle motivates the information search. Information retrieval and interpretation is a form of managing changed expectations.

Study IV reveals the problems of current self-management approaches, which through the abandonment of or major changes in existing habits lead the individual to acquire new ways of daily operating resulting from illness-related needs. Based on the social practice theory, the empirical evidence explains why these approaches often fail and are not adopted until at least five years after the diagnosis.

1.1. Study questions

The main objective of my dissertation is to explain the role of information-related practices within the illness experience based on the example of patients of PD in Estonia, and my study questions are:

1. **What is the role of illness-related information seeking in the management of an incurable progressive illness?**
 - 1.1. How do (changing) public understandings of health and illness influence the popular conceptualisation of personal chronic illness management?
 - 1.2. How are information needs and information-seeking behaviour conceptualised in patients' self-management approaches?
 - 1.3. How can the practice theoretical approach contribute to the conceptualisation of the role of illness-related information seeking in patients' adaptations to living with a chronic illness?
2. **Based on the example of Estonian PD patients, how are illness-related information search and interpretation connected with patients' adaptations to a chronic illness?**
 - 2.1. What strategies of illness-related information search and interpretation can be empirically described and how are they connected to the stages and progression of the disease, general media use habits and the socio-demographic backgrounds of patients?
 - 2.2. What characterises the information needs in different stages of disease and social contexts?

- 2.3. How does illness and treatment information seeking help or hinder personal chronic illness management: the maintenance of social relations and subjective life quality and the (re)construction of dignity?
 - 2.4. How do illness and treatment information search and interpretation vary across different power contexts and social roles (the physician-patient relationship versus the supplier-consumer relationship)?
 - 2.5. How do Estonian PD patients use illness-related information in adjusting their lifestyles and everyday habits?
- 3. Based on the example of Estonian PD patients, how is it possible to arrange illness-related mediated communication to support patients in their lifestyle modifications in the conditions of a progressive disease, while preserving subjective quality of life and autonomy as much as possible?**
- 3.1. How does the current information provision from medical institutions, patients' societies and mass media hinder or support patients' gradual coping with PD and independent readjustments of their lifestyles?
 - 3.2. How can mediated communication supplement (instructive) interaction with physicians and nurses during different stages of illness?
 - 3.3. What changes in illness-related mediated communication are needed in order to support, as much as possible, patients' gradual, independent readjustments of their lifestyles and social relationships to meet the physical and mental changes that come with the progression of PD?

The cover article is divided into five chapters. In the first chapter, I answer the first question by contextualising the object of research – illness-related information seeking – theoretically and in relation to the existing empirical research, and give an overview of the Estonian context and PD. The second chapter, “Methodology”, explains in detail the methods that were used in all studies. In this part, the relevant aspects of the empirical studies (e.g. study participants, procedures and analysis) are described. Also, the methodological challenges and limitations are discussed. The third chapter presents a summary of the study results, which addresses the second research question. The fourth chapter, “Discussion”, answers the third study question by elaborating further on the obtained results and relating them to previous studies and findings from earlier literature. The final part, “Conclusions”, summarises the cover article.

2. SETTING THE PROBLEM

In this chapter, I will explain the theoretical conceptualisations of chronic illness and the related public norms and expectations. I first examine how the (changing) public understandings of health and illness influence the popular conceptualisation of personal chronic illness management.

Then, I consider how patients' information needs and information-seeking behaviour are conceptualised in patients' self-management. After discussing the relevant research findings, I look at how the practice theoretical approach contributes to the conceptualisation of the role of illness-related information seeking in patients' adaptation to living with the chronic illness.

2.1. The conceptualisation of chronic illnesses in today's society

Health and illness are both biomedical and socio-cultural phenomena. Some scholars have even stated that medicine should be conceptualised as a social science, as the "boundary between scientific medicine and society /.../ has been blurred" (Ule et al., 2014: 19). Authors argue that medical science has to interact more with other fields, including social sciences, because the problems shift from disease-related questions to illness-related questions, i.e. from pathology to the social phenomena that accompany health and disease (ibid.).

Chronic illness³ has become a key issue today, with the majority of ill people suffering from one or several chronic conditions (WHO 2011, Ward et al. 2014)⁴. In general, the longer life spans and the consequent ageing of (economically developed) societies are strongly connected with the development of medicine, as there has been a continuous increase in instances of chronic diseases (Larsen, 2013: 4)⁵, so the experience of being chronically ill also involves the aspect of age and ageing.

Changes in the balance of diseases from acute to chronic have forced social institutions to look for other approaches and solutions in order to adapt to a situation where many society members suffer from various chronic conditions. This need has brought the management of chronic diseases into the foreground.

³ The terms *disease* and *illness*, are not used interchangeably, but in a way described by several authors (e.g. Kutner et al., 1999, and Larsen, 2013: 4), where *disease* refers to pathophysiological aspects of a clinical condition and *illness* expresses the individual experience of a condition, including the perception of a disease by the patient, the family and general society.

⁴ According to the World Health Organization's (WHO) "Global status report on non-communicable diseases 2010" (2011), deaths caused by chronic diseases reached 63% of overall deaths in 2008 worldwide. Based on U.S. data, Ward et al. (2014) conclude that one in four adults suffer more than one chronic condition.

⁵ In the context of neurodegenerative diseases, such as Parkinson's disease, the main influence of the ageing population is evident in the increase in the number of patients.

It is critical to help people with chronic diseases adapt to their illnesses while maintaining, as much as possible, their ordinary ways of life and social relations (**Study IV**). Adaptation is a complex, multidimensional and holistic process involving whole life readjustment, due to the physical, social and psychosocial implications caused by the development of the disease (Larsen & Hummel, 2013: 88; Bury & Monaghan, 2013: 72). According to the psychological approach, adaptation has to be dealt with on an individual basis and unique circumstances include personal traits, past experiences, culture and values (Larsen & Hummel, 2013: 75). In addition to physical interventions, successful adaptation requires other aspects of daily life – cognitive, emotional, behavioural and psychological – to be taken into account (*ibid.*: 91).

This thesis approaches the adaptation and communicative mechanisms of this process from the (communication) sociological point of view by analysing individual adaptation and individual ability to live with illness in the context of social norms and practices of the society in which the individual operates on a daily basis. Approached from the concept of social *structuration* (Giddens, 1984), social structures play a strong role in shaping individual adaptation to illness (Cockerham, 2013: 128), but also individual chronic illness management may shape the social structure. Today's patient management approaches (e.g. shared decision-making, patient-centredness, self-management, caregivers' involvement etc.) enable and expect individual participation, but in real life may be difficult to implement due to the lack of resources, legislation etc.

Developed countries have become ageing societies where large parts of populations have to negotiate social practices and relations with chronic illness and, by doing so, contribute to social restructuring. The increase in the number of people with chronic conditions has led to societal changes in many Western countries. These changes include legal changes, such as the raising of the age of retirement by the Estonian parliament ("The amendment act of the state pension insurance and associated acts", Riigi Teataja, 2010), governmental encouragement of employing older people, e.g. flexi-time and other remedies offered by the Department for Work and Pensions of the UK government ("Employing older workers. An employer's guide to today's multi-generational workforce", 2013), an increase in institutions dedicated to the management and research of chronic diseases (e.g. the Chronic Disease Prevention and Health Promotion division of the Centres for Disease Control and Prevention in the US, the Department of Chronic Disease of the National Institute for Health Development in Estonia etc.). The activities of institutions that support patients' rights have also intensified. All of these societal activities aim to help people with chronic conditions by supporting the continuation of active participation in social life as long as possible.

At the same time, people with chronic illnesses participate as agents in the labour market, education, leisure etc. and their actions shape, directly or indirectly, the performance of their colleagues, schoolmates and others, creating both opportunities and tensions.

The described processes have contributed to *medicalisation*, the penetration of rules and criteria used in medicine – as one sub-system of society – into the daily processes of other sub-systems of society, such as economics and governance. As a result, daily issues are treated as diseases (Conrad, 1992: 209). For example, obesity, hyperactivity and alcoholism are treated as medical pathologies. Advice from physicians, pharmacists and other medical professionals is considered in decisions related to the production and supply of food, transport arrangements etc. (Uibu & Vihalemm, 2017: 346).

Conrad states (ibid: 9) that “/.../ medicalization is a form of collective action” meaning that not only medical professionals, but also other patients, lay people (ibid.) and holistic approaches (i.e. CAM methods) (Lupton, 2012: 131) can (re-)produce medicalisation, which extends the structural influences over agency. Therefore, medicalisation is seen as the expansion of medical power and expertise within society, which limits individual choices and agency.

On the other end of the scale, the Western neoliberal⁶ approach of governance intervenes in medicine. Patients are expected to contribute actively to the adaptation process, i.e. to participate in self-management programmes which teach the skills to manage long-term chronic conditions (e.g. Lorig et al., 1999, 2001). Also shared decision-making (SDM), which is described as a process where “clinicians and patients share the best available evidence when faced with the task of making decisions /.../” (Elwyn et al., 2010), is a specific form of empowerment of the patient to adapt to a chronic condition. Despite the good idea of involvement, SDM has been criticised and questioned in the light of patients’ real ability to actively participate in SDM or any other processes because of the lack of knowledge and skills (Cockerham, 2013: 128). Although the SDM definition also mentions “support to consider options” (Elwyn et al., 2010), it is important to note that it is only medical and clinical information under discussion and not the emotional and/or cultural aspects and the interpretation of the meaning of illness that are actually needed (Ule et al., 2014: 27). The routine form of medical communication is currently connected with disease-related information: symptoms, aetiology, treatment options, self-management tools etc. There is little or no attention paid to the social life aspects of the illness that direct people to alternative channels. This generates bottom-up demand for media production, which is influenced by medicalisation trends.

The socio-cultural interpretations of health and illness are offered in mass media. The active participation of audiences is today the natural part of all mediated areas, including health and illness, life and death (Livingstone, 2013).

⁶ In the context of this thesis, the term *neoliberal* is used in line with the understanding of medical sociology, i.e. the neoliberal approach reflects the growing number of individuals who take responsibility for their health and seek or choose goods or services to improve their health (see e.g. Fries, 2009; Nettleton, 2013; Dutta, 2015). However, according to this understanding, individual responsibility is limited mainly to the biomedical understanding of “right” actions, goods or services.

The health- and illness-related information that circulates on public channels can offer some support to patients' struggle in their self-management and social re-positioning that is not provided by the medical system. The role of mass media as a supporting agent is increasing, because only a few institutions, such as patients' and rehabilitation organisations, support patients in their social transition, and they do not include all people who need support. The general structural mechanisms motivate the (semi-)independent health- and illness-related information search, interpretation and application among people with chronic diseases.

Therefore, chronically ill people face **several challenges during the course of the illness**: the processes of medicalisation and mediatisation (see chapter 2.2) provide institutionally and publicly recommended norms, choices and expectations. The adaptation process of chronically ill people is influenced by these clear prescriptions and sets even higher demands and pressures "to act right", not only in terms of medical institutions, but also in terms of public expectations of "right actions", which develop together with the widespread availability of medical recommendations (i.e. the occurrence of medicalisation) offered through media, which construct further acceptable meanings (i.e. the occurrence of mediatisation). All of these structurally provided regulations and understandings influence the experience and exert pressure on chronically ill people.

On the other hand, chronically ill people have to manage opposing neoliberal health expectations, which increase the pressure to take individual responsibility for adaptation and self-management. The challenge is that, in order to be structurally accepted, the "individual" must act in accordance with institutional rules and recommendations. This somewhat conflicting situation may create individual tensions, leading to contradictory actions, e.g. turning to complementary and alternative medicine (CAM), which may lead to conflicts with institutional authorities and public norms (see the findings presented in chapter 3.3). In addition, shifts in meanings (of "being ill", of "the right actions" etc.) influence personal social relations and, therefore, people need to learn to navigate not only the physical challenges of the disease, but also the social challenges that the illness brings about, influencing a wide range of the total adaptation process.

2.1.1. Public and professional conceptualisations of the chronic illness

The patient-physician relationship has been and will remain an important part of the chronic illness experience. Economic and political conditions influence the patient-physician relationship directly, for example through limited time for visits, and long waiting times between doctor's visits, and indirectly, through public norms. This sub-chapter proceeds from the premise that illness-related information search and interpretation is strongly shaped by the social norms of "being" ill. Therefore, this sub-chapter elaborates on the conceptualisations of health, illness and being ill, and discusses individual agency in this context.

Public and (medical) professional understandings of illnesses, social relationships and responsibilities of ill people have changed throughout history. In the distant past, diseases were publicly understood as religious problems that might involve punishment (for past sins), redemption (in the case of death) or the hope of a miracle (in the case of healing) (Ule et al., 2014: 20). Due to its revolutionary success in treating and preventing diseases, medicine achieved a prominent societal position and strong influence during the 20th century (ibid.:11). This position has enabled medicine to cross boundaries and take on a prominent and authoritative role in other spheres of social life (Nettleton, 2013: 5). Due to its authority, medicine determines “right” and “wrong” behaviours, which are related to various aspects of (social) life, lifestyle etc. and not only in regard to disease-related and specific clinical aspects.

A modern institutional conceptualisation of illness has been provided by Parsons (1951a: 431), in which illness is seen as a “state of disturbance in the 'normal' functioning of the total human individual”, including both biological and social aspects of the individual’s life. This premise sets the social requirement for the ill person (the patient) to cooperate with medical specialists in order to get well as soon as possible and “return” to society. In characterising his concept of the sick role, Parsons (1951a: 437) wrote:

“There seem to be four aspects of the institutionalised expectation system relative to the sick role. The first is the exemption from normal social role responsibilities /.../ The second closely related aspect is the institutionalised definition that the sick person cannot be expected by 'pulling himself together' to get well by an act of decision or will. In this sense also he is exempted from responsibility – he is in a condition that must be 'taken care of' /.../. The third element is the definition of the state of being ill as itself undesirable with its obligation to want to 'get well' /.../ the fourth /.../ is the obligation/.../to seek technically competent help.”

Although described from the perspective of an ill person, this quote indicates the rights and responsibilities of the medical professional as well. According to Parsons, only the medical professional can decide about the diagnosis and “grant” the patient status and thereby temporary exclusion from the “normal” duties of a member of society (Parsons, 1951b).

However, the concept of the “sick role” does not match the needs of social systems in the light of the prevalence of chronic conditions. People with chronic conditions usually carry on with (most of) their social relations and duties. Since in chronic conditions it is not possible to talk about final recovery, ending these social relations would mean life-long isolation, which is psychologically and socially unimaginable. No less important is the fact that due to the high prevalence of chronic conditions Western societies is in danger of losing a remarkable amount of its work force, which would place an enormous burden on the rest of society (Ward et al., 2014). Both Parsonian and neoliberal approaches to health and illness (see chapter 1.1) promote the role of the individual in taking care of him/herself and searching for help (Fries, 2009; Dutta,

2015). The main difference is in the understanding of responsibility: while Parsons (1951a) declares that the responsibility is institutional, the neoliberal approach stresses individual responsibility (Dutta, 2015: 115).

The shift of responsibility is related to the “discursive shift from sovereign power to disciplinary power” proposed by Foucault (Petersen, 2012: 8), which indicates the changing role of (medical) institutions. The paradigmatic change in the doctor-patient relationship prescribes changing tasks. In terms of the medical sphere, the role of medical professionals is to guide people towards higher self-monitoring and teach them “techniques of self” in order to develop self-governing capabilities (ibid.). Together with the rise in the importance of patients’ active participation in the treatment process, the role of individual responsibility has increased.

Therefore, medical professionals are no longer the dominant figures in the process, but instead facilitators representing the “links in a set of power relations” (Lupton, 1997: 99). Although the policies of patient-centredness, SDM etc. promote patients’ own monitoring and control, this does not mean a decrease in institutional medical control. This situation can be explained by Foucault’s “pastoral power”, which appears benevolent – guiding people towards happiness – but can be seen as serving as a “mechanism of control” (Petersen, 2012: 14). Out of that grows the wider discursive context in health and illness related to the moral obligation to be or to get healthy (Townsend et al., 2006), which is communicated both by the medical system and by healers. Therefore, ill people develop a wide range of techniques in order to become well (Rose & Novas, 2005).

According to the neoliberal approach, people should take individual responsibility and individual actions to proactively improve their health (Fries, 2009; Dutta, 2015: 32). These social norms seem to have an impact on the public understanding of those who suffer from chronic illnesses. The neoliberal approach treats health as a commodity and is driven by consumer culture; therefore, specific health needs and related products are offered to consumers by “connecting the responsibility to consume with the responsibility of self-care, positive thinking, and positive connections with other consumers” (Dutta, 2015: 114–115). Specialised illness-related web pages, TV broadcasts, magazines and health-related smartphone apps have increased the opportunities to track one’s health (Santoro et al., 2015). The problem is that people may lose interest after multiple uses (Voncken-Brewster et al., 2014). The availability of a wide range of diverse sources contributes to the development of expert patients who relate to scientific and related expertise (Petersen, 2012: 13), but online communities of expert patients also act as informal self-management programmes (Willis, 2014). However, as Dutta (2015: 62) notes, the “appropriate” communicative messages are formed by experts, which leads to a decrease in or absence of agency. The flip side of expert-driven messaging and communication is that these are one-directional (ibid: 13) and experts represent “elite teams that derive their class power from the distance between the experts and the recipient communities they target” (ibid: 220).

Based on the information above, the study proceeds from the following general premises about the structural context of chronic illness-related communication:

- 1) the epidemiological transition from acute to chronic diseases and the multi-dimensional process of *medicalisation* “normalises” diseases throughout society and supports the circulation of health-related information, products and services produced by medical, commercial and public actors;
- 2) shifted understandings inside the medical system, from treatment to patients’ being active in terms of their illness with the help of specialised nurses and patients’ support groups, and means of self-monitoring and self-care.

These general trends strongly shape the norms related to the “good practice” of being chronically ill. Professional and public understandings of accepted and recommended performances, and references to “good” and “bad” actions according to the logic of the medical system (Stein, 1990:9 8; Fries, 2009; Lupton, 2012: 10) and of the general society may support or oppose each other. Thus, chronically ill people may be faced with conflicting norms: obedience to medical instructions versus taking individual responsibility to maintain as good physical and social condition as possible (Fries, 2009; Lupton, 2012: 134). There seems to be a paradoxical lack of clear opinion within the medical community regarding this matter: while physicians are dissatisfied with people who do not take responsibility and lack initiative, they are also dissatisfied with people who do take initiative (Kendall et al., 2011).

2.1.2. Conceptualisation of the individual management of illness: the question of agency

The neoliberal stress on individual responsibility, medicalisation and promotion of self-technologies has led to criticism from medical sociologists (see e.g. Cockerham, 2013:128 and 2015: 163; Abel & Frohlich, 2012; Cockerham & Scambler, 2010), who problematise the structural limitations of lifestyle choices:

“/.../ health lifestyles are shaped from the top down by structural influences that people adopt as their own. In this scenario, structure channels health and other lifestyle practices down particular pathways instead of others that could be chosen” (Cockerham, 2013: 128).

Cockerham calls for re-opening the structure-agency debate in health concepts, as many daily practices influence health outcomes (ibid).

Authors hold opposing views in relation to individual agency and activity in the condition of medicalisation and the mass circulation of relevant information. Gabe (2013: 52) states that medicalisation involves “portraying the individual patients and the lay public as essentially passive and uncritical in the face of modern medicine’s expanding jurisdiction”. Other researchers (e.g. Kohler

Riessman, 1989; Williams & Calnan, 1996; Ballard & Elston, 2005) hold the opposite position, saying that people are becoming more active and critical (e.g. people speak up on such topics as vaccination and actively request prescriptions and clinical tests). Nettleton (2013: 129) states that “patients do not necessarily accept medical interpretations for medical advice, and are not therefore as easy to manipulate /.../”. Thus, people’s trust in medicine is not taken for granted in today’s society. Rather, there is a need to constantly struggle for legitimacy (Paradis et al., 2013) and practices of other areas of life (e.g. practising citizens’ right to decide over their bodies or clients’ right to ask for service) merge into the medical system by supporting the agency of individuals. Accordingly, a chronically ill person can take initiative and express a critical position towards medical services.

According to authors who postulate the increasing agency of individuals, information serves an important role in empowering individual agents (see Kohler Riessman, 1989; Willis & Calnan, 1996; Ballard & Elston, 2005). Sceptical authors (e.g. Cockerham, 2005 and 2013; Lupton, 2012) point to the structural (e.g. class and ethnic) differences in regard to health information (to be discussed in detail in the next sub-chapter) as well as problems in relation to the implementation of information, e.g. in SDM and the personal management of illness (e.g. Lupton, 2012; Paradis et al., 2013; Cockerham, 2013).

Cockerham (2005, 2013) has postulated the thesis of transformative medicalisation, based on the concepts of the theory of *field* and *habitus* (Bourdieu, 1977; 1984; 1990), in which individual actors have little agency in the medical field (Cockerham, 2005; Cockerham, 2013: 134–136). According to Bourdieu, practices used within certain fields are designed to gain and maintain social relationships that are orchestrated by actors holding dominant positions and determined to maintain the present power structure and keep the system stable (Bourdieu, 1990: 53). Social, political and economic changes have led to changes in the medical field. There are a growing number of institutions (governments, parliaments, ministries, national health services, pharmaceutical marketers, alternative health care providers etc.) that interact with the medical field and set their own conditions (Ule et al., 2014: 18), including financial and administrative restrictions (e.g. short visit times and organisational consolidation). The opportunities provided by information communication technologies (ICT), e.g. digital internet-based services, shape the channels, styles and contents of communication. Due to media transformations, doctor-patient interactions are changing (Meier, 2014: 115), quality checks and privacy issues will grow in importance (Santori et al., 2015), and the collective, lived expertise of patients will continue to spread via social media (Meier, 2014: 115), further transforming doctor-patient interactions. There are usually several print materials and web sources available about a particular (chronic) disease, treatment options etc., which are distributed by doctors or via patients’ societies. However, as **Study I** revealed, there is not always a readiness to read these materials or, as shown in **Study IV**, the information does not match the precise situation-determined individual information needs, which are often related to

everyday habits. This leads to a situation where systemic changes implicitly or explicitly assume the patient is able to search for or at least is able to interpret information and construct meanings actively and (partly) autonomously, but the patient is not supported or assisted in this regard most of the time during illness.

The reasons for the (perceived) lack of support can be economic and political, but also derive from the chronic nature of the illness itself. Due to the chronicity, it is not possible to support people in every single illness-related detail or question. Therefore, communication is fragmentary and often limited to urgent and technical disease-related information (Ule et al., 2014: 95), and patients have to manage the varied rules of the medical field and conduct different types of interactions that may not fit harmoniously into the overall treatment plan in terms of quantity and quality.

To sum up, the thesis proceeds from the approach that structural mechanisms play an important role in individual adaptation to a chronic illness and in the communication and mediation of this process. I will take a closer look at how health- and illness-related communication is influenced by these transformations and the role of illness-related information search and interpretation in the adaptation to living with a chronic illness.

2.2. Information search and interpretation in the formation of the experience of living with a chronic illness

Nowadays, media are a part of people's everyday lives and as they contribute to the construction of our social world, there is not always the need for the direct usage of media (Couldry & Hepp, 2017: 15; Kramp, Carpentier & Hepp, 2014: 9). Due to the participation in the construction of the social world, the social world "is not just mediated but mediatized: that is, changed in its dynamics and structure by the role that media continuously (/.../) play in its constructions" (Couldry & Hepp, 2017: 15).

Therefore, as Couldry and Hepp (ibid.) state, new forms of mediated communication saturate many aspects of our daily lives and this is true for health and illness as well. Mediatisation involves media in the process of institutionalisation, leading to the increased role of institutions in mediating the construction of the social world, and thereby influencing the degree of agency (Couldry & Hepp, 2017: 22–24). Through these large-scale processes, mediatisation influences the ways people perceive social expectations related to their illness experience and thus, institutionally prescribed expectations regarding illness-related (communicative) activity may evoke tensions, resistance or even confrontation (see chapter 3 regarding the role of information and communication in the processes of adaptation and (re)socialisation and the role of information in bodily and social coping).

In the following sub-chapters, I will take a look at media's role in constructing illness-related public understandings and chronic illness-related information, and the practice theoretical approach to illness-related communication.

2.2.1. The mass media in constructing the public understanding of illness and health

Guttman (2000:1) has stated, “public health communication interventions are purposeful attempts to bring about desired health-related changes”. She claims these interventions are social phenomena engaging individuals and organisations (ibid.: xv).

Due to the paradigmatic shift in the understandings of the roles of patients and physicians, media play an important role in providing a unique opportunity to signify public understandings of (health) risks (see e.g. Mercado-Martinez, 2001; Driedger et al., 2009). The importance of mass media is related to their capacity to provide current information in the context of information shortage, especially on topics where the first-hand experience may be lacking (Driedger et al., 2009). Some authors (ibid.) have concluded that the influence of the mass media is greater on people with lower levels of knowledge. Other researchers have claimed that by raising awareness, mass media may form an important tool in reducing health discrepancies between social classes (Jung et al., 2015), and they also have the power to shape public understandings and knowledge (Goodfellow et al., 2013; Portnoy et al., 2014). The latter is achieved via the promotion of good health, healthy lifestyles and the prevention of diseases (Mercado-Martinez et al., 2001). Media structures help to move neoliberal ideas and values into daily practices (Dutta, 2015: 18). However, media may also create negative perceptions and attitudes, e.g. in the case of mental illnesses: “consistently over time, media coverage of mental illnesses has been overwhelmingly negative and often inaccurate” (Sieff, 2003). Therefore, media can contribute significantly to health- and illness-related public perceptions.

Opposing opinions have been expressed regarding several problems. Sengupta and Wang (2014) claim that the effectiveness of personal sources is higher than that of mass media sources in impacting both attitude and intention. The importance of personal or non-medical sources is higher in more extreme cases. These cases involve vaccination (Holton et al., 2012), and the usage of complementary and alternative medicine (CAM), especially in life-long and/or incurable diseases (Wanchai et al., 2010). A wide variety of sources, including friends, family and media, are used (ibid.), and these sources can be more prominent in CAM-related topics than in evidence-based medical sources. **Study III** revealed that a negative (media) frame does not necessarily influence attitudes when CAM usage is considered or desired and approved by non-medical “important others”.

Although friends and other personal sources are commonly used, there are multiple sources for health information gathering (Jardine et al., 2015; O’Hara et al., 2012). Several health communication studies address the impact, usage and importance of traditional media (e.g. Burzynska et al., 2015; O’Hara et al., 2012). Other researchers (e.g. Della et al., 2008; Meier, 2014) acknowledge the importance of new media (Internet and Web 2.0 technologies). However, Della et al. (2008: 169) also warn health marketers and communicators that new

technologies are not just extensions of existing sources; rather, there is a need to carefully contribute to the content, which should integrate constructs from interpersonal and mass communication. Similarly, the findings of **Study IV** highlight the importance of content, the need to adjust content and not only the structural forms of information provision. Dutta (2015: 192) has analysed the role of technology in health communication research and has stated that technology itself is seen as a magic bullet to influence target populations, but the importance and favouring of technology has led to the erasure of “fundamental questions of communication that highlight interpretation, meaning and discourse” from discursive spaces (ibid.: 195). Thus, the focus is on technological innovations of communication sources or message-related platforms while leaving other issues (societal-level impacts etc.) unexamined (ibid.).

Muussees et al. (2012) have related different factors to the usage of different information sources. According to their results, the main importance of the availability of a variety of sources is that each source provides specific opportunities to fulfil patients’ information needs (ibid.).

Media can also contribute to the process of decision-making (Holton et al., 2012). There are a lot of studies describing the positive and important role of information in illness-related decision-making (see e.g. Spies et al., 2006; Jordan et al., 2013; Liebherz et al., 2015). Mass media may also influence decisions that are not favoured by physicians (Holton et al., 2012). Therefore, the role of media in information provision can be either positive or negative in terms of biomedical context, but it still has an influence on the decisions and actions of lay people.

The study of Holmes et al. (2009) clearly indicates the changed nature of health communication, which relies more on mass media than on direct contact with health care providers. However, as various authors have concluded, there is a need to take ethical aspects into consideration when planning (effective) communication (ibid.).

2.2.2. Information-seeking about chronic illness: patients’ access, format and content-related problems

Dutta-Bergman (2004) has examined marginalised populations and has stated that health communication is intertwined with issues of power. More specifically, he says that power issues are related to differences in access to the medical system (ibid.). He argues that the status or influences of social structures determine access to evidence-based medicine (Dutta-Bergman, 2004) and healthy choices (Dutta & Basu, 2007). Therefore, marginalised people seek multiple treatment options (i.e. both allopathic and homeopathic medicine), which “challenges the modernist conceptualization of health, illness and treatment” (ibid: 119). Although Dutta-Bergman’s focus is on the marginalised population in India, it is possible to draw a parallel with Western ageing populations in that there are institutional restrictions that appear as access issues due

to increasing pressures on the medical system (**Study IV**), but there are also expectations of individual actions that may lead people to search for solutions outside of conventional medicine (**Study III**).

Most of the research on the delivery and reception of chronic illness-related information focuses on individual support, the development of patients' skills and knowledge related to the disease. Researchers have addressed the consumption of particular media and sources of information provision (e.g. Kutner et al., 1999), patients' information-seeking behaviour (e.g. Muussees et al., 2012; Johnson, 1997), the role of health literacy in the physician-patient relationship and treatment outcomes (e.g. Roumie et al., 2011), shared decision-making (e.g. Hain & Sandy, 2013; Edwards & Elwyn, 2009) etc. However, as Hummel (2013: 324) has stated, medical professionals often overestimate patients' abilities to process received information. As the results of **Study I** showed, there is not always readiness to accept illness-related information, especially when it does not deal with social adaptation. Received information may be perceived as inappropriate or insufficient, because it sets expectations on changing daily functioning that match the needs of the illness rather than individual habits and routines (**Study IV**).

Much of the topical research refers directly or indirectly to the uses-and-gratification approach that was popular in audience research in the 1960s and which assumes that people will use media rationally and functionally in order to gain something personally useful (Katz, 1959). As Katz (1959: 23) has stated, this particular approach assumes that media usage is related to "people's values, their interests, their associations, their social roles". According to this approach, illness-related information can be predefined and is meant to manage functional problems accompanied by the disease or socially raised tensions that could jeopardize social status. These studies investigate, for example, the rate of information-seeking activities of chronic disease patients or their caregivers (e.g. Reifegerste & Hartleib, 2016), the role and trust in social media in terms of health topics (e.g. Lin et al., 2016), information seeking in terms of information needs and decision making (e.g. Kilicarslan-Toruner & Akgun-Citak, 2013), the role of socio-cultural factors in information seeking (e.g. Rooks et al., 2012) etc. This approach follows the Parsonian institutional conceptualisation of illness and the role of the patient.

Authors have criticised the uses-and-gratification approach because it limits the use of media for collective, "social", political, economic or cultural purposes (Jensen, 2002: 161), and it overlooks the habits of media use. Only having a functional need for information does not ensure an information search if it is not a habitual behaviour (**Studies II and IV**). The need to maintain the existing lifestyle is mainly related to the perceived symbolic meaning that everyday practices carry: the role of habitual activities is related to (self-) dignity. The capability of performing activities in a routine manner provides assurance that the illness has not (yet) affected the ways people perceive themselves. When the illness progresses, people need information and support regarding how to implement changes gradually and in the least disturbing manner.

Regarding information on chronic illness, Mercado-Martinez et al. (2001) have claimed that disseminated information in print media is incomplete and biased compared to the information on acute diseases. Van der Wardt and co-authors (1999) came to a similar conclusion and suggest more frequent and more accurate media coverage of chronic diseases. Participants also stated the need for more and better health-related information in a study by Diomidous et al. (2012), but there is also the need for appropriate forms of information.

In addition to the need for more information, Mercado-Martinez et al. (2001) claim that even when information on chronic illness is published, it focuses on the reproduction of the “biomedical model of disease”. Therefore, social and other relevant aspects of illness-related information are excluded, although they are of greater interest to patients in terms of adaptation to the illness and individual actions (ibid.). In the context of supporting self-management, Been-Dahmen et al. (2015) have also stated that support is largely related to the medical aspects of illness, while social and emotional aspects are overlooked. The diagnosis of a chronic illness reveals a need to reformulate the social roles within the context of work, family and other social relations. Lupton (2012: 85–86) highlights the social nature of illness by claiming that even when an illness is not fatal, it “removes people from their social roles and activities”. The change in social roles can be notable as a “seriously ill /.../ person becomes a permanent patient, involving a major change of status” (ibid.).

Another problem regarding health messages is related to the mobilising information (MI) proposed by Holton et al. (2012). As they explain, this is similar to the concept of “call to actions” used in mass communication research. “MI enables people to act on existing ideas and motivations” and is related to the media’s role in empowering people, but they conclude, similarly to earlier studies, that media may cover the topic, but do not offer solutions: what kind of additional information public or health sources could provide etc. (ibid.).

Not all information needs of chronic illness patients are related to the practical management of the illness; some are connected to the emotional aspects of illness experience, as well as to social relations and power problems (McDonnell et al., 2009). Based on a survey among chronic obstructive pulmonary disease patients, Paap et al. (2014) claim that social life is among the three main domains of health-related quality of life. Another study by Dietz et al. (2013) investigated the renegotiation of social roles in the case of chronic aphasia⁷ and discovered three main themes where people need renegotiation of social roles: a person’s social and interpersonal lives, community interactions and hobbies, and communication changes. Therefore, in order to manage one’s illness successfully, there is a need for more than physical treatment. The management of social issues contributes to the general illness experience. Mahon et al. (2014) have found that chronic illness patients, among other

⁷ Although speaking difficulties may appear only in the later stages of Parkinson’s disease, other visible motor symptoms may create the same kind of shifts in the same spheres (see chapter 4.3).

problems, struggle to adapt to a new (social) life as they have to continuously make changes in their lives, and that this makes them dependent on others.

Authors investigating illness and health information have rarely approached the issue from the classic encoding/decoding concept of reception analysis developed by Stuart Hall (1973[1980]). This approach proceeds from the premise that an encoded meaning may change in reception: audience members may negotiate or oppose an ideological message. The principal difference between earlier approaches and encoding/decoding is the understanding that meaning can change during the communication process. As Hall (1973[1980]: 120) explains: “‘distortions’ and ‘misunderstandings’ arise precisely from the *lack of equivalence* between the two sides in the communicative exchange”. Although every communicator would prefer the decoding of messages via dominant-hegemonic readings, there is still the possibility that messages are decoded either via negotiated or oppositional reading (Hall, 1973[1980]: 125–127). In this theory, Hall clearly indicates that audiences create meanings and this again reveals the weakness of the majority of health communications research. In health communications research, the “right” meanings are supposed to be created by the medical professional as a communicator, and negotiation or oppositional reception is abandoned or seen as a deviation from the mainstream.

The methodological problems with research also show the attempt to translate study results in the way they are verbalised, i.e. hidden meanings remain undiscovered or results are described based on the researcher’s point of view on how recipients might interpret studied phenomena (Michelle, 2007). To use the researcher’s view in an interpretation can be misleading, as the actual process of meaning creation happens at the level of reception, not at the level where it is constructed (ibid.). Audiences play an interpretative role, they are engaged in all spheres of lives and they are no longer passive, but active participants in the communication process, which requires focussing more on the views of the audience in communication studies (Livingstone, 2013).

So, when we take a closer look at current health communication studies, they fall more under the structural functionalist paradigm, where the leading role and power is seen to belong to (medical) authorities, who create (medically hegemonic) messages, establish the process of communication and draw conclusions based on feedback and measurable outcomes. In addition, the question of the physical embodied aspects of long-term illness adaptation arises.

2.2.3. The practice theoretical approach in analysing illness-related information seeking

Practice theory is something scholars have different views on; there are various concepts and understandings (Schatzki, 2001: 1). As Rouse (2006: 499) explains, “practices can range from ephemeral doings to stable long-term patterns of activity”. Because of this wide range of understandings of what practices are, the scope of practice theory and respective research varies. Practice, as a carrier

of meaning, has become a primary object of research (ibid.), but the emphasis changes according to the point of view. In the current thesis, I follow the approach of Cockerham (e.g. 2013), who, based on the concepts of field, habitus and capital developed by Bourdieu (1977, 1984 and 1998), emphasises structure over agency. The individual aspects of practices are also discussed in the light of the role of institutional or structural influences, indicating that although individual decisions may be shaped by structure, individual everyday aspects also play an important role in the development of new practices (e.g. Schatzki, 2013: 36; Vihalemm et al., 2015: 42).

In terms of the patient, there is no readiness or willingness to adopt new media routines just because the illness “forces” them. On the other hand, doctors feel that the system provides everything necessary (i.e. all important illness-related information) to support adaptation, but that patients themselves may be resistant. The study of Ward et al. (2004) on health communication revealed that information-related intervention can worsen the treatment outcome and increase symptoms, indicating indirectly that pure information provision has low efficacy. A newer study on e-health tools showed that content has to match individual interests, as well as provide new information in order to ensure not only the first, but also repeated, usage of these tools (Voncken-Breswster et al., 2014). Another reason for avoiding information regardless of the source could be that information about possible developments and further symptoms can be frightening and create or intensify uncertainty. The reaction to potentially unpleasant information may lead to a worsening of symptoms, because there is a lack of emotional readiness to absorb overly advanced information and, therefore, (semi-)automatic bodily routines are interrupted. In order to protect him/herself, an avoidance strategy towards illness-related information might be chosen (**Studies I and II**).

The core concept of habitus contributes to understanding this process (Bourdieu, 1977: 72–95). Bourdieu (1977: 79), by claiming that “subjects do not know what they are doing”, refers to the unconscious nature of habitus, which is a set of dispositions organised as strategies, although not intended as strategies (ibid.: 73), which shape individual behaviours, and personal and social expectations (Scambler, 2012: 74). The decisions the agent makes within the field, together with the external influences from the structure, are also incorporated into the habitus (Cockerham, 2013: 136).

It is important to note that habitus, according to Bourdieu, is not only something characteristic to individuals, but the term can be widened to include different social groups who develop their own habitus, i.e. forms of reactions and actions (Bourdieu, 1998: 7). In the context of chronic illnesses, it is possible to talk about (collective) patient habitus determining the ways the behaviour of a “good patient” are seen and understood in terms of individual responsibility and structural commitment or obedience. The relationships within the field and power struggles are related to the presence and skilled usage of capitals, which are the resources any agent or social group might have. Examples from the medical field reveal that specific medical knowledge is a capital enabling the

power and status of authority. In any other field, the authorities of the medical field would occupy a lower position in terms of the power hierarchy. The unequal distribution of capitals is understood to be the result of the social reproduction of power (Abel & Frohlich, 2012), i.e. it is how collective habitus has agreed to treat respective functions. Finally, the habitus, capitals and field are parts of practices and these practices are reproduced within the field in order to maintain social stability.

Close to the notion of collective habitus is the concept of the social practice, defined as “a routinized way in which bodies are moved, objects are handled, subjects are treated, things are described and the world is understood” (Reckwitz, 2002: 250). Thus, there are certain ways people do things and are used to doing them and, since these actions are routinised, they also frame the tackling of novel actions. The early approaches of the practice theory saw social practices as rather static, meaning that each structure reproduced itself by reproducing practices performed by individual agents (Rouse, 2006; Shove & Pantzar, 2011). It is important to note that different activities can be parts of one or more practices and practices form bundles (Schatzki, 2013: 34–36). This complex nature of activities and practices provides one explanation of why individuals or groups do not immediately change their habitual actions in slightly changed situations. As Schatzki (2013: 39) claims, the emergence of the practice bundle takes time because at first people must know which bodily action to perform and then there is a delay before practical understandings and bodily repertoires change. In the case of a chronic disease, there are several practices that need to emerge, e.g. interpreting new information, and acting differently in some situations because the abilities of the body have changed. What makes the situation complicated is the fact that according to the general understanding of “being ill it is still expected that ill people will make drastic changes after diagnosis”. As this usually doesn't happen (at least not immediately), these patients are seen as rebels who are not taking individual responsibility for their situations (at least in terms of general [medical] understanding), and are fighting against the structural “norms” or even the system and its authorities (i.e. are engaged in power struggle). As Rouse (2006) concludes, although practices are individual performances, they take place in a certain context (e.g. a social structure) that must be taken into account. In addition to the knowledge of how to act bodily, practices also require continual and routine reproduction to emerge and persist (Shove & Pantzar, 2011), which provides an additional explanation of why the existing general understanding persists and why new skills or ways of doing things are rejected.

The other side of the continuum is the dissolution of the practice bundle, which happens only when “overwhelming, frequent, or large-scale changes occur” (Schatzki, 2013: 42). In the case of a chronic illness, this situation can be related to the extensive physical change caused by the disease, which influences regular activities, e.g. car-driving or potato peeling. The dissolution can be related to activities which also affect self-definition, and this can cause a feeling of being stigmatised because of the inability to perform some bodily action.

Despite the possibility of getting stuck in the individual nature of practices, practices are still seen from and related to the macro-level, giving practice theory a wider social scope (Schatzki, 2001:14). The theory of social practices approaches health and illness communication from another perspective. Firstly, it does not view illness as a condition, but sees the process of illness-related communication as an integral part of a person and other areas of his/her life. Secondly, it helps to understand how individual choices are related to the previous life of a person, including acquired skills, knowledge, habits and practical influences. And finally, it takes into account the role of structural influences that might affect individual choices.

There is a growing “invasion” of the medical field by other experts who have started a power struggle over the dominant role and, in this changed political and economic context, medical knowledge is no longer the only capital that ensures authority (Ule et al., 2014: 12). This is seen in discussions related to alternative health care options. The consumerist approach treats patients as equal partners who are able to evaluate goods and services and make informed choices regarding usage. This leads to a decrease in the authoritative and control power of medicine in the process of the daily management of chronic illnesses. Alternative approaches might be abandoned due to the lack of ability to discuss them: these approaches exist outside of the scope of evidence-based medicine. It is likely that, in situations like this, the power of the medical profession is used in order to give the “right”, i.e. medically approved, instructions for further actions.

This thesis seeks to explain individual information-seeking strategies in the context of structural prescriptions and affordances regarding the development of cultural and socio-economical influences, i.e. in terms of critical conditions. I share the critical view of Cockerham (2005) regarding the individual behaviour change paradigm, as well as the concern of Ule et al. (2014: 83) about the overly specific or technical language and narrow, pre-defined options of medical communication. It is not only a matter of developed speaking and writing skills, but it is also important that there is an actively communicated understanding that a patient has been heard and understood (ibid: 84). Patients’ organisations offer additional structural support by providing more emotional support. Even when there is improvement in these aspects, success is not guaranteed, as the emphasis is on technical solutions. The auditory and reception research of communication theory helps to explain why a chosen tactic may lead to unsuccessful communication.

In the following sub-chapter, I will explain the reasoning behind the selection of Parkinson’s disease patients for this study.

2.2.4. Parkinson’s disease patients as subjects of research

Parkinson’s disease (PD) is the most common neurodegenerative disorder, causing motion disorders in approximately 1% of people age 60 or older (Tabata et al., 2008). The onset of PD is usually between 50 and 70 years of age, the

peak onset being in the sixties (International Parkinson and Movement Disorder Society). The incidence rate of PD in Estonia is 152 cases per 100 000 inhabitants and it is estimated that there are around 3000 PD patients in Estonia (Taba & Asser, 2003).

According to the Estonian treatment guidelines (Taba et al., 2008), the symptoms may be non-specific (fatigue, decrease in mood, difficulties in performing daily actions etc.) during the first years of the disease, causing a delay in diagnosis. The specific symptoms can be divided into motor (tremor, hypokinesia, rigidity and postural instability) and non-motor (psychiatric or autonomous disorders). The symptoms disturb and complicate the performance of regular daily activities. As the disease progresses, an individual has to adjust his or her routines at some point during the course of the illness, because the continuation of actions in a habitual way becomes difficult or impossible.

There is a need to support PD patients in their re-socialisation because of the chronic nature of the disease, long-term suffering and the ageing population.

The target group of this study consisted of Estonian patients with a diagnosis of PD, who in a sociological sense can be regarded as a sample of critical cases (Patton, 1990: 174). A critical case sample is a targeted sampling strategy in qualitative research, where the study focuses on a case that shows the target of the study in its maximal or minimal conditions of existence, i.e. “if it happens there, it will happen anywhere” or, vice versa, “if it doesn't happen there, it won't happen anywhere” (ibid.).

The reason PD patients represent a critical case is related to technical and socio-cultural barriers. The survey “Me. The World. Media” showed that people older than 65 years have limited usage of foreign and Internet-based sources. Therefore, their main sources of information are doctors and special books that are distributed to the patients by both doctors and the Estonian Parkinson's Association (Taba et al., 2007). The availability of this kind of information makes this target group well informed. Technical and socio-cultural barriers promote individual passivity⁸ in information seeking and lead patients to follow the instructions given by medical professionals. Due to the usage of selected sources, PD patients are less affected by the general medicalisation process and illness construction.

2.3. Estonian context

The study site was Estonia, which regained its independence 25 years ago, after the collapse of the Soviet Union. The society has gone through significant political and economic changes. The focus during the transition period was on market liberalisation and global integration, and Estonia has been viewed as a positive example in terms of market reform (Pashkov, 2011: 464). At the same

⁸ Passivity and lack of interest may also be non-motor symptoms of the disease (related to possible depression).

time, the development of social services has not been satisfactory according to public opinion, and this has led to the general public understanding that social transformation has been less successful than expected (ibid.)

The 25 years of independence have brought about major changes in the healthcare system. The meaning of “being ill” has changed together with the socio-political changes and in Estonia the intertwined processes of medicalisation and individual responsibility have influenced the understanding of “being ill”.

Together with the development of medical science, the changes in the health care sector have been economic in nature, i.e. the focus has been on health care effectiveness (Lai et al., 2013; Aaviksoo & Sikkut, 2011). Unfortunately, this has limited the development of the medical system in relation to the needs of today’s society: although the number of doctors is comparable to the EU27 level, there are considerably fewer nurses, which limits the support for the management of chronic conditions (Lai et al., 2013). Another problem connected with the lack of human resources is the limited time per patient, leaving little time for health topics besides those directly related to present health status and treatment plans. Based on a report by Lai et al. (2013) another question arises: could the current Estonian medical system manage the health requirements even without the problems in human resources? This brings us to the development of the health sector in Estonia.

As mentioned, the transitions and reforms in the health care system have been generally based on economic factors. These reforms have involved medical training and the development of health policies and health sciences. Health policy research is conducted under the authority of the Department of Public Health and research interests are mainly involved with “applied research on public health, health management and health economics, as well as providing training in public health and health management” (Lai et al., 2013: 58). There have also been notable steps taken to develop interdisciplinary research in behavioural and health sciences, which is internationally highly regarded. Still, these research interests do not cover health communication, which indicates the lack of local evidence-based developments in the health communication area. According to current curricula, health communication disciplines form only a very minor part of the total medical studies of both physicians and nurses and the subject is taught at very early stages of studies.

The general understanding needs to be shifted to strengthening positive health and to getting people to actively participate and take responsibility for their health (Uibu & Vihalemm, 2017: 348). This is supported by the expansion of the capitalist consumer society, which promotes the neoliberal view of active search and consumption of available health care products and services, as well as the role and importance of individual responsibility (Fries, 2009). Yet, as the used sources may not always be evidence-based, this might unwittingly position a patient in confrontation with the medical system.

The results of the nationally representative survey “Me. TheWorld. Media” indicate that higher agency in health-related questions is related to younger age,

being female and higher education (Uibu & Vihalemm, 2017: 353). In addition, people with more active and individual health habits are willing to be critical of medical opinions, leading to medical pluralism (see the empirical evidence in Chap. 4.3), involving not only the usage of alternative methods, but also different conceptions of health and illness (ibid.).

The higher agency and level of confrontation of biomedicine can be related to the wide Internet usage characteristic to Estonia. As the results of “Me. The World. Media” indicate, the use of the Internet among the younger generation is nearly one hundred per cent, but the older generation has also adapted rather well to info-communication technology (ICT). A total of 46% of people aged 65–79 have Internet connections at home and 42% use the Internet regularly (among the middle-aged group, these numbers are 84% and 82%, respectively).

The reason why Internet (or mass media) usage has increased in importance, including in health areas, is due to the above-mentioned issues: problems with access to professional help, and the need to find solutions to individual problems. Audiences, including Internet audiences, are not seen as passive observers of communication, but as active participants who can produce content by themselves (Livingstone, 2013). The exchange of experiences via web sources can provide some relief. Reliable health-related web sites do exist, and there is also an official web page and forum for Parkinson’s disease patients (www.parkinson.ee). However, the usage is rather low and irregular, indicating the low importance of the Internet for getting answers to situationally connected questions from sufferers. For the current elderly generation, this might be related to the lower usage of the Internet. With the ageing of the current middle-aged and younger people, the importance of Internet-based information searches regarding health- and illness-related activities will likely increase.

To conclude, besides the development of economic aspects, there is a need for the development of the social aspects (a sufficient number of medical professionals, the development of supporting structures for adaptation etc.) of the Estonian health care system. It is likely that the focus on comprehensive adaptation in supporting the development of the management of chronically ill people will lead to further economic developments in the ageing society.

3. METHODOLOGY

Data collection, methods and analysis are described in detail in the relevant part of each publication. Table 1 summarises the data collection and analysis of all of the studies:

Table 1. Overview of data collection and analysis

	Data collection	Analysis	Connection to study questions
Study I	Qualitative research, where 36 standardised interviews of PD patients passed through secondary textual analysis. Interviews were conducted in the InfoPark study in 2002.	Respondents' comments were coded and analysed comparatively according to the cross-case method. The coding scheme was developed deductively after reading, and multiple units of analysis were used. Text units were divided into two categories, of which one described information-seeking strategies and the other represented the different stages of the disease.	1.1; 1.2; 2.1; 2.2; 2.3; 2.5; 3.1; 3.3
Study II	Quantitative research, where 144 standardised questionnaires were used (response rate 57.6%). In addition to pre-defined answers, the participants also had the opportunity to add additional sources and their own thoughts in the free format of open-ended questions. The study was conducted in 2011–2013.	The survey data was analysed with SPSS software. For the analysis of open-ended questions, content analysis was used.	1.1; 1.2; 2.1; 2.2; 2.5; 3.1; 3.3
Study III	Qualitative research, where 22 interviews were conducted in the formats of individual in-depth interviews and focus groups. The study was conducted in 2013–2014.	The coding of interview transcripts was performed following the grounded theory approach. The analysis involved general self-positioning regarding CAM and/or evidence-based medicine. There were several coding categories defined, which led to the more general categories concerning the medical and economic fields and to the relevant self-positionings as patient, consumer or patient-as-consumer.	1.1; 1.2; 1.3; 2.3; 2.4; 3.3

	Data collection	Analysis	Connection to study questions
Study IV	Qualitative research, where 16 interviews were conducted in the formats of individual in-depth interviews and focus groups. The study was conducted in 2013–2014.	The empirical analysis was based on the grounded theory approach. The development of the coding scheme was built on two categories. Practice elements formed the first category and adoption of self-management skills, bodily movements, daily routines (eating, dressing etc.) and information seeking practices formed the other category.	1.1; 1.2; 1.3; 2.1; 2.3; 2.5; 3.2; 3.3
Additional analysis	Qualitative research of 16 interviews, conducted in 2013–2014, in the formats of individual in-depth interviews and focus groups.	Interview texts were coded based on categories derived from the study questions of the current thesis. Categories for analysis were: 1) Information-based (e.g. information search, abundance and deficiency, and constructing meaning), 2) Information seeking strategy-based (used strategies, relation to personal social life/relations/habits etc.), and 3) Mediated communication-based (e.g. current versus expected communicative support)	All research questions

3.1. Methods

I used both quantitative (questionnaire) and qualitative (cross-case analysis and the grounded theoretical approach) methods in this thesis.

To understand the general trends of illness-related information-seeking strategies, I used the quantitative research method, specifically a standardised questionnaire with additional open-ended questions.

For this thesis, the quantitative research was needed to get a wider understanding of the general trends in illness-related communicative needs, i.e. how and from where information was searched for and how current media consumption influences information searches and interpretation during illness. The quantitative research (**Study II**) made it possible to map problematic areas, and provided hints for detailed research in **Studies III** and **IV**.

For qualitative research (**Studies I, III and IV** and the current thesis), I used in-depth interviews. The data collection and analysis are explained in detail in the sub-chapters 2.2 and 2.3.

3.2. Study sample and data collection

The target group of this study were PD patients. The reason for choosing PD patients is explained in detail in chapter 2.2.4.

In **Study I**, I used the pre-collected data of the InfoPark research project (data collected in 2003), which contained 36 interviews with PD patients (Taba et al., 2003). The data was collected as structured interviews, and the initial aim of the InfoPark study was to evaluate PD-related expectations and the information needs of patients, caregivers and medical professionals (ibid.). Taking into account the context of this thesis, only 36 interviews of PD patients were used as a study sample, i.e. no interviews with caregivers or medical professionals were used in the thesis.

For **Study II**, I conducted individually disseminated questionnaires; the help of local neurologists was used in the five biggest cities of Estonia: Tallinn, Tartu, Narva, Kohtla-Järve and Pärnu. The initial information about the study, the participation agreements and the signed informed consents were disseminated at doctors' offices. A total of 250 questionnaires were given out, of which 144 were returned (response rate 57.6%).

Data collection for **Studies III and IV** and the present thesis was continuation research of **Study II**, involving patients who confirmed their readiness to participate in this follow-up to the questionnaire. I conducted in-depth semi-structured interviews (both individual and group) with 16 PD patients. In addition to their readiness to participate in the follow-up study, I also took into consideration the participants' answers to open-ended questions in the questionnaire. Different illness-related background variables were taken into account in the selection process in order to allow for the varied study population which would characterise further clusters. The illness-related background variables were duration of the disease, membership in a PD Patients' Society and cluster affiliation.

In prior interviews I had explained the aims of the research, and the study participants had signed informed consent forms.

The study participants quoted in the current thesis were given codes in order to guarantee their anonymity. A code reflects a respondent's gender (M/F), age and cluster (I, II or III, based on the cluster analysis of **Study II**). For example, the code for a female respondent of age 68 in Cluster II is F68-II.

In addition, I used the findings of the analysis based on the study "Me. The World. The Media" (2011 and 2014).

3.3. Analysis

For **Studies I-III**, all interviews passed through repeated close reading and respondents' answers were coded.

For **Study I**, I performed a secondary analysis of the interviews, which was comparatively based on the cross-case method. In the coding scheme, I used thematic categories of information-seeking strategies (1) rejection versus readiness for new information, 2) the type of missed or avoided information, and 3) wanted or unwanted arrangement of communication). As these structured interviews had inner divisions of information seeking during different time

dimensions (i.e. pre-diagnostic time, time of diagnosis or time after diagnosis), I also took this distinction into account. However, the final analysis focused only on the last two stages⁹ of the disease, which form the focus of the current thesis.

For the quantitative analysis (**Study II**), the SPSS analysis software tool and Cramer's V statistical analysis were used. For qualitative analysis, the texts of open answers were coded thematically according to the information's content types. I developed the coding system by using the grounded theory approach in interpreting the actual answers in the framework of theoretical categorisations of illness-related information offered by authors: illness representations (Leventhal et al., 2001) and key problems with chronic illness (Strauss et al., 1984). In order to give a more detailed overview of the information-seeking strategies, a cluster analysis was used.

Also in **Study III and IV**, the grounded theory approach (Glaser and Strauss, 2012; Walker and Myrick, 2006) was used in order to predefine workable theoretical concepts and categories of analysis. The relationship between general self-positioning and CAM and/or evidence was coded as the first step. The used categories included 1) attributes of appropriate action or relation, 2) authorities, facts and sources of information used for planning, and 3) liability and rights to act in certain ways. The more general categories of the medical and economic fields formed from the primary coding, and made it possible to define relevant self-positionings as patient, consumer and patient-as-consumer. The reason for the usage of the grounded theory approach is that it made it possible to explain the complexity and nuanced nature of CAM.

In order to analyse everyday lifestyle and the circumstances that evoked changes, a coding scheme with two large categories was used (**Study IV**). One of the categories contained practice elements, i.e. practical understandings, rules, teleological structures and general understandings described and characterised by Schatzki (2013: 34). The other category contained such characteristics as adoption of self-management skills, bodily movements, daily routines and information seeking.

For the thesis, I performed an additional analysis of qualitative data collected during 2013–2014. For the coding, I used three large categories that represented the themes of the research questions. The first category was based on information-related topics, such as the details of individual information search, information abundance and deficiency, and the interpretation of information in constructing the meaning of the illness. The second category was based on information-seeking strategies and how they influenced the individual's (existing) lifestyle and social relations, including patient-physician and patient-patient relationships. The third category was based on mediated communication, focussing on the issues and influences of both current and expected communication (the content, flexibility and suitability of information).

⁹ The periodisation of the disease into early and later stages is not in line with medical scales (e.g. The Hoch-Yahr scale). The stages are specific to the system that is used throughout Studies I–IV (i.e. earlier stages up to five years, and later stages after five years).

3.4. Limitations

This research has some limitations.

Firstly, the involvement of medical professionals, who were directly responsible for the treatment process and were active participants in the patient-physician relationship, might have influenced the decision to participate. In addition, an indirect influence was possible due to the unconscious attempt to provide “correct” answers, although after the initial agreement to participate, respondents received closed envelopes. This was the last involvement of medical professionals and the following steps (including possible post-communication) were handled by me. The study participants received closed envelopes that contained questionnaires, together with informed consent forms and stamped envelopes with return addresses. They had the opportunity to answer the questionnaire in the most suitable time and place for them.

Secondly, the rather low number of participants (5–6% of the total PD patient population in the quantitative study) made it possible to determine trends, but limited extended conclusions.

The second limitation is related to the third, i.e. narrowing the chronic disease patients down to PD. The disease concretises visible physical conditions and related problems, common age groups etc. which make PD patients a rather homogeneous group; therefore PD may not be directly comparable to other chronic illnesses that do not present motor symptoms (hypertension, diabetes etc.). However, considering the chronicity of the illness as a connecting link, the recommendations of this thesis can be widened to other chronic conditions.

4. EMPIRICAL FINDINGS

In this chapter I give an overview of my study results; the chapter is divided into three parts.

The first part of this chapter focuses on the analysis of health communication as an influencer in adaptation. The second part examines illness-related information-seeking patterns and, in the third part, I analyse the role of communication in social space and social structure.

4.1. The role of health communication in the adaptation to a chronic illness

In contemporary health communication studies the idea of “the more (info about the disease) the better (outcome, quality of life etc.)” is widely accepted. As **Study I** shows, this might not always be the case.

In order to manage the abundance of information, people might choose avoidance or, as Miller (1987, 1995) has called it, a “blunting” strategy. It is noteworthy that the results of 2003 and 2013 show the same tendencies and do not differ much in terms of understanding “the right amount” of information: when there was an individual perception of “too much” information at early stages of the disease, it might be frightening and hence people used the blunting strategy:

M68-I: I do not want to strain myself on a daily basis about what it is (the disease) and I don't want it [information]. /.../ I never talk about my disease.

As seen in this excerpt, even if there is not a full denial of the disease in the early stages of the disease, there is still some resistance to illness-related information. Therefore, it is understandable that a patient might limit the inflow of illness-related communication. It is likely that during the early period of the disease, illness-related communication means only communication and information related to doctor's visits and practical treatment-related matters, either medical or non-medical. This type of behaviour is characteristic to patients who are in the early stages of the disease, but who are active in information seeking and prefer to “dose” the amount of information themselves. The desire for “self-dosing” is seen in the phrase *daily basis*, which indicates mild or moderate information acquisition in terms of individual needs and readiness to adopt it. Based on the excerpt above, it's clear that people use their individual strategies to cope with the amount and the content of information in order to protect themselves.

The reasons for a lack of readiness to cope with illness-related information and the need to protect themselves from potentially frightening perspectives can vary: there might be the fear of harm to aspects of life: losing or changing personal and social relations, losing a job or worsened working conditions,

inability to practice hobbies etc. For these reasons, people also do not admit to having PD, and may even deny the fact.

F45-I: Actually, I did not say anything to anyone directly. My best friend, who is also my colleague, she knows...it makes me feel good that she knows /.../ I had to tell my boss (about my disease), because I have a disability, but not directly /.../ I said I had a disease of the nervous system.

This quotation indicates that even when there are physical consequences of the disease, there is still a lack of readiness to openly admit having the disease. It might be that the general understanding about ill people is connected more to the Parsonian sick role, which increases the fear of becoming isolated and strengthens the feeling that the illness must be hidden. The level of the fear of being socially stigmatised is high, leading to the “switching off” of rational understanding and, in order not to be misinterpreted by others, people may avoid helpful and adaptive information.

People also gather information by observing surrounding situations and people. This creates another way to control information inflow and avoid an over-abundance of information. As in **Study I**, the interviews in 2013 confirmed that there is no great readiness to become a member of a patients’ society in the early stages of the disease. It is likely that the same influence of medicalisation is experienced, due to which this option is either abandoned or put “on hold”. Here, information control occurs as an avoidance of meeting other patients, especially in advanced stages of the disease, who might have symptoms that early stage patients are not ready to see. Several respondents highlighted psychological resistance, as a person being *morally not ready to join this society and to see my tomorrow there*.

When information deficiency is experienced, these patients are ready to search for additional information and not only through traditional channels (e.g. doctors and nurses), but by searching for information from other sources, including new media. As in **Study I**, the need for more detailed information might appear in later stages of the disease after overcoming the emotional reactions and denials of the early stages. However, in later years, there also might not be a readiness to see patients who have more severe symptoms and more difficult physical conditions.

So, the main problem with information and its provision seems to be that, although (or because) it is rich, versatile and provides answers to various topics in a variety of ways, it might not meet the exact needs of patients at a particular time.

Therefore, there is a need for illness-related information on a situational basis. If there is too much information available that potentially frightens or creates unwillingness to accept, then individuals will adjust their strategies to deal with it on their own terms, which may mean avoidance or denial of received information.

People rarely identify what it means to be ill on their own, because this process is seen as the right of medical institutions. Several respondents mentioned medicine's right to control any medical knowledge and information, as doctors have "*the keys*", and medical knowledge is "*their territory*". By claiming this, the responsibility for one's own health is transferred to doctors, as it seems impossible for someone who is not a medical professional to use "these keys".

There are different potential reasons why physicians are not able to contribute to this process. One reason is related to the institutional organisation of the medical system, i.e. the short amount of time during regular visits (particularly in Estonia, the visit time is 20 minutes per patient and this is related to the current financing system of medicine). Patients accept this institutional limitation. Another problem is related to the wide variety of available (both scientific and non-scientific) information, and therefore medical professionals might lack the skills to interpret the information that patients have or are interested in. This might be the case with complementary and alternative medicine (CAM), which covers a very wide area of different approaches. It is noteworthy that the inability to comment on or evaluate every single CAM-method is not the main issue, which is the way these topics are rejected: *it is all rubbish* is how one female patient described the doctor's reaction. The issues of CAM are presented and discussed in more detail in Chapter 4.3.

In the interviews, patients expressed the feeling that they were left alone with their unanswered questions, but that does not mean that they forgot about their questions. Instead, they started to create their own meanings, which was not always helpful in the general adaptation to new conditions caused by the disease.

Passive information-seekers seem to most easily accept their new condition as something inevitable and these patients resemble most closely the Parsonian "sick-role", where the patient is expected to retreat from social interactions and obey official instructions. The understandings about the illness and what it means are rather simplistic and operate on the dualistic scale of "good-bad":

M65-III: I didn't know about it (PD) before and can't remember much...just that it is a bad disease...that it is difficult to manage...

This excerpt indicates that the meaning of an illness develops based on symptoms and how these make (daily) practical life worse. It is very likely that this patient came up with the phrase "bad disease" by himself, i.e. it was not provided by any doctor. Considering the possible information that he used as a basis for his opinion, it should be possible to determine how this patient ended up with this kind of conclusion. Firstly, it is very likely that the received information contained descriptions of the symptoms, which might be frightening and indicate possible disruption of daily life. Secondly, as PD is a chronic disease, there is a need to constantly take medications and visit doctors for the rest of the patient's life. And thirdly, despite taking all medications properly, the symptoms and disease will progress. All of this information creates the image of some-

thing bad and this might be the reason why it is perceived in this way, but also why passive patients are not motivated to become active: a bright future seems impossible. As stated in **Study I**, these conclusions might be related to the difference between how much information is received and how much the respondent is able to process that information. The lack of ability to process information alone and negatively perceived initial information create a vicious circle, which frightens an individual even more, and there is even more fear of damage to personal and social relationships. This fear prevents any further social developments, e.g. admitting having the disease to friends or colleagues, and prevents seeking additional illness-related information.

Long-time sufferers may adopt the role of the “good patient” derived from the general understanding of the medical system and society in general. According to **Study II**, people who have moved beyond the early stages of the disease (Cluster II) are more likely to join patients’ societies, which strengthens their connections to medical structural understandings even more. Active participation involves the seeking and acquisition of information that helps to “domesticate” the disease and, due to the intertwined relations with the medical system, their illness-related meanings match those provided by the medical structure, but can also be affected by the progress of the disease. This means that they have personal experience of the worsening of symptoms due to which they have been forced to adjust their everyday lifestyles. In the later stages of the disease they also do not have expectations of non-progression of the disease and it is easier for them to comply with the provided explanations of their illness.

Active and independent information-seekers (Cluster I) are characterised by increased challenges to structural opinions and understandings, e.g. questioning the diagnosis:

M68-I: the (GP) said that the neurologist had overreacted and then I had an agreement with my GP that for half a year I would not take any medication.

Here, the denial is expressed as doubt about the presence of the disease itself, which is derived from the unwillingness to acknowledge it. In this example, there is also competition between opinions, but what is interesting is that the winning opinion is the one that better suits the wishes of the patient and not reality; although many respondents in all of the studies admitted the superiority of the opinions of specialists over general practitioners, when there was a need to deal with relatively negative personal information, there was a readiness to “fool oneself”, as it was emotionally easier. As shown in **Study I**, when there is a suspicion that not everything that can be done has been done, there is resistance to acknowledging the diagnosis as finally confirmed fact, and hope for a better outcome remains. Patients need guidance and support in interpreting information and constructing the personal meaning of an illness, but flexible communication and support in this process can be very challenging due to limits on time and financial resources.

Previous findings emphasise the need for emotionally adaptive information that allows for continuation of the existing lifestyle in the early stages of the disease. The role of illness-related communication during the early period of the disease has several functions. First, there is a need to “break through” the denial of the disease and bring patients out of purely emotional reactions. Next, there is a need to support continuation of daily life in a habitual manner as much and as long as possible. And only then can illness-related information create a foundation for understanding the nature of an illness.

As shown in **Study IV**, only having plain illness-related information available is not enough for patients to cope with the disease physically, because people often lack the skills and knowledge to process it in a useful way.

Rather, the information can create more confusion than support and can contribute to the maintenance of blunting as a coping strategy. In addition to potential problems and further (unanswered) questions, messages dealing with physical coping might be interpreted as forced adoption of the “sick role” and may be perceived as leading to social isolation, due to which the information is blocked.

Together with the progression of the disease, channels of mediated communication develop. Medical professionals remain important information sources, but other sources are added.

When a person has suffered from the illness for more than ten years, a source of information can be as simple as the patient information leaflet (PIL) in a medication package:

F70-II: I was not warned about falling /.../ I thought it was related to my hip problem, but then I read in the instructions of my medication that falls are related to it.

Although here the information is clear without the need for additional explanation, this example is exceptional in that it is the ideal situation, where the information exactly matches a situation that has arisen. However, very often situations that arise cannot be solved with leaflets or booklets, because “black and white” information rarely fits particular situations. And of course, there are not many people who (regularly) read PILs in order to meet their illness-related information needs.

But no matter the channel, people with longer illness experience admit that from a bodily coping point of view, there is a need to know what symptoms to recognise and how to relieve them:

F68-II: people need truthful information/.../ so, I am not frightened if some problem arises. When it appears I recognise it and know what to do.

Both of these examples are in accordance with the finding of **Study I** that people with longer illness experience prefer the freedom to determine the time and amount of information. It is likely that the shift in understanding (from

rejection to possession of information in advance) is related to the stage of the disease: in later stages of the disease, a person has experienced some progression of symptoms and in such a case knowing more is an advantage and not as intimidating. Yet, as the same respondent said, information is one thing, but *there is also the need to implement this knowledge* in real life actions and *this requires willpower*. The message receiver not only has to be ready to receive information and interpret it, but also implement it in daily life. Media usage and related issues are discussed in detail in the next chapter.

The members of Cluster III use a passive strategy in information seeking and, therefore, mediated communication does not play a big role in their bodily coping, especially as there is acceptance of the presence of an incurable disease and hence no motivation to make any adjustments to daily activities that would increase the awareness of the illness or ease the health condition in general.

To summarise, 1) information should be available gradually and on a situational basis, 2) despite the availability of information, there is a need for support to process information in order to give meaning to the information in terms of social repositioning of the self in society and 3) the role of mediated communication changes and is dependent on the duration of the disease and activeness in information seeking.

Although patients are aware of institutional rights, expectations and limitations, the acceptance of institutional norms does not guarantee individual coping and self-management, as particular information needs may arise. This is why regular health communication tools might not be adopted, leading to potential failure in adopting (self-management) techniques that support adaptation and the contribution of the practice theoretical approach. The role of (general) media usage in the acquisition of illness-related media usage is discussed further in chapter 4.2.

4.2. Illness-related information seeking strategies

Study II reveals that it is possible to distinguish three typical strategies based on the connections between information-seeking strategy and background variables. Cluster-based analysis (**Study II**) helps to explain controversial strategies that people use in adaptation, and the role of health communication in terms of adaptation and as an influencer of social structures. It is very important to note that clustering is not the same as psychological approaches that distinguish between different types of people. In the context of the current thesis, clusters represent the stages that people may pass through during the course of the illness and, even more importantly, there is no such thing as “reaching the final destination” in terms of illness-related communication and adaptation. People may pass through the stages several times and there is a constant need to make adjustments in order to continuously adapt to the current situation. The process is influenced by the progress of the disease and the success of previous adjustments.

One of the important findings of **Study II** is the statistically significant connection between general mass media usage and illness-related media usage (the association coefficient of Cramer's V .287 was $p < 0.0001$). This result indicates that if a person uses a wide variety of channels with high intensity to gain information on general topics (e.g. news), then he or she will most probably continue this during illness and regarding illness-related information. The same is true for the opposite situation of information consumption with low intensity among a small number of channels.

Thus, this finding indicates that people accommodate their media-related habits to new situations. The problem nowadays is that there are many different channels and there are divisions within the channels, which increases the complexity even further. While this can be seen as positive in terms of diversity of media, a problem may arise from another point of view, which is verbalised in the next example:

F68-II: I placed an announcement in a newspaper, but only one or two people will come to the event, because people don't read newspapers. Also radio channels are fragmented; people listen to different stations /.../ there are so many programmes now, so many options, so it is difficult to find a way to distribute information so that it reaches people...

An issue referred to in this particular quotation is the multitude of channels, which has become a problem and may act in conflict with someone's intentions. Individually, an information deficit may be perceived because information is available on alternative channels. Objectively, information is there, but available via sources that are not used. The mentioned problem regarding newspapers refers to general media usage, i.e. it is possible that among sufferers the newspaper is not the main information source. It is also likely that the newspaper is not seen as a potential source of illness-related information. In addition to the "natural" lack of interest and low level of media usage, it must be taken into consideration that PD may evoke a lack of interest as a symptom of the disease and deepen general passivity even further.

Therefore, relevant information may be missed on a channel which is perceived as unconventional in terms of illness-related information. The Estonian-specific aspect of the issue may be related to the general management of daily life: the average pension was 386 euros in 2016 (Statistics Estonia, <https://www.stat.ee/58095>) and the need for newspapers can be relatively unimportant compared to the need for food, medication, household expenses etc.; as a result, newspapers are not read on a daily basis. This does not exclude the possibility that newspapers are read, for example, in libraries, but this may result in selective reading (i.e. not every day) or in a delay in terms of news or announcements that require immediate attention or reaction.

An additional media-related aspect is the usage of new media, which may be complicated among the older generation. The latest results of the national survey "*Me. The World. Media.*" (2017) show that the usage of the Internet de-

creases with age: while there are 68% of regular users in the age group 55–64 years old, there are only 48% of regular users in ages 65–74 and only 26% of regular users between age 75 and 79. Combining the last two groups, there appear to be 42% of regular Internet users age 65 years and older. The same was pointed out by one of the respondents who claimed, “*younger people use the Internet, but I know in my group there is only one person who uses it.*” And although she said that it was a problem among people aged 80 years and older, one of the respondents from Cluster III age 65 said that he did not use it:

M65-III: no, I don't have a computer /.../ well, I don't know how to use it. /.../ the closest place to use the Internet is three kilometres away. I do not go there often.

This excerpt confirms the findings of **Study II** and **Study IV**: when there are no habits or skills in using computers, the illness will not promote using new media in order to gain (illness-related) information. Similarly, if there is no habit of reading books, the main freely available information source (a special brochure for patients and their caregivers) will not be read. As mentioned previously, one of the reasons why this source may be abandoned is related to the completeness of the material, i.e. it contains too much information in one package and there is no willingness to take in all of this information at once. Besides content-related problems, print material may be abandoned because the individual habitus does not support the usage of it.

The results of the cluster analysis (**Study II**) based on intensity and diversity of mass media and illness-related media usage help to contextualise differences in information-seeking strategies during chronic illnesses, as well as in terms of different theoretical approaches used in this thesis.

There are three characteristic clusters related to information-seeking strategies. In two clusters, the typical information-seeking strategy can be described as active and in one it is passive. The strategy of active information seeking involves using various channels in order to find necessary information. The strategy of passive information seeking is basically not to look for additional information, and if information is received, hesitation to act on it is still high. The indication is that the diagnosis of a chronic progressive, yet not life-threatening, disease is not a trigger that encourages or leads to changes in any – including media usage-related – existing lifestyle.

Information-seeking clustering reveals that the main differentiator between the strategies of Clusters I and II is membership in a PD patients' society: members of Cluster I do not join and members of Cluster II do join these societies.

The stage of the disease is important in terms of readiness and willingness to join a society and to meet with other co-sufferers. Therefore, the cluster analysis of **Study II** does not attempt and is not meant to differentiate specific illness-related personality types. Rather, the clustering aims to explain different illness-related information-seeking strategies that people use in order to cope with the changes they face.

Cluster III is characterised by a passive information-seeking strategy: the results of **Study II** show that this is the only cluster where more than 40% of the members have not searched for additional information. This is very likely related to the type of media use and previous habits of media consumption or (additional) information search. Compared to the other two clusters, the strategy of members of Cluster III is to use fewer sources in order to fulfil information needs. Interestingly, there are also relatively fewer people who have unanswered questions, which indicates general passivity:

M65-III: I could ask my GP /.../ but I haven't asked yet.

No recommendations seem to arouse interest or trust, and there is also a lack of interest in finding out more. As mentioned above, it is possible that the lack of initiative is a symptom of the disease. Based on earlier studies, it may also be the result of existing habits. At the same time, in interviews these respondents expressed an interest in everyday news, developments in medical science etc., so at least partly it is a coping strategy rather than illness-related. This indicates that there is a need to be careful in claiming that a patient is disinterested in illness-related information in order not to mix it up with the self-protective strategy of blunting. The most complicated task is activating people of Cluster III, but is there any need to do so if these patients do not have any problems with their passivity? It might seem the individual right of these patients and a choice that no one should interfere with. "Activating the passive" is also in the interest of structural medical systems, as the shift from blunting to monitoring leads to practical adjustments and self-management during the course of the illness.

It might seem that people who use the passive strategy (Cluster III) feel the safest emotionally: since they do not search for additional information they protect themselves from negative news. However, this may be misleading as the avoidance expresses rather predictable negative feelings common in the early stages of the disease. It is of course questionable what kind of communicative support these people need, but some action should be taken.

The characterisation of clusters shows that clusters are flexible units, and people, according to their information-seeking strategies and the stage of the disease, move freely between clusters. Despite the increased likelihood of joining a patients' society in the later stages of the disease, there are definitely a lot of people who remain independent in searching for information, as they are keen to maintain their (information-seeking) habits.

To conclude, a big part of illness-related information-seeking is related to the general process of mediatisation (see chapter 2.2), but also to earlier habits regarding general media, which determine the level of activity of information searches and the types of used channels. These factors have a linear relationship, i.e. the more channels and the higher intensity of general media, the more channels and the higher intensity of illness-related topics. In particular, members of Cluster I search for information through a variety of channels. At the

same time, the need for support and guidance in interpreting information can be higher (**Studies I and II**), especially because people might find information about CAM-related topics or commercial services and goods that promise well-being, use scientific terms and can therefore cause misinterpretations. In the next chapter I analyse in detail the influences of mediated communication on social relations.

4.3. The role of illness-related information seeking in patients' management of social relations

The communication process is largely affected by several understandings and beliefs of participants regarding communication. As the interviews reveal, it is a very challenging task that currently seems not to be working: available illness-related information does not support the management of current social networks, because it provides new forms of actions. **Study IV** indicates that people want to continue their lives in their habitual manner for as long as possible and not make (drastic) changes driven by the requirements of the illness. The same applies to social relations. The patients' society offers an example: it is possible to create new relationships and social networks that are based on a common disease, but this is an acceptable option mainly in the later stages of the disease. The fact that the society provides a new network, which might be an additional reason to join, is not considered at the beginning of the disease. There is no willingness to create new social relationships during this emotionally vulnerable stage, especially when this new network forces someone to think about the disease more than he or she is ready to.

When the illness is accepted, that does not automatically mean that it is acknowledged to important others. The need to maintain the general stability of present social relationships adds an additional dimension to denial: the disease is concealed because there is a fear of how the disease could change present social relations:

M54-I: Practically none of my friends know about my disease. It is hard to say how my friends would react. In general nothing has changed (in our relationship), because they do not know anything about it.

This excerpt and several similar opinions expressed by participants indicate that social relations remain the same mainly because important people from relevant social networks do not have information about the illness. It could also be believed that if "important others" knew, the relationships would definitely become worse.

Surprisingly, the illness may be kept secret even if a friend is a sufferer of the same disease and has visible symptoms:

F70-III: She came to visit me. I noticed immediately that she had a very strong tremor. /.../ She doesn't want to talk about the disease.

The quotation indicates that the disease (especially with visible symptoms) is considered a sort of taboo that should be hidden. In a situation like this, there should not be any fears of losing a friend as both suffer from the same disease. If this is the case even between people who are long-time acquaintances and share the same disease, then naturally the presence of the illness will be hidden from the general public.

The general attitude towards the status of “being ill” does not support social activeness and patients often drop some activities (**Study IV**). Individual decisions to drop some habitual actions due to the fear of public opinion are actually the consequences of widely accepted social understandings (**Study IV**).

The acceptance (or non-acceptance) of different people has specific manifestations in the Estonian context: for years, it was a norm in our society that ill people were socially isolated and the changing of norms takes time. Until there is a change, people will hide their disease, and change or adjust their own habits and activities in order to maintain their social status and -relationships.

4.3.1. Management of power relations

In the medical system, power positions and social relationships have been more rigid and persistent compared to other systems, because besides acquiring medical knowledge there is a need to place this information in the appropriate context. Therefore, at least the (perceived) need for approval or acceptance by medical professionals remains.

The medical system can influence how the illness experience is perceived. According to this logic (which actually matches the logic of medicalisation as well), a patient will go to a doctor, who has the right to give illness-related information throughout the course of the illness. Medicalisation includes the right to determine the content of information that supports the (new or “right”) construction of social self-determination. However, this might be problematic, because rigid hierarchical rights do not support the switch from blunting to monitoring, even if this is tried with CAM-related activities. An additional content-related problem is that the right content in the biomedical sense is usually different from the right content in the context of everyday (media usage) practices, or daily routines and the desire to maintain them.

If the patient uses an active, but independent information-seeking strategy (Cluster I), the actions demanded by power relations may contradict the habitual information-seeking strategy (**Studies II and IV**). As people do not adjust their information-seeking habits because of the illness, they risk confrontation and potential problems in the patient-physician relationship. The problems appear in the interpretation of information, where the help of medical professionals might be needed (**Study III**).

People search individually for additional information, but when this information is perceived as unacceptable to medical professionals they do not tell the doctor about it (**Study III**). The “advanced level” of avoidance is related to the knowledge of to which doctors they may talk about alternative information and methods. The selection is based on the extremeness of the reactions of doctors.

None of the respondents had experienced that any alternative method (except for those which were already in practice, e.g. different types of massages) was accepted or recommended by doctors:

M65-II: I can't remember anything the doctor would have approved /.../ "you may try it /.../ but it will not help".

The knowledge of to whom to talk does not exclude actions, either searching for alternative information or using the methods, i.e. there is a clear understanding that a power struggle is inevitable when rules of the medical field are violated (**Study III**). Therefore, people position themselves no longer as patients in the medical field, but instead as in the economic field, where they act as customers taking responsibility for their individual (consumption) decisions. One of the ways to avoid confrontation is for medical institutions to accept the right of a patient-consumer approach (proposed in **Study III**), which allows for real participation, decision-making and responsibility in the treatment process. As one respondent stated, *one's own brain should be used* in order to analyse all of the information that is received through any channels, confirming that patients analyse and want to analyse received information.

Even if there is a willingness for individual contributions, the need for help and support in processing data remains.

Another way to move these discussions to another social level may be silent usage, which is based on product promotion or individual research on internet forums or other web-sources. People create their own qualitative criteria to measure the trustworthiness of web sources, and thus rely on collective cultural capital by using general skills to filter “real things” or through direct information exchange about experiences.

To conclude, mediated communication does not sufficiently support the management of social relations influenced by a chronic illness. This leads to even more efforts to hide the disease in order not to damage and/or lose accustomed social networks. Therefore, people develop skills and know-how regarding under which circumstances and to whom to talk about CAM in order not to jeopardise either patient-physician or social relationships. Manoeuvring between patient and consumer positions makes it possible to be a “good” and responsible patient.

5. DISCUSSION

5.1. Conceptualisation of communication in the illness experience

In today's society, communication related to chronic illnesses is a multi-dimensional task involving several areas of life (illness-related, social, emotional and other aspects). As I highlighted in the theoretical framework, individual-driven health communication seems not to work in the adaptation to long-term conditions, because of the reciprocal influences between the structure and the individual. Therefore, the provision of only (simplified) medical knowledge to chronic illness patients has minor intended efficacy, because illness-related information might not meet patients' actual information needs (Ule et al., 2014).

The approaches of shared decision-making, patient-centredness, self-management etc. are designed to involve patients in the whole illness management process. As our research with PD patients (**Studies III, IV and additional analysis**) reveals, people may be resistant to participating in these programmes. If they get involved, their understanding and conceptualisation may differ from the original and biomedical intentions (e.g. people may turn to searching for and using CAM; **Study III**). The ideas of structuration theory (Giddens, 1984) conform to patient-involving activities in the sense that the individual is expected to contribute to his or her own health and illness status by changing the patterns of individual actions. These approaches do not take into account the possibility that people may fall back on routine actions, creating potential problems in illness-related areas.

People try to match their need to maintain existing lifestyles and habits for as long as possible with the requirement to adopt new, illness-related practices (**Study IV**). These findings are in line with previous studies indicating the desire to maintain habitual practices for as long as possible (see e.g. Charmaz, 2002; Ahlin & Billhut, 2012; Fritz, 2014), as well as with Schatzki's (2013) conceptualisation of the emergence and persistence of practice-bundles. The results are connected to the symbolic (social) meaning that everyday lifestyle has: the adjustments and changes may be perceived as threats to the social self. People negotiate the range within which they are able to construct (social) meaning in a change. This process eases over time and people negotiate their practices in the context of the size of the loss, i.e. they are willing to make adjustments in order to partly maintain their lifestyles (although lifestyles are transformed). Therefore, instead of recommendations for lifestyle changes, illness-related communicative support must contribute to the (re-)negotiation of the existing lifestyle i.e. what it is reasonable to keep or change, and in what ways, and how this influences negotiations and gives meaning to the illness in general.

Derived from that, there is the mismatch in illness-related content (between provided and needed information) and this is one of the biggest problems: provided information is illness-centred, while there is a need for gradual and situationally related information matching everyday lifestyles (**Study IV**). The

results of previous studies support this finding: Kang and Ellis-Hill (2015) have shown that people consider themselves successful in their illness experience when they are able to maintain existing lifestyles. In order to maintain existing habits, there is a need to shift the focus of illness-related information from the illness to the person. The focus should be on the “domestication” of the illness to the person, while currently the focus is on the illness and there are expectations placed on the individual, who has to make (drastic) changes in living arrangements and habitual activities. The evidence of the biomedical focus of illness-related communication is presented by Been-Dahmen et al. (2015), who have pointed out that in supporting the development of self-management, nurses tend to prefer biomedical aspects, rather than emotional and/or social support, which are actually needed. As the authors (ibid.) concluded, the nurses lack sufficient training and practical experience to provide support to meet patients’ needs. The conclusions of this study indicate the general problem of medical training, which focuses mainly on biomedical aspects of the disease and less or not at all on the social and emotional aspects of the illness. Although biomedical information is necessary, there is a need for other information, and non-biomedical information (e.g. social aspects, emotional support etc., as described in patients’ brochures [Taba et al., 2007]) is desired gradually. This is due to the lack of readiness to know too much information in advance (**Studies I and II and additional analysis**), which leads to blunting and potential blocking of incoming information in order to protect social interactions.

Digital sources may provide a solution here: there are web pages owned by clinics, medical societies (e.g. the society of Estonian neurologists and neurosurgeons) and a patients’ society (www.parkinson.ee). Although the web page of the patients’ society includes a forum, it is rather rarely used, limiting the opportunity to get answers to situationally related questions. This may change in the future with the change of generations. The usage of digital sources for the acquisition of information is increasing and people own more home computers, decreasing the limitation on access to various digital sources (Vihalemm & Kõuts-Klemm, 2017: 251). Since there are opportunities to receive the same information from new media channels, people have replaced paper newspapers with digital media (ibid.: 254).

It is important to note that the addition of (illness-related) sources still does not guarantee success: media repertoires involve more than the number of sources and just adding sources does not contribute to better adaptation. Knowledge gathered via various media channels must support, complement and be meaningfully related to the everyday lifestyle, and only then will an additional source be used regularly (Couldry & Hepp, 2017: 55). This can be seen in the fact that the platform exists, but has remained rather inactive for long periods¹⁰.

¹⁰ Currently, the latest post is from 12 May 2017 (previous posts under the same topic were made on 16 December 2016 and 4 August 2015). Before that, there was an uncommented on post under the “Announcements” regarding information about the events of Parkinson’s Day of 18 April 2017. (The comment was updated on 17 May 2017).

This may indicate a lack of interest, but it is also very likely that there is no habit of using such platforms. Several forum users said that they had found the platform accidentally, showing the lack of promotion of these electronic environments. This indicates that today's patients (who are mostly over 60 years old) do not see themselves as active audiences (Livingstone, 2013) who participate and contribute to illness-related media production.

The low usage of platforms may also indicate a lack of appropriate content. Voncken-Brewster et al. (2014) claim that although it is possible to integrate web-based solutions into the self-management of chronic illness, and people may find them appropriate and usable, it is challenging to make the tools work for regular, multiple and repeated uses. In order to make the tools more usable, there is a need for more variations (for different people), changing content, individual monitoring options etc. (Voncken-Brewster, 2014), and therefore it is also a matter of resources (financial and human) whether the platforms work or not.

This problem requires rethinking roles, functions and resources, i.e. whether and to what extent to implement experience counselling, which has been started in some areas already, but unfortunately doesn't exist for PD. Willis (2014; 2016) has investigated the role of expert patients in online communities. Her conclusion is that information and experience exchange with peers having the same chronic condition acts as a self-management programme (ibid.). Willis's findings indicate the potential of co-sufferers, which is known, but as the empirical analysis of the current thesis shows, there is a lack of willingness to meet with other patients through the patients' society. Therefore, reworked concepts combining the role of peer patients and online tools could provide some gradual and situation-related communicative and informational support.

5.2. Individual responsibility and structural influences

The occurrence of several factors (the mismatch between provided and needed information, the neoliberal requirement of individual responsibility and action etc.) might promote individual actions that are not always approved by science-based medicine or even "mainstream" consumption approaches. These actions involve the area of complementary and alternative medicine, with its goods and services. The reasons for CAM usage may be related to its "perspective that the 'whole' person must be considered when physical health is the issue" (Lupton, 2012: 127). Participants mentioned this during the interviews and the primary focus on illness may be one of the reasons why illness and related aspects may be emotionally and socially unacceptable and, therefore, illness-related information is rejected. Lupton (ibid.) has also stated that CAM "encourages individuals to take responsibility for their own health by rejecting the disempowered role of the submissive patient", which could be another reason for people trying CAM methods. As consumers, people are aware of the individual right to make their own choices, but also the neoliberal approach to health

communication emphasises individual responsibility for health decisions (Fries, 2009; Dutta, 2015). Although a person may adopt self-management through the usage of some CAM products (e.g. “natural” supplements), CAM users are seen as non-compliant patients, not as individual and responsible consumers (Warren et al., 2012). The perception of CAM usage as deviant is expressed in an understanding according to which success in self-management is related to adherence to medically prescribed treatment, while failures are seen as a result of deviation from medically prescribed instructions (ibid.). Similarly, Scambler et al. (2014) have stated that the role of individual participation is ambiguous: people are expected to make choices about their health care, but at the same time medical experts, by controlling the mechanisms to measure the success of self-management, decrease the relevance of individual actions. This leads to a situation where people do not admit the usage of CAM (**Study III**), but compliance does not increase, as people continue individual (self-management) activities in order to maintain control of their sense of “normality” and existent social roles (Frost et al., 2016).

Despite the fact that people are widely using CAM methods, medical professionals do not approve of them for objective reasons. This may be related to the general changes in the area of spirituality; although still seen as niche, there are signs of mainstreaming spiritual practices (Uibu, 2012; Uibu, 2016). There is increasing usage of methods that cannot be explained scientifically, leading to hiding this activity in order to prevent potential conflicts with physicians. Uibu (2016) has described this kind of avoidance of revealing the usage of spiritual practices as a common strategy because of the likelihood of conflicts: as he states, usually “conflicts cannot be avoided” (ibid.). CAM usage may indicate the taking of individual responsibility in order to find physical or emotional relief. Sceptics tend to describe non-scientific CAM methods using pejorative terms and CAM is compared with illnesses, both metaphorically and literally (Uibu, 2012). The author concludes that following non-scientific ideas is perceived as a stigmatising activity (ibid.). Orthodox medicine is seen as the right and rational approach while CAM is accused of over-promising “magical” results (Lupton, 2012: 130). However, the very sharp condemnation does not stop the usage of CAM, and the main result may be that people only stop sharing information about CAM. CAM practitioners see themselves as rational and critical, just like the sceptics (Uibu, 2012). Besides, as Lupton states (2012: 130), for most people the symbols and rituals of orthodox medical care “are just as mysterious as those used in CAM”.

Cockerham (2005, 2013) has discussed the influence of structural factors on individual actions. In terms of health and illness, Estonian society as a structure is rather rigid. The cultural and societal understanding of “being ill” sees illness as a deviation and ill people as not fully (capable) of participating in social life. Current legislation provides limited opportunities for ill people to continue active working lives, due to which employers are not interested in hiring these persons, and it might also not be beneficial for employees to continue working. The sharp change in social activeness could be one of the reasons why people

are not willing to admit their illness, even to themselves. The ageing of the population is an issue that should force changes on a structural level. The aim of those changes would be to encourage and allow for flexibility for both individuals and businesses to continue, restructure and reorganise working life despite chronic illnesses.

In addition to financial-political changes, there is a need for changed cultural understanding of “being ill” and what it means in light of the ageing population, which could mean that at some point there would be more employees with chronic conditions than without.

The information and media society offers several ways to raise individual awareness, and structurally provided messages about health and illness also contribute to raising the awareness of individuals. As a result, higher awareness tends to influence agential activities in terms of health and illness. In the context of the current thesis, the agential activities are expressed in individual information-seeking activities and decisions regarding CAM. The results of the current thesis indicate higher agency, both in information seeking and in the usage of alternative methods by patients who actively use mass media. People try to balance the neoliberal prescription of individual responsibility with obedience as a patient. This may lead them to the adoption of (hybrid patient-) consumer behaviour that makes both possible (**Study III**). Dutta (2015: 141) has stated that “meanings of health have been framed in the logic of the market/.../” indicating the possibility of at least partial adoption of the consumer role in health situations. Acting as a consumer does not automatically mean confrontation with the medical field. However, if this happens, controversial outcomes are possible. Some theorists assume that there is very little room for individual agency due to medicalisation (e.g. Conrad, 2007) or because of asymmetry of information between doctor and patient (Lupton, 2012: 109). On the other hand, this power asymmetry is accepted, because “patients are socialised into normalising the dominance of biomedicine” (Scambler et al., 2014). Even when individual responsibility is expected, the process is controlled by structural influences (Dutta, 2015: 62). On the other hand, neoliberal communicative spaces represent discursive inequalities (e.g. knowledge- or technology-based inequalities) leading to potential impossibilities of participation (ibid.:225).

All of the above-mentioned processes indicate that individual responsibility in information seeking is currently more a theoretical than a practical working approach: as soon as individuals make use of non-approved methods, this allows the medical system to label this activity as deviant. The problem is that by (re)producing negative perceptions, the system fails to provide communicative support either for the maintenance of or adjustments to the existing lifestyle in a manner that is suitable for patients. Specialised nursing service or peer counselling could provide some help, but only with substantial changes in the content of illness-related information.

5.3. Mediated communication

The relationship between media practices and everyday life has become the focus of media researchers: the question is not whether such a relationship exists, but how media and communication influence everyday practices (see e.g. Kramp et al., 2014; Couldry & Hepp, 2017). Therefore, it is acknowledged that mediated communication contributes to the construction of the social world and that it influences everyday agency (ibid.). As Couldry and Hepp (2017: 223) conclude regarding the influence of mediated conditions, “the social construction of reality has been implicated in a deep tension between convenience and autonomy, between force and our need for mutual recognition /.../”. This quotation summarises the main contradictions and dichotomies that chronically ill people face in their societal experience of the illness: 1) the tension between expectations for individual responsibility in supporting overall well-being and obedience to medical instructions, and 2) the tension between the maintenance of existing practices (that carry the symbolic meaning of embodying dignity) and the requirement to acquire new self-management skills derived from the needs of the illness. Habitual individual actions prevail and lead to manoeuvring between different roles, at least at the beginning (**Study III**). This may lead to additional misunderstandings and tensions with the medical system and to concealing some non-approved activities. Although representatives of the medical profession remain important information sources, new media sources provide the kind of information that enables the patient to be active or to assume the hybrid position of patient-consumer, a position which widens the individual’s range of actions and opportunities to take individual responsibility. In response, structural conditions may change in order to support individual activity and to be consistent with social norms (Cockerham 2013: 150).

However, as the results of the current thesis show, illness-related mediated communication cannot provide the context for the (re-)construction of the meanings of the social self. Illness-related mediated communication requires the adoption of the role of the patient, placing the illness at the centre of the individual’s life. As the findings reveal, there is no readiness to make changes just because of the illness (**Studies I and IV**). In order to retain a sense of “normality” and maintain existing social roles, self-management practices must support the maintenance of the habitual lifestyle (Frost et al., 2016). Thus, the big problem in mediated illness-related communication seems to be the content of information, as it does not match the (social) needs of patients and there is a need for different kinds of mediated communication than the one provided currently. Meier (2014: 118) states that one of the reasons for this mismatch is related to the change in roles of both the patient and physician compared to the roles and expectations described by Parsons. She declares that, in addition to the need to handle the change in roles in terms of related economic, political and legal changes, there is a need for a discussion of communicative change, because “roles and relationships are constructed through communication” (ibid.). Therefore, only the communication of changed roles could transform

public perceptions and this could bring about changes in the expectations that the public has regarding (chronically) ill people.

As authors (e.g. Meier, 2014; Couldry & Hepp, 2017) have stated, the changes (including in the physician-patient relationship) are mostly driven by the third wave of medicalisation: digitalisation. Digitalisation also brings about changes in the creation of content, i.e. everybody can create content in social media platforms. On the other hand, this requires a more advanced level of source critique in order to distinguish the appropriate information (Lupton, 2012: 133). As seen with CAM, this situation may intensify the “struggle for power” in the framework of structure and agency in the medical field. As most likely this situation will develop further, there is a need to contribute to the change in the content of illness-related information, but also to support a change in roles. The neoliberal expectation of individual responsibility has created a potential rise in agency. Still, agency is not free from structural influences and, in the context of health and illness, this may also mean confrontation between structure and agency. Changes in structural arrangements have the power to initiate changes in the context of structure and agency, leading to changes in general perceptions of “being ill”.

5.4. Recommendations

In order to support people in their (re-)negotiation of self in the light of lifestyle changes and the meaning of these changes, changes on the structural and political levels are needed.

The areas of illness-related communication that need development and reconsideration are the following:

1. Illness-related content must provide answers situationally and gradually in order to support monitoring strategies over blunting, to match and to support adjustments in people’s everyday practical needs. Regarding concrete actions, illness-related materials could be made more accessible by dividing them into smaller portions (e.g. thematic leaflets or mini-brochures instead of universal brochures; thematic categories on a web-page, i.e. eating, exercises etc. with possible exercise videos using patients, instead of pictures and explanations etc.).
2. Peer counselling and/or a nursing service to ensure quick access to illness-related discussions. The development of peer or nursing counselling could serve as appropriate support and an effective tool in general healthcare management (at the state level), e.g. in dealing with the lack of financial, temporal or human resources in medicine.
3. There is a potential to develop a patients’ forum on a more active platform than at present. One of the potential directions is that government, together with associations of medical professionals and patients, contribute to the development of a general chronic illness forum where it is possible to select both universal and disease-specific themes. A unified platform has the poten-

tial to increase the level of usage, general awareness and coverage among the public while sharing costs between different public and private organisations. This could bring together people who can reproduce new content based on evidence-based illness-related information (medical professionals, including general practitioners, specialists and nurses) and based on personal experiences (patients, caregivers etc.). The creation and maintenance of a unified environment could benefit patients in that all information and communication would be accessible on one platform. The benefit from society's point of view is that it could provide some relief to current human resource and financial problems of the health care system. It is also possible that the PD Patients' Society, with the help and support of neurologists, general practitioners and (specialised) nurses, could contribute to the existing platform to further develop it as described.

In the context of future research, there is a need to further test the role of information-seeking strategies in adaptation for other chronic disease patients, to find out the influences 1) when the patient is originally dependent on caregivers' information consumption habits (e.g. in childhood chronic illness and parents' information-seeking strategies) and 2) when chronic illnesses do not show visible and/or discernible symptomatic (e.g. mild to moderate hypertension) or drastic (e.g. dietary) changes pre-requisite to treatment (e.g. diabetes). However, it is likely that, as in the case of PD, people with other chronic illnesses also need information on a situational and gradual basis to "domesticate" their illness and make adjustments on their own terms to maintain the social self for as long as possible.

6. CONCLUSIONS

The findings of this thesis highlight that in order to learn to live with PD, people need emotionally, socially and physically adaptive information. The role of comprehensive health communication is to take into account the previous (“illness-free”) lifestyle and everyday practices. Thereby, illness-related information supports the “domestication” of an illness rather than the rearrangement of a life to suit the illness. In the following list of conclusions, I provide a detailed overview of which kinds of illness-related communication contribute the most to this process, and how, for PD patients.

1. What is the role of illness-related information seeking in the adaptation to an incurable progressive illness?

1.1. How do the (changing) public understandings of health and illness influence the popular conceptualisation of personal chronic illness management?

- The public understandings of chronic illness – as interpreted by chronically ill people – are contradictory: while assuming significant individual responsibility for the management of the illness (**Studies I, III and IV**), following institutional prescriptions is considered a normal practice of being ill (**Studies II, III and IV**).
- Chronically ill people interpret public norms and understandings of individual responsibility as biomedical understandings, i.e. only those individual actions that are in line with the biomedical approach are approved (**Studies I, III and IV**). This is sharply expressed especially in topics that are beyond the scope of evidence-based issues, such as CAM, where the mainstream public opinion is considered to share the view of the medical system, leading to hiding the usage of these methods (**Studies III and IV**).

1.2. How are information needs and information-seeking behaviour conceptualised in the patient’s self-management approach?

- According to the self-management approach, medical professionals aim to deliver a wealth of information about the illness but patients need information in small units and situationally related (**Studies I, II and IV**). Self-management programmes require individual responsibility, but are designed by professionals, which limits individual actions. This leads to the (at least partial) failure of these programmes, because they do not consider the role of the habits of information search and usage (**Studies I, II and IV**).
- Currently provided illness-related information focuses mainly on biomedical aspects of the illness, but people need emotionally and socially adaptive information (**Studies I and IV**).

- The mismatch in information content leads to the avoidance of illness-related information provided by medical professionals (**Studies I, II and IV**). Independent information searches have major risks, such as the usage of medically non-approved methods, e.g. CAM (**Studies III and IV**).
- 1.3. How can the practice theoretical approach contribute to the conceptualisation of the role of illness-related information seeking in patients' adaptation to living with a chronic illness?
- The practice theoretical approach highlights the importance and role of bodily-performed routines forming the basis of daily habits, which is one component of perceived quality of life (**Studies III and IV**).
 - The practice theoretical approach makes it possible to take into account both structural and individual influences, thereby contributing to explaining the reasons for failure and factors of success in the development of self-management skills during chronic disease (**Study IV**).
- 2. Based on the example of Estonian PD patients, how are illness-related information search and interpretation connected with patients' adaptation to a chronic illness?**
- 2.1. What strategies of illness-related information search and interpretation can be empirically described, and how do they connect with the stages and progression of the disease, general media use habits and the socio-demographic background of patients?
- People develop strategies in order to control illness-related information inflow. At early stages, information can be avoided (the "blunting" strategy) in order to secure emotional well-being and social status. People use the avoidance strategy both in patient-physician and in patient-patient communication. When the avoidance of information is not possible, people develop the skill of recoding the content through accusation and non-naming (**Study I**).
 - Among the sample studies, socio-demographic factors, such as ethnicity, age and education, had no statistically significant connection with illness-related information-searching activity. The results indicate that women have more questions about their disease (**Study II**).
 - Illness-related information-seeking activity is related to the activity of general information seeking from mass media. The intensity of use and variety of sources of general news media are linked with the variety and searching activity of illness-related information (**Study II**). The active search for illness-related information from other sources besides physicians and nurses is (partly) related to

the wish to maintain existing media use habits despite the appearance of the illness (**Study IV**).

2.2. What characterises the information needs in different stages of disease and social contexts?

- The stage of an illness influences the information-search strategies that people use. In the early stages, people are either passive in information seeking or independently and actively seek information from various available sources (**Study II**).
- In later stages of the diseases (more than 5–10 years), the importance of other patients as information sources increases. The role of the patients' society as a mediator of information exchange between ill people increases (**Studies I and II**).

2.3. How does illness and healing information seeking help or hinder personal chronic illness management: the maintenance of social relations and subjective life quality and the (re-)construction of dignity?

- In order to take individual responsibility, people use different strategies, e.g. they search independently for information about goods and services that may improve their health status. These goods and services may be both publicly and medically approved (e.g. different types of massage, physical training, food supplements etc.) or not approved (e.g. CAM methods that are not evidence-based). The latter bring about the usage of cultural, social and economic capitals and at least a temporary increase in subjective well-being, as well as the strong feeling of agency derived from manoeuvring between medical and economic fields (**Studies I, III and IV**).

2.4. How do illness and healing information search and interpretation vary across the different power contexts and social roles (e.g. the physician-patient relationship versus the supplier-consumer relationship)?

- People understand that power relations differ between the medical and economic fields and both of these fields have their own, specific rules and socially approved forms of conduct. In order not to jeopardise the patient-physician relationship, people may avoid the discussion of potentially harmful topics or activities (**Study III**).
- The switches between patient and consumer positionings lead to problems in the patient-physician relationship: individual, but non-accepted, behaviours are considered to range from inappropriate to rebellious. This leads to a strategy where CAM methods are used, but the use is not admitted to doctors (**Study III**).

2.5. How do Estonian PD patients use illness-related information in adjusting their lifestyles and everyday habits?

- Previous everyday habits play an important role in adaptation to life with the chronic illness because they are important in maintaining social agency and social roles for as long as possible. People's information strategies are devoted to meeting this goal and unmet needs may lead to abandoning institutionally provided recommendations (**Study IV**).
- The space of negotiation depends on different factors: illness-related physical causes, the duration of an illness, general understandings about ill people or the ill person's perception of general public understandings or of the self and their own capabilities. The longer duration and more severe symptoms of the disease together with positive understandings about public opinion and the self support adjustments make it possible to continue the habitual lifestyle longer. Otherwise, information about potentially helpful adjustments is abandoned and activities are discontinued, at least temporarily (**Study IV**).
- The purpose of illness-related information is to support gradual changes smoothly, with the focus on the person. While the focus is person-centred rather than illness-centred, people find the motivation and willpower to implement recommended adjustments in lifestyle (**Studies I, II and IV**).
- Information-search tools (e.g. innovative technologies) and sources (experience counselling, web-pages, forums etc.) must comply with the patient's habitual information acquisition strategy in order to be efficient and used as intended (**Studies II and IV**).

3. Based on the example of Estonian PD patients, how is it possible to arrange illness-related mediated communication to support patients in their lifestyle modifications in the conditions of progressive disease, while preserving subjective quality of life and autonomy as much as possible?

3.1. How does the current information provided by medical institutions, the patients' society and mass media hinder or support patients' gradual coping with PD and the independent adjustment of their lifestyles?

- People need support in constructing the meaning of an illness: in addition to medical professionals, mass media contribute to this process and frame wider understandings of the meanings of being ill. Therefore, people using mass media channels for information search and interpretation experience different adaptations because public perceptions of illnesses and ill people influence them. This leads to deeper avoidance due to the fear of stigmatisation (**Studies I and II**).

- Too detailed illness-related information at the time of diagnosis and in the early stages of the illness hinders the adaptation process. In order to maintain existing social relations and protect emotional status, people avoid illness-related (practical) information (**Study I**).
- 3.2. How can mediated communication supplement (instructive) interaction with the physician and nurse during different stages of illness?
- People need information based on their needs and in smaller pieces, which enables people to switch from the blunting strategy to monitoring. Additionally, as gradual communication also allows gradual adaptation, people are able to continue their everyday lives in habitual ways. This may prevent massive avoidance and denial of the illness, which leads to better emotional coping and willingness to make adjustments when needed. Therefore, structural ways of illness-related communication should feature gradual informing (**Study IV**).
- 3.3. What rearrangements in illness-related mediated communication are needed in order to support patients' gradual, independent as possible adjustment of their lifestyles and social relationships to physical and mental changes that come with the progression of PD?
- The blunting strategy is not viable for a long period and, therefore, it is necessary to encourage patients to adopt the monitoring strategy. Flexibility in timing and in content of information has the potential to support this switch in strategy (**Studies I and II**).
 - People prefer a gradual information inflow matching their situationally raised needs and questions (**Study IV**). Therefore, at the time of diagnosis and in the early stages of the disease, information should be provided in small amounts to allow smooth and individually appropriate (emotional) adaptation to the new situation. Practically, this means the increasing importance of specialised nurses and peer patients (as experience counsellors), but also the availability of psychological support without requiring a psychiatric diagnosis.
 - There is a need for the content of incoming information to support the maintenance of the existing lifestyle and habits for as long as possible, allowing for smooth adaptation (**Study IV**).
 - In order to increase peer-to-peer communication based on experience exchange or counselling, future developments should focus on the diversification of forms of support (**Studies I, II and IV**).
 - Currently, the content of illness-related information is not satisfactory to patients because it focuses on the disease rather than on the ill person. There is a need for information supporting the conti-

uation of the existing lifestyle as much as possible and for as long as possible (**Study IV**).

- People need the opportunity to discuss and get support in the interpretation of all kinds of information (including CAM-related topics) without the fear of stigmatisation (**Study III**).

In summary, structural support should be based on the needs and development of the individual illness experience. The content of illness-related information should support the maintenance of habits. In order to make recommendations work, structural changes must be made on the political level, which leads to strategic goal setting and financial investment.

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SUMMARY IN ESTONIAN

Infootsingu ja -tõlgendamise roll kroonilise haiguse korral Eesti Parkinsoni tõve patsientide näitel

Vananev ühiskond on toonud arenenud lääne ühiskondadele uued väljakutsed. Järjest enam on meie hulgas inimesi, kes põevad üht või enamat kroonilist haigust ja seda arvestatava osa oma eluajast. Kui ajal, mil oli suurem nakkuslike haiguste osakaal, valitses arusaam, et haige-rollis peab inimene ajutiselt loobuma tavapäraest sotsiaalsetest rollidest haiguse vältel (Parsons 1951a), siis nüüdisühiskonnas, kus kroonilised haigused on väga levinud, tuleb nii haigetel kui tervetel ühiskonnaliikmetel harjuda kroonilise haigusega/haigetega koos elamisega, säilitades maksimaalselt sotsiaalseid rolle ka haiguse vältel. Ühiskondlikud väljakutsed on nii poliitilis-majanduslikud kui ka sotsiaalsed ja eetilised: kuidas tagada krooniliste tõve patsientide ligipääs tööturu- ja tervishoiuteenustele, kuidas kujundada ühiskondlikke hoiakuid krooniliselt haigete inimeste suhtes? Krooniliselt haiged inimesed pelgavad võimalikku haigusest tulenevat stigmatiseerimist ning ei kipu oma haigustest lähikondsetele ja kolleegidele teada andma. Väga oluline on toetada inimesi kogu haigusega kohanemise ja sellega elamise protsessi vältel. Ühe lahendusena on nähtud individuaalset aktiivsust ja ka sellest tulenevat vastutust oma tervise eest. Aga ka siin võivad tekkida erinevad arusaamad isikliku vastutuse ulatusest ja sobivusest ja seda nii kroonilist tõbe põdevate inimeste kui ka medistiinisüsteemi esindajate (arstid, õed) poolt. Kui poliitikate muutmiseks kaasatakse eksperte ja töötatakse välja tegevuskavasid, siis väärtuste ja hoiakute kujunemisel mängib suurt rolli kommunikatsioon.

Uuringute järgi saavad haigusega seotud väljakutsetega paremini hakkama need inimesed, kellel on piisavalt haiguse-alast infot (Kutner et al., 1999; Clayman et al., 2008). Samal ajal on osa uuringuid näidanud, et liigne informatsioon võib ravitulemust ja haigusega hakkamasaamist hoopis halvendada (Ward et al., 2004), mis tõstatab küsimuse, kas pakutav haigusealane info on erinev sellest, mida vajatakse haigusega hakkamasaamisel?

Käesoleva doktoritöö “Infootsingu ja -tõlgendamise roll kroonilise haiguse korral Eesti Parkinsoni tõve patsientide näitel” peamine **eesmärk on selgitada haiguse füüsiliste, psühholoogiliste ja sotsiaalsete muutustega hakkamasaamist toetavaid ja takistavaid, infokäitumisega seotud tegureid.**

Dissertatsiooni teoreetilise aluse moodustab sotsioloogiline (patsientide) agentsuse kontseptsioon (Bourdieu' [1984] ja Cockerham'i [2013] käsitlused), mis on kriitiline haigusega seotud sotsiaalsete muutuste individuaalsete käsitluste osas. Nagu Cockerham (2013: 128) on öelnud, siis on terviseteevaliste valikute puhul alati küsimus, kas need individuaalsed otsused tegelikult ikka on individuaalsed või on nad struktuuri poolt ette antud. Oma töös olen ennast positioneerinud pigem Bourdieu' ja Cockerham'i järgijate poolele. See on viinud mind teoreetilise raamistiku loomisel sotsiaalsete praktikate teooriani

(Schatzki, 2013). Käsitlen tervise- ja haigusealast kommunikatsiooni tugevas seoses inimese elu keskkondlike ja kehaliste aspektide ning elustiiliga. Sotsiaalsete praktikate teooria aitab see mõista, kuidas individuaalsed valikud on seotud olemasolevate teadmiste, oskuste, keskkonna, asjade ja elustiiliga.

Doktoritöö aluseks on neli artiklit, mis käsitlevad haigusealase informatsiooni ja kommunikatsiooni erinevaid aspekte. **I uuring** käsitleb informatsiooni hankimise strateegiaid haiguse erinevates staadiumites ning selgitab, kuidas inimesed kontrollivad haigusealase informatsiooni sisu ja hulka. **II uuring** selgitab seoseid inimeste üldiste massimeedia tarbimise harjumuste ja haigusealase informatsiooni otsimise vahel. Nii **Uuring I** kui **Uuring II** selgitavad erinevaid infootsingu ja tõlgendamise seotud strateegiaid.

Uuringus III võtsin kroonilise haigusega inimeste infootsinguliste praktikate väljaselgitamisel näiteks täiend- ja alternatiivse meditsiini kasutamise. Tulemused osutavad, et täiend- ja alternatiivse meditsiini puhul kasutavad inimesed erinevaid info otsimise ja hindamise strateegiaid, soovides olla edukad nii patsientide kui tarbijatena. Kui tarbijana kasutatakse õigust (ja kohustust) võtta isiklik vastutus oma tervise eest ja sellest tulenevalt ollakse valmis proovima tooteid ja teenuseid, millel puudub tõendus põhjus, siis patsiendina loodetakse vähem endale ning püütakse oma tarbijaotsuseid ja -tegevusi varjata, et mitte ohustada oma suhet arstidega.

Uuringus IV on vaatluse all haigusega seotud enesehooldeteemaatika, tuues esile inimeste vajaduse situatiivselt ja astmeliselt pakutava informatsiooni järele, mis toetaks nende vajadust säilitada olemasolev elustiil ja harjumused võimalikult pikemaks ajaks. Doktoritöö raames teostasin täiendava analüüsi, mis koos artiklitega aitab kontseptualiseerida kroonilise haiguse kogemust.

Uurimismeetoditena olen kasutatud nii kvantitatiivseid (**Uurimus II**) kui ka kvalitatiivseid lähenemisi (**Uurimised I, III ja IV** ning täiendav analüüs). Uuringu sihtrühmaks olid Parkinsoni tõve (PD) patsiendid Eestis. Üldisemas krooniliste haiguste ja haigete infokäitumise kontekstis moodustavad PD patsiendid kriitilise juhtumi valimi¹¹.

Käesoleva doktoritöö peamised järeldused ülaltoodud uurimisküsimustele Parkinsoni tõve patsientide näitel on alljärgnevad:

- I Milline on haigusealase info-otsingu roll kroonilise, progresseeruva haigusega hakkamasaamisel?
 - Krooniliste haigete endi tõlgendustes on avalikkuse arusaam kroonilistest haigustest vastuoluline – kui ühelt poolt eeldatakse isiklikku aktiivsust (**Uurimised I, III, IV**) ja vastutust, teisalt aga institutsionaalsete ettekirjutuste täitmist (**Uurimised II, III, IV**).

¹¹ Tegemist on kvalitatiivuuringu kasutatava suunatud valimi strateegiaga, kus juhtum avab uuritava nähtuse selle maksimaalsetes või minimaalsetes olemasolutingimustes (ehk „kui see juhtub siin, siis see juhtub ka paremates tingimustes“ või „kui see ei juhtu siin, siis see ei saa juhtuda ka kehvemates tingimustes“).

- Kroonilisi haiguseid põdevate inimeste tõlgenduses on ühiskondlikud normid ja arusaamad individuaalsest vastutusest siis õiged ja kohaldatavad kui need on kooskõlas tõenduspõhise meditsiini arusaamadega (**Uurimused I, III, IV**). See tuleb eriti reljeefselt esile näiteks täiend- ja alternatiivse meditsiiniga seotud küsimuste puhul, mis jäävad väljapoole tõenduspõhise meditsiini raamistikku (**Uurimused III, IV**).
- Inimestele pakutakse rikkalikku haigusealast informatsiooni enesehooldes programmides, kuid tegelikult vajatakse infot situatiivselt ja väiksemate osadena (**Uurimused I, II, IV**). Vastuolu pakutava ja vajatava vahel võib viia (vähemalt osalise) ebaõnnestumiseni individuaalsele kohanemisele ja enesehooldes tugevdamisele suunatud programmide juurutamisel (**Uurimused I, II, IV**).
- Pakutav haigusealane info keskendub peamiselt biomeditsiinilistele aspektidele, aga inimesed vajavad pigem emotsionaalselt ja sotsiaalselt kohandavat infot (**Uurimused I, IV**).
- Vastuolu vajatava ja pakutava informatsiooni vahel võib viia info vältimiseni (**Uurimused I, II, IV**), samal ajal kui iseseisev infootsing hõlmab ka meditsiiniliselt tõendamata vahendeid ja meetodeid (**Uurimused III, IV**).
- Praktikatereetiline käsitlus tõstab esile kehaliste rutiinide tähtsust igapäevaharjumuste kujunemisel, mis mõjutab tunnetatud elukvaliteeti (**Uurimused III, IV**).
- Praktikatereetiline võtab arvesse nii struktuurseid kui individuaalseid mõjutusi ning selgitab seeläbi enesehooldes võimalikke ebaõnnestumise põhjuseid ja õnnestumise tegureid (**Uurimus IV**).

II Kuidas on haigusealane informatsiooni otsimine ja tõlgendamise seotud patsientide kohanemisel kroonilise haiguse korral (Parkinsoni tõve patsientide näitel)?

- Inimesed kujundavad endale välja strateegiad, mille abil kontrollida info sissevoolu. Haiguse varajases järgus kasutatakse info vältimist ja seda nii arsti ja patsiendi- kui ka patsientidevahelises suhtluses. Kui info vältimine on võimatu, siis omandatakse oskused saadud sisu ümberkodeerimiseks, näiteks süü ja vigade otsimine või umbmäärase kõneviisi kasutamine (**Uurimus I**).
- Kasutatud valimi hulgas ei omanud sotsio-demograafilised tegurid (näiteks rahvus, vanus ja haridus) statistiliselt olulist seost haigusealase info-otsingulise aktiivsusega. Uurimngu kohaselt on naistel rohkem küsimusi oma haiguse kohta (**Uurimus II**).
- Haigusealane info-otsinguline aktiivsus on seotud üldise info-otsingulise aktiivsusega. Üldine massimeedia kasutusintensiivsus ja allikate mitmekesisus on seotud haigusala kasutusintensiivsuse ja allikate mitmekesisusega (**Uurimus II**). Aktiivne iseseisev haigusala info otsimine on (osaliselt) seotud sooviga säilitada olemasolevaid meedia-kasutusharjumusi, mis ei sõltu haiguse olemasolust (**Uurimus IV**).

- Individuaalse vastutuse võtmine väljendub erinevate strateegiate kasutamises, näiteks iseseisvas info-otsingus, et oma tervises seisundit parandada. Sellise info-otsingu tulemusel leitud tooted ja teenused võivad olla ühiskondlikult ja meditsiiniliselt nii heakskiidetud (erinevad massaažid, treeningud, toidulisandid jne.) kui ka mitte heakskiidetud. Viimatinimetatute kasutamisel rakendavad inimesed rohkem oma kultuurilist, sotsiaalset ja majanduslikku kapitali, mis loob (ajutise) subjektiivse heaolutunde. Meditsiini- ja majandusvälja vaheline manööverdamine tugevdab patsientide sotsiaalset agentsust ja vähendab isoatsiooni (**Uurimused I, III, IV**).
- Inimesed mõistavad võimusuhte, sotsiaalsete normide ja spetsiifiliste reeglite erinevusi meditsiini- ja majandusvälja vahel. Seetõttu võidakse vältida arutelusid, mis võivad potentsiaalselt ohustada arsti-patsiendi suhet (**Uurimus III**).
- Ümberlülitused patsiendi ja tarbija positsioonide vahel võivad kaasa tuua probleeme, mis viib strateegiani, kus täiend- ja alternatiivse meditsiini meetodeid kasutatakse, aga seda kasutust ei tunnista (**Uurimus III**).
- Haigusega kohanemise protsessi mõjutavad olemasolevad harjumused, mis on olulised sotsiaalse agentsuse ja -rollide säilitamisel. Inimeste infokäitumise strateegiad on suunatud selle eesmärgi täitmisele ning rahuldamata vajadused viivad institutsionaalsete soovitude hülgamiseni (**Uurimus IV**).
- Läbirääkimisruum sõltub erinevatest teguritest: haiguse füüsilistest põhjustest, haiguse kestusest, üldistest arusaamadest haigete inimeste kohta või haigete inimeste arusaamast üldiste arusaamade, iseenda psüühiliste ja füüsiliste võimekuste kohta. Olemasoleva elustiili jätkamiseks vajalike muutuste tegemist soodustavad pikem haigus kestus, tõsisemad sümptomid koos positiivse suhtumisega avalikku arvamusse ja iseendasse. Teistel juhtudel võidakse potentsiaalselt kasulik informatsioon hüljata, mis võib kaasa tuua ka (vähemalt ajutise) tegevuste lõpetamise (**Uurimus IV**).
- Haiguslase informatsiooni otsimise ja tõlgendamise eesmärk on teada järkjärgulisi ja sujuvaid muudatusi elustiilis, fookusega inimese olemasolevate sotsiaalsetele rollidel ja elustiili, mitte haigusel, motiveerib inimesi ja annab tahtejõudu viia ellu soovitatud elustiili muutusi (**Uurimused I, II, IV**).
- Selleks, et uuendusi kasutataks, peavad info-otsingu tööriistad (näiteks innovatiivsed tehnoloogiad) ja allikad (näiteks kogemusnõustamine, veebilehed ja foorumid) sobituma inimese harjumuspärase informatsiooni omandamise strateegiaga (**Uurimused II, IV**).

III Kuidas korraldada haigusealast kommunikatsiooni nii, et see toetaks patsiente olemasoleva elustiili kohandamisel ja muutmisel säilitades samal ajal subjektiivselt tajutavat elukvaliteeti, sotsiaalseid suhteid ja isiklikku autonoomiat nii palju kui võimalik (Parkinsoni tõve patsientide näitel)?

- Inimesed vajavad haiguse tähenduse konstrueerimisel toetust ja abi – lisaks meditsiinitöötajatele panustab sellesse protsessi ka massimeedia, mis raamistab haiguse laiema ühiskondliku tähenduse. Inimesed tajuvad kohanemist erinevalt – hirm stigmatiseerimise ees, mis tuleneb avalikust arvamusest haiguste ja haigete inimeste kohta, võib viia vältimisstrateegia kasutamiseni (**Uurimused I, II**).
- Liiga detailne info diagnoosi saamise ajal ja haiguse varajases staadiumis takistab kohanemist. Inimesed väldivad haigusala (praktilist) infot, et kaitsta olemasolevaid sotsiaalseid suhteid ja emotsionaalset seisundit (**Uurimus I**).
- Inimesed soovivad oma vajadustel põhinevat informatsiooni väikeste osadena. Astmeline kommunikatsioon võimaldab astmelist kohanemist ja seega olemasoleva elustiili jätkamist, mis võib ära hoida haiguse eitamist ja info vältimist ning viia parema emotsionaalse kohanemiseni ja valmisolekuni viia vajaduse korral ellu elustiili muudatusi. Seetõttu peaks struktuurne haigusala kommunikatsioon võimaldama astmelist info saamist (**Uurimus IV**).
- Vältimisstrateegia pole pikaajaliselt jätkusuutlik ja seetõttu tuleb inimesi suunata seirestrateegia ülevõtmisele. Ajaline ja sisuga seotud paindlikkus toetavad sellist strateegiate muutmist (**Uurimused I, II**).
- Inimesed eelistavad astmelist informatsiooni sissevoolu, mis vastaks nende situatiivsetele vajadustele ja küsimustele. (**Uurimus IV**). Seetõttu peaks diagnoosi saamise ja sellele vahetult järgneval ajal pakutud informatsioon olema saadaval väiksemate osadena, mis võimaldaks sujuvat ja individuaalselt sobivat (emotsionaalset) kohanemist. Praktikas tähendaks see spetsialiseerunud õdede ja kaaspatsientide kui kogemusnõustajate tähtsuse kasvu, aga samuti psühholoogilise toe olemasolu ilma psühhiaatrilise diagnoosi vajaduseta.
- Informatsioon peab toetama olemasoleva elustiili säilitamist võimalikult pikka aega ning sujuvat kohanemist. (**Uurimus IV**).
- Tuleviku arengusuunad peaksid keskenduma võimaluste mitmekesistamisele, et toetada kogemuste vahetamisel ja kogemusnõustamisel põhinevat patsientidevahelist suhtlust (**Uurimused I, II, IV**).
- Praegusel hetkel pole haigusealane informatsioon patsientide vajadustele vastav, kuna keskendub rohkem haigusele kui haigele inimesele. Inimesed vajavad informatsiooni, mis toetaks olemasoleva elustiili jätkamist nii palju ja nii pikka aega kui võimalik (**Uurimus IV**).

Inimesed vajavad võimalust arutada ja saada tuge erilaadse informatsiooni tõlgendamisel (sh täiend- ja alternatiivse meditsiini alase info) hirmuta stigmatiseeritud saada (**Uurimus III**).

PUBLICATIONS

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- Vihalemm, T. & Lubi, K. (2013). Välja haiguse kapslist? Kroonilise tõve diagnoosiga inimeste kommunikatsioonivajadustest ja nende uurimisest. [Out from the disease's capsule? Communication needs of chronic disease patients]. *Kaja: kommunikatsiooni ja suhtekorralduse ajakiri [Estonian Communication Journal Kaja]*, 7, 8–11.

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Lubi, K., Vihalemm, T. & Taba, P. (2014). Patsiendid infootsijana: väljakutsed, võimalused ja ohud Parkinsoni tõvega patsientide näitel. *Eesti Arst*, 93 (2), 76–82.

Vihalemm, T. & Lubi, K. (2013). Välja haiguse kapslist? Kroonilise tõve diagnoosiga inimeste kommunikatsioonivajadustest ja nende uurimisest. *Kaja: kommunikatsiooni ja suhtekorralduse ajakiri*, 7, 8–11.

**DISSERTATIONES
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