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FROM "NO WAY" TO "EVERY DAY"

How Liminal Phase Shapes Medication Adherence in Chronic Disease

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How Liminal Phase Shapes Medication Adherence in Chronic Disease

DOCTORAL THESIS

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LIST OF ABBREVIATIONS

To enhance understanding, the dissertation begins with a list of abbreviations, which clarifies the multiple phenomena and constructs used throughout the overview and analysis (see 1. Table)

1. Table: List of Abbreviations

Abbreviation	Full Name	Description
AADQ	Acceptance and Action Diabetes Questionnaire	Measures psychological flexibility and acceptance in chronic disease management.
AFF	Financial Affordability Scale	Assesses the impact of financial constraints on medication adherence.
AVE	Average Variance Extracted	Represents the proportion of these indicators' variance accounted for by the latent variable
BMQ	Beliefs About Medicines Questionnaire	Assesses patients' beliefs about their medications' necessity and concerns about potential adverse effects.
BMQ_C	BMQ - Concerns Subscale	Subscale of BMQ. It focuses on concerns patients have regarding their medications.
BMQ_N	BMQ - Necessity Subscale	Subscale of BMQ. It focuses on the necessity patients feel regarding their medications.
CB-SEM	Covariance-Based Structural Equation Modeling	A form of structural equation modelling that involves covariance to fit the model to data.
CFA	Confirmatory Factor Analysis	A statistical method tests the fit of a hypothesised measurement model on a set of single items.
CFI	Comparative Fit Index	Measures the model fit by comparing the target and independent baseline models.
EFA	Exploratory Factor Analysis	They are used to identify the underlying relationships between manifest items and discover latent structures.
HTMT	Heterotrait-Monotrait Ratio of Correlations	Assesses discriminant validity between constructs in SEM. Two latent variables should represent distinct theoretical concepts.
INAS	Intentional Non-Adherence Scale	Measures the intentional decisions by patients not to follow the medication regimen.
INAS_RI	INAS - Resisting Illness Subscale	INAS subscale. It focuses on patients' resistance to accepting their illness as part of their identity.
INAS_TT	INAS - Testing Treatment Subscale	INAS subscale. Assesses patients' attitudes towards testing the necessity and effectiveness of their treatments.
KSH	Central Statistical Office (Hungary)	The primary government agency responsible for official statistics and census data in Hungary.
MARS5	Medication Adherence Report Scale (5-item version)	A self-report questionnaire was used to measure adherent behaviour to medication regimens.

Abbreviation	Full Name	Description
PLS-SEM	Partial Least Squares Structural Equation Modeling	A type of SEM to model complex relationships between observed and latent variables by maximising the explained variance of the dependent variables.
RMSEA	Root Mean Square Error of Approximation	Indicates how well the model, with optimally chosen parameters, would fit the population covariance matrix.
SEM	Structural Equation Modeling	A statistical technique that examines the structural relationship between manifest items and latent constructs.
SRMR	Standardised Root Mean Square Residual	Measures the difference between the observed correlations and the model's predicted correlations.
TLI	Tucker-Lewis Index	Also known as the Non-Normed Fit Index, it adjusts for the complexity of the model in assessing model fit.
WHO	World Health Organization	A specialised agency of the United Nations is responsible for international public health.

Source: edited by the author

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DEDICATION

I dedicate this thesis to my parents and grandmom, who have supported me throughout my life with their love. Köszönöm Anyu, Apu és Nagyanyó!

1. INTRODUCTION

According to WHO data, approximately 41 million people die yearly from chronic diseases. This number represents more than two-thirds (71%) of all deaths. The characteristic of chronic diseases is that they have a slow progression, and their symptoms negatively affect the quality of life not only for the patient but also for their close relatives who are directly connected to them.

The relationship between chronic diseases and consumption is a two-way road. On one hand, our lifestyle (including our consumption habits) plays a relevant role in developing chronic health issues. Several studies investigated this direction, primarily approaching the problem from a healthcare or macroeconomic perspective. On the other hand, there is less available research literature on how developed chronic diseases influence individuals' and households' consumption habits. While numerous studies explore healthy eating habits, there is a lack of deep investigation into the causal effects of the disease on consumption.

This research investigates the potential factors regarding food choices and medication usage, especially when the patient still desires forbidden elements from the previous "healthy" phase. Through the theory of liminality, a deeper understanding of food consumption behaviours and commitment to specific medications was sought.

1.1 Structure of the Dissertation

This dissertation is structured into main sections (see 2. Table***1*****. Table**) as detailed below*:*

Introduction: This section underscores the unique challenges faced by consumers and households affected by chronic diseases. Given the alarming rise in the prevalence of such diseases globally and specifically in Hungary, it is imperative to comprehend the unique struggles these individuals face. This section also introduces the specific characteristics of general chronic disease patients, with a particular focus on those under diabetes care, highlighting the need for tailored solutions and interventions.

Literature Review: This section provides a comprehensive overview of the key phenomena and concepts that will be explored in the dissertation. The primary focus areas are liminality, its health and marketing-related aspects, and medication adherence. Each

phenomenon is discussed in detail, accompanied by subchapters that introduce the relevant measurement scales.

Conceptual Framework: This section outlines the theoretical frameworks guiding the research. It begins by presenting the conceptual framework, which feeds the research model..

Empirical Research: This section is divided into a detailed methodological and an analytical chapter. It discusses ethical considerations presented before the sequence of studies that capture liminality's role in medication adherence. Empirical research has a preliminary and a primary phase, with two stages in the primary phase: qualitative and quantitative.

Preliminary Quantitative Phase: The preliminary quantitative phase employed Partial Least Squares Structural Equation Modeling (PLS-SEM) where INAS Resisting Illness moderated the effects on medication adherence behavior. While 'Resisting Illness' acted as a moderator, it had some methodological and interpreting imitations. This resulted in the conclusion that there is a need to indicate additional measures to capture liminality. A disease acceptance (AADQ) scale was proposed as a potential moderator in later stages.

Primary Qualitative Stage: The qualitative stage involved in-depth interviews. This stage aims to understand nuances not fully captured by the preliminary model. Results suggest a possible gap between the time since the diagnosis and medication taking. Thus, "time since diagnosis" might be a potential moderator as an improvement compared to the first model setting.

Primary Quantitative Stage: Building on the preliminary quantitative findings and qualitative insights, the primary quantitative phase tests "AADQ" and "time since diagnosis" as moderators. The results indicate that "AADQ" is not stable enough to moderate the effects. Still, time since diagnosis significantly moderates the effects, confirming the qualitative findings about the critical role of time since diagnosis and emphasising the unique characteristics of the liminal phase of the disease.

The *Summary and Limitations* chapter highlights this dissertation's key findings and limitations. It encapsulates the significant impact of psychological and temporal variables on medication adherence and discusses the methodological constraints. Additionally, it

addresses further research and development for more reliable measurement tools capturing the liminal phase.

The *Theoretical Contributions and Managerial Implications* chapter elaborates on how the study extends existing academic discussions by integrating liminality with medication adherence, thereby enriching the literature on chronic disease management. Furthermore, it outlines the managerial implications, emphasising the value of tailored interventions that adapt throughout a patient's treatment journey.

2. Table: Structure of the Dissertation

PART	DESCRIPTION		
Introduction	relevance and prevalence		
Literature review	liminality in chronic disease and consumer studies + measurement scales		
Research Methodology	**PRELIMINARY quantitative phase**	**PRIMARY qualitative stage**	**PRIMARY quantitative stage**
	PLS-SEM - INAS Resisting Illness is moderating Correlation analysis	In-depth interviews	PLS-SEM - time since diagnosis is moderating + EFA, CFA, moderation analysis
Research Results	Resisting Illness is a moderator but has limits. -> Other liminality measure is needed -> **The disease acceptance (AADQ)** scale needs to be investigated as a moderator	- There might be a gap between diagnosis and medication taking. **- Time since diagnosis** should be investigated as a moderator	Test both AADQ and time in the moderator role **- AADQ** is not stable enough **- Time** has a moderating effect
Conclusions and limitations			
Theoretical contributions and managerial implications			

Source: edited by the Author

2 TOPIC RELEVANCE

2.1 Chronic Disease

Definition of chronic disease

Health limitations and deviations from what is considered "normal" can be categorised in multiple ways. The first way to organise is based on the origin, whether physical or mental illness. The second approach is based on the origin of the disease's origin. Some conditions are present from birth due to genetic factors, such as Down Syndrome. Others may also manifest early in life due to birth-related traumas, like disabilities resulting from oxygen deprivation. Some conditions can arise from accidents, leading to outcomes like limb loss or paralysis. Other diseases, like asthma or diabetes, can develop at any point over one's lifetime. Some, like Parkinson's disease or dementia, are often associated with ageing. However, there are conditions, such as autism, whose exact causes remain unknown (Pavia & Mason, 2012).

The term "chronic," derived from the medical Latin word "chronicus," signifies something persistent or long-lasting (Brencsán et al., 2002). It is frequently used in contrast to "acute," which denotes a rapid onset. Many diseases, such as chronic polyarthritis, incorporate this term in their names.

Regarding terminology clarification, the World Health Organization (WHO) approaches chronic diseases in two ways. Firstly, these conditions are described as "noncommunicable diseases (NCDs)" to distinguish them from traditional infectious diseases. However, it is noted by the WHO that an infectious component can be present in several chronic diseases, as exemplified by cervical cancer. Consequently, the term "lifestyle-related" diseases is used as an alternative description, emphasising the influence of daily habits and lifestyle on the development of certain illnesses. This terminology is also recognised as imperfect, as the development of communicable diseases can also be significantly promoted by lifestyle.

Finally, the WHO has formulated four criteria for describing chronic diseases:

1. A chronic disease typically takes decades to become widespread (non-communicable).

2. Their slow progression nature allows for numerous prevention opportunities over time.
3. Long-term management strategies are the key to effective treatment.
4. Healthcare providers need to coordinate the treatment of these chronic conditions alongside acute and infectious diseases (World Health Organization, 2005).

The development of these diseases is influenced by risk factors categorised into four main groups: (1) Metabolic or biological factors such as high blood pressure, elevated blood sugar levels, overweight, and obesity; (2) Low levels of physical activity; (3) Excessive consumption of alcohol; and (4) Smoking (World Health Organization, 2014)

The most frequently mentioned and investigated chronic diseases are cancer, cardiovascular diseases, diabetes, chronic liver diseases, chronic respiratory diseases, and cerebrovascular diseases (Eurostat, 2018).

Chronic diseases manifest over extended periods and significantly influence the long-term quality of life of the affected individual. Consequently, the patient's immediate environment and family must acclimate to the altered circumstances.

2.1.1 Chronic Diseases in Numbers

When addressing chronic diseases, relevant statistics highlighting the prevalence and challenges faced by those living with chronic conditions are beneficial. International bodies, such as the World Health Organization (WHO), the Organization for Economic Co-operation and Development (OECD), and EUROSTAT, play an instrumental role in collecting, processing, and disseminating public health-related data. On a domestic level, Hungary's Central Statistical Office (KSH) also contributes to this information package.

A central understanding of the scale is necessary to realise why WHO labelled NCDs an epidemic (World Health Statistics 2023). This is not just about understanding the numbers but also about responding to chronic illnesses' inherent challenges and needs.

While many chronic conditions are worthy of examination, diabetes stands out as an emerging area for focus. Its widespread incidence, long-term health implications, and broader effects on consumer behaviour make this disease a first-class target group of analysis. This particular disease serves as an illustrative case, allowing for extrapolation and inferences about the broader landscape of chronic illnesses. Whether discussing

strategic healthcare decisions, creating policy recommendations, or providing care for patients, the data around diabetes offers valuable insights that can often be applied to other chronic conditions as well.

Global Impact of Chronic Diseases

According to the World Health Organization (WHO) data, an alarming 41 million people globally lose their lives due to chronic diseases yearly, representing 71% of the global mortality rate. A closer examination of this data shows that cardiovascular diseases account for 17.9 million deaths. Cancers are behind with 9.0 million deaths. Respiratory diseases are responsible for 3.9 million deaths, followed by diabetes, which causes 1.6 million fatalities. Together, these four categories of diseases contribute to over 80% of all deaths related to chronic illnesses.

Adults living in less developed regions are at an almost doubled risk of facing premature death due to these dominant chronic diseases compared to those who live in better-developed countries (World Health Organization, 2022).

Chronic Diseases in the European Union

Non-communicable diseases (NCDs) like diabetes and heart disease cause around two-thirds of all deaths in Europe. There is a wide gap in life expectancy between the rich and developing countries within the EU. These diseases do not just shorten lives; they represent 77% of European health issues. They bring personal distress and result in financial threats for households. The overall societal cost of these diseases is expected to rise as the EU population ages. The cost for the EU yearly is approximately €115 billion, which is 0.8% of the entire EU economy. This includes direct healthcare costs and other costs like lost work productivity and increased demands on social care systems (Kotzeva, 2022).

The European Union reported that 555,000 individuals died at the age of employment due to chronic diseases. The EU estimated the economic loss associated with this reduced employment and productivity rate to be 115 billion euros annually (OECD & European Union, 2016). According to data from 2019 (pre-pandemic), circulatory diseases and cancer were the leading causes of mortality in the EU. Circulatory diseases were

responsible for over 1.6 million deaths, making up 35% of all deaths, while cancer accounted for almost 1.2 million deaths, representing 26% of all deaths (OECD, 2022).

The European Union examines regions to determine where mortality rates from chronic diseases are highest. It is disheartening to note that a Hungarian region (Northern Hungary) occupies first place in the TOP 5 most affected regions, and another local region (North Great Plain) occupies last. The situation becomes graver when considering specific diseases. In terms of mortality caused by cancers, all seven Hungarian regions are listed in the EU's TOP 10 most affected regions (Eurostat, 2018).

Chronic Diseases in Hungary

In Hungary, cardiovascular diseases such as ischemic heart disease and stroke are the leading causes of death, accounting for over 40% of all registered deaths in 2021. This significant health burden is reflected in the prevalence of chronic diseases among the elderly population; half (47%) of Hungarian men aged 65 or older and more than two-thirds of women in the same age group report suffering from multiple chronic conditions. This rate is among the highest in the European Union (OECD, 2023).

The following trends were observed in the age group of 0 to 18 years 3. **Table: Disease Prevalence in Hungary (number of cases / 10.000 individuals)**3. Table). The diabetes incidence has more than doubled since 2003, reaching 28,6 cases per 10,000 individuals in 2021. The high blood pressure incidence had a 43% increase, rising to 59,6 cases per 10,000 individuals by 2017, and after that, it started to decrease slightly. Asthma has achieved the most significant growth. The number of cases escalated to 633,1 per 10,000 individuals in 2017, marking more than a 2.5-fold increase over the 15 years, but prevalence also decreased by 2021 (the total population also decreased).

For the adult population, diabetes has more than doubled, with a reported 1406,4 instances per 10,000 individuals in 2021 3. **Table: Disease Prevalence in Hungary (number of cases / 10.000 individuals)**3. Table). High blood pressure has risen 60% in cases, reaching 4006,6 cases per 10,000 individuals in 2021 (almost every second adult has high blood pressure). Heart diseases have increased by nearly three-quarters, with 1419,6 cases per 10,000 individuals reported in 2021 (KSH, 2024, 2019).

3. Table: Disease Prevalence in Hungary (number of cases / 10.000 individuals)

Age group	Disease	2005	2007	2009	2011	2013	2015	2017	2019	2021
0-18 years	**diabetes**	13,8	16,6	20,4	22,9	23,6	25,5	27,4	28,0	28,6
	high blood pressure	46	53,1	62,5	64,5	62,9	64,7	59,6	58,3	50,7
	asthma	287,3	398	476	548,9	578,4	626,2	633,1	625,1	585,0
Adults	**diabetes**	679,4	859,1	974,1	1072,0	1131,2	1243,4	1321,4	1378,6	1406,4
	high blood pressure	2501,1	3135,9	3405,4	3482,2	3683,0	3854,7	3959,7	3979,9	4006,6
	heart diseases	914,3	1237,7	1345,4	1349,9	1435,2	1523,4	1517,3	1475,0	1419,6

Forrás: KSH, 2023

Diabetes and hypertension will be elaborated upon in the upcoming chapters, as these two diagnoses are highly prevalent among the dissertation's qualitative research participants.

2.2 Diabetes

Diabetes requires a multi-approach that consists of lifestyle modifications and medical interventions to maintain optimal blood glucose levels and prevent complications. The primary goal is to keep blood sugar levels within a target range, which can reduce the risk of complications such as neuropathy, retinopathy, and cardiovascular diseases (American Diabetes Association, 2019).

Diabetes can be classified into three primary categories: type 1, type 2, and gestational diabetes mellitus. Other specific types are also acknowledged in medical practice, arising from distinct causes.

Type 1 diabetes—T1DM: This type predominantly affects individuals under 30. It is characterised by the complete loss of insulin secretion due to either an idiopathic attack or an autoimmune destruction of the insulin-producing beta cells in the pancreas. The exact cause of this type is still not fully elucidated, and it is primarily managed through insulin replacement therapy (Atkinson & Eisenbarth, 2001).

Type 2 diabetes – T2DM: is the most prevalent form worldwide, mainly affecting adults over 30 years of age, although an increasing number of cases are observed in

children dominantly struggling with obesity. This diabetes type is characterised by reduced but not complete insulin production loss. This type was formerly referred to as non-insulin-dependent diabetes mellitus (NIDDM) or late-onset diabetes terms. Nowadays, it is rather avoided since it has caused confusion; thus, classification relies on the nature of the disease instead of the treatment (Abutaleb, 2016).

Gestational diabetes mellitus – GDM: manifests as glucose intolerance first detected during pregnancy. While the exact pathogenesis of GDM is mainly unknown, studies indicate that it involves dysregulation and defects in the insulin signalling pathway, leading to decreased glucose uptake and transport in skeletal muscles and adipocytes (Buchanan & Xiang, 2005).

Other specific types of diabetes stem from identifiable underlying defects or disease processes, including diseases of the exocrine pancreas and conditions secondary to the use of certain medications like corticosteroids (Abutaleb, 2016).

Diabetes management is built on four essential pillars. For effective disease control, it is crucial not to overlook the following four components.

Self-monitoring of blood glucose serves as a fundamental part of diabetes management. This regular practice provides insights into the daily fluctuations of blood glucose levels, thereby assisting patients and healthcare professionals in making grounded decisions regarding medication, dietary habits, and physical activities (Polonsky & Henry, 2016). *Medication adherence* is essential in diabetes care. For type 1 diabetes, insulin therapy is necessary, while type 2 diabetes might be managed with oral antidiabetic agents, non-insulin injectables, or insulin, depending on the disease's progression and severity (Davies et al., 2018). It is not possible to separate *dietary management* in diabetes care. Eating according to a balanced diet focusing on low-glycaemic index foods, which cause a slower and more gradual rise in blood glucose levels, is highly recommended for patients with diabetes (Evert et al., 2019). *Regular physical activity,* tailored to an individual's capabilities (for example, age, weight, blood pressure) and preferences, can improve insulin sensitivity and glycemic control (Colberg et al., 2016).

Diabetes Globally

Diabetes, as a chronic disease, progressively worsens the affected individual's condition. Its progression is slow, lasting possibly for decades. Diabetes is often referred to not as a disease but as a condition.

The affected population is enormous; the number of patients worldwide increased from 108 million to 422 million between 1980 and 2014 and from 4.7% to 8.5% of the adult population. High blood sugar accounts for half of the causes of death in people under 70. Diabetes has numerous severe consequences, ranging from blindness to kidney failure, and can cause heart attacks and strokes, thus meaning significant risk (World Health Organization, 2016). Due to these factors, this group of diseases is suitable for studying the effects of chronic diseases or conditions in the case of this group of diseases in the future.

Diabetes in the European Union

If we narrow down the global survey, we can see that even in the predominantly better-off European region, the number of people living with diabetes is very high. According to 2014 data, the number of those struggling with diabetes in Europe was estimated at 64 million (7.3%) (World Health Organization, 2016).

Diabetes in Hungary

According to data from the Hungarian Central Statistical Office in Hungary, among the population aged 19 and older, there were 596,7 cases of diabetes per 10,000 inhabitants in 2003. By 2013, this number had risen to 1,127.3 cases (KSH, 2015).

Of all the registered diabetic patients, 94% have type 2 diabetes, while 6% suffer from type 1 diabetes. As mentioned, this 6% represents approximately 45,000 individuals with type 1 diabetes, which is considered accurate. However, there are significantly more people with type 2 diabetes than registered (Elek, 2023).

2.3 Hypertension

Hypertension, commonly known as high blood pressure, is a prevalent medical condition that significantly impacts public health due to its association with various cardiovascular diseases and other complications (Singh et al., 2017). Older age is a key patient characteristic in treatment-resistant hypertension (Egan et al., 2010). Uncontrolled hypertension and apparent treatment-resistant hypertension are defined by specific blood pressure levels and the number of antihypertensive medications taken (Egan et al., 2011). The clinical characteristics of hypertension can vary, symptoms like dizziness and

headaches are prevalent in hypertensive individuals and are closely related to blood pressure levels (Middeke et al., 2008). Hypertension is a significant risk factor for cardiovascular diseases, contributing to a third of all deaths globally (Senarathne et al., 2021).

Worldwide, approximately 1.28 billion adults aged 30–79 suffer from hypertension, with the majority—about two-thirds—residing in low- and middle-income countries. Alarmingly, nearly half (46%) of those with hypertension are unaware of their condition. Only 42% of adults with hypertension are both diagnosed and receiving treatment. Furthermore, just 21% of those being treated have their hypertension under control, highlighting significant gaps in awareness, treatment, and management of this global health issue (WHO, 2023). In 2019, a significant portion of individuals in the EU aged 15 years and above indicated the presence of high blood pressure. When examining the prevalence of high blood pressure among EU countries, it is worth noting that Croatia had the highest percentage, with 37% of individuals aged 15 years and older being affected. Similarly, Latvia and Hungary also had significant shares, both recording a rate of 32% (Eurostat, 2021).

3 LITERATURE REVIEW

3.1 Concept of Liminality

Liminality has its origin in anthropology. Liminality's name derives from the Latin word "limen," which means "threshold" (Noble & Walker, 1997). The first author, Van Gennep (1960), wrote his book “The Rites of Passage”, explaining life as a sequence of important individual and collective life events embedded into the individual’s life, such as weddings, having a child, or death. These life events have a ’before’ and an ’after’ phase, and there is a threshold in between that must be crossed. According to this crossing event, he has identified three main phases. The first is a preliminary phase, a transition phase signed as a liminal period, and a post-liminal period (Van Gennep, 1960). The original description of the liminal stage focused only on life events, but Van Gennep had some examples explaining that the threshold might be in space or time (Darveau & Cheikh-Ammar, 2021).

Turner has further developed the concept and applied liminality as he explained that belonging to a particular group or achieving status is also a liminal situation (Turner, 1967). He explained that the liminal stage is interesting since it is an “*interstructural*” situation as the culturally defined roles are not valid anymore in the past phase. However, the post-phase role description is still not applicable yet. This is the foundation of the view that liminal people are invisible in several ways, as there is no classification for them since they are “no longer but not yet” and also “betwixt and between” (Turner, 1967).

The person passing one structural state and entering another is called the “*liminar*”. This particular person has a unique identity for the threshold state, called the *“liminal persona*”. This term, derived from the liminality concept, captures a person's unique identity during this threshold phase. “*Limbo*” describes the between phase or state where the potential outcomes are not predetermined (Barrett, 1998).

Specific liminal experiences have been labelled "liminal-like" or "*liminoid*." This distinction arises from the fact that liminoid experiences, unlike other liminal experiences, are typically chosen and playful rather than obligatory and essential (Turner, 1974). For instance, such events could include participating in a festival or embarking on

a pilgrimage. While these experiences represent liminal states, they are voluntarily chosen and do not entail a change in one's identity (Appau et al., 2020).

There is no exact time limit for being in the liminal stage, as refugees may find themselves in the liminality phase while awaiting their citizenship status. However, even after receiving legal documentation or residency permits, they do not automatically become fully integrated into their new society but continue to exist in what can be termed the "liminal" category. This term reflects how these individuals remain betwixt and between social positions assigned to them through law, custom, convention, and ceremony - neither here nor there (Sagbakken et al., 2022).

Liminality can be classified into three categories based on the work of (Pettigrew et al. 2014). *Situational liminality* occurs when families encounter specific, often unexpected, events that temporarily disrupt their standard patterns. Such events might include job loss, which can shake the family's financial stability or illnesses that demand significant adjustments to daily life and roles within the family. Travel or relocation presents a temporary challenge as families adjust to new surroundings and social landscapes. *Functional liminality* is tied to the natural evolution of family roles over time. It's seen during life stages like adolescence, where the individual and familial roles shift in response to developmental changes. Pregnancy is a preparatory period of anticipation and adjustment to include a new member. Wedding ceremonies and the ensuing honeymoon phase symbolise the initiation of a new family unit. *Structural liminality* represents a more enduring transition state, often by persistent socio-economic conditions. Poverty, for example, can impose long-standing constraints that require one to adapt continuously to financial strain. Migration leads to a fundamental reconfiguration of the family's cultural and social context. Lastly, dealing with a permanent physical disability or an incurable illness within a family member requires ongoing adjustments to family roles.

Structural liminality can be linked to household life cycle theories in consumer studies. Family life cycle theories play an important role in consumer behaviour literature because they highlight how changes in a family's demographic situation also lead to changes in consumption habits (Neulinger & Simon, 2011). Traditional household life cycle theories track the classic family model from the single young adult to the elderly "survivor" couple. Various authors use different stages; however, five distinct stages are observable in all models: (1) single young adult, (2) young couple without children, (3) couple with children, (4) couple with children who have left home, (5) elderly single (Hofmeister-

Tóth, 2006). The household life cycle significantly influences health expenditures; households in later life stages (empty nest couples, retired couples with adult dependents) are the highest spenders on health care. Conversely, the younger and single stages of the household life cycle (single or young couples with/without children) exhibit the lowest percentages of households with positive health insurance expenditures (Du & Kamakura, 2006).

3.1.1 Healthcare Applications of Liminality

While it may have previously been considered a niche field, there has been growing interest and recognition of its significance in recent years. Understanding liminality allows researchers to gain deeper insights into various aspects related to health transitions and experiences.

Chronic illness and disability are also the fields of science where liminality is applied. However, this area requires several reconceptualisations since the origin of liminality is rooted in rituals in small-scale society (Barrett, 1998). Turner has taken the first steps towards widening the application circle: "*Liminality may be the scene of disease, despair, death, suicide, the breakdown without compensatory replacement of normative, well-defined social ties and bonds. It may be anomie, alienation, angst, the three fatal alpha sisters of many myths"* (Turner, 1967, p. 46). An essential step to applying liminality in health conditions was Murphy et al. (Murphy et al., 1988) work on physical disability and social liminality. Their starting point is the established fact that physical disability significantly influences an individual's social experiences, often leading to social exclusion—the process by which people are marginalised or isolated from mainstream society. The reason for marginalisation might be missing communication functions or lack of mobility, and they become isolated since "normal" people feel weird about their losses; thus, they pretend they do not even recognise the disabled person around them. This state of invisibility is defined as a liminal state for those who are neither sick nor well, who are neither fully alive nor completely dead (Murphy et al., 1988). Owing to their marginalised status and association with mortality, the liminal individuals are perceived as socially hazardous, warranting their isolation from mainstream society. Engagement with this group is recommended solely under the protective shield of ceremonial protocols and established formalities (Murphy et al., 1988).

Liminality has found its place in several healthcare dimensions as well. In the case of mental illnesses, liminality was applied to understand the different categories of schizophrenia, as a patient with this disease has a rather liminal personality (Barrett, 1998). Being in psychiatric care might have been experienced as a liminal phase and place by the patients. Being hospitalised is a vulnerable and uncertain phase since the patient does not know how to live after the care period. Not only did the weakened authority cause a problem, but the psychiatric patients doubted the treatment they had received. The core of the ambivalent feelings was that they wished to receive care and treatment and escape from the uncomfortable caring hospital (Hagen et al., 2020).

The sick role differs from the disability role since the patient's temporary closure of standard rights and responsibilities is accepted and validated based on the statistically prevalent assumption of eventual recovery. Upon recovery, a person is reintegrated into society, resuming their full range of roles and their previously interrupted existence (Murphy et al., 1988).

While health can exist independently of illness, the reverse is untrue; illness cannot exist without health. When disease emerges, it becomes integrated into the ongoing health experience, altering it in diverse ways. This modification can impact the overall quality of the experience, potentially changing feelings and perceptions of health (Lindsey, 1996).

Thus, the multifaceted dimensions of liminality contribute significantly to the discourse on health transitions and experiences, shedding light on the intricate interplay between various health conditions and the liminal states.

3.1.1.1 Liminality as a lens for chronic diseases

Liminality serves as a framework, capturing the dynamics of accommodation and adaptation during illness while respecting individual experiences (Little et al., 2022). Chronic diseases could show a liminal state marked by the absence of normalcy; however, they cannot be diagnosed definitively. In some medical conditions, individuals can have delays or even eternally in gathering a precise diagnosis. For example, in chronic pain conditions, it is not unusual for some patients to undergo waiting periods of up to five or six years for diagnostic findings. (Honkasalo, 2001).

Living with one or more chronic conditions has the characteristic of living in uncertainty constantly, as this is a fluid state for the patients. Patients often struggle to balance their current, known quality of life and uncertain future well-being. Under these conditions, decision-making involves the possibility that choices requiring sacrifices to the present quality of life may not result in positive outcomes in their future quality of life (Allen et al., 2015).

Bruce et al. (2014) have collected narratives on liminality based on a chronic diseased sample. The stories touched upon an aspect of the participants' experiences. During the early stages of diagnosis, patients' attention was focused on the disease and its treatments. As time passed and the illnesses stabilised, a longing for an everyday life emerged beyond illness. Ordinary life is not all the time available or achieved in a different way. Experience of a renewed sense of living and the desire to break free from constant illness emerges as time passes. Participants longed for their illness not to dominate their identity entirely, recognising its integration into their lives while still striving to maintain their individuality.

Little et al. (2022) applied the concept of chronic illness based on a cancer sample. In their view, the phenomenon diverges from the traditional frameworks such as van Gennep's three-phased liminal stages sequence (separation, a liminal phase, and eventual reincorporation (Van Gennep, 1960). The experience of chronic or life-threatening illness does not fit these previously defined stages. Instead, it presents liminality as an ongoing and dynamic condition. Moreover, in contrast to the perspective offered by Murphy et al. (1988), an individual does not need to have a clearly defined and chronic impairment to go through an extended period of existential liminality. Being labelled by cancer diagnosis has enough power to cause and sustain the extended state of liminality and uncertainty that individuals with cancer commonly around. The present conceptualisation of liminality aims to go beyond the primary classification of changes in social relationships resulting from illness. Instead, it seeks to represent the fundamental nature of the individual experience when confronted with illness. In essence, this interpretation of liminality in the context of illness emphasises its dynamic, enduring, and deeply personal nature, underlying the importance of the subjective dimension as a central facet of the liminal journey through chronic or life-threatening illness (Little et al., 2022).

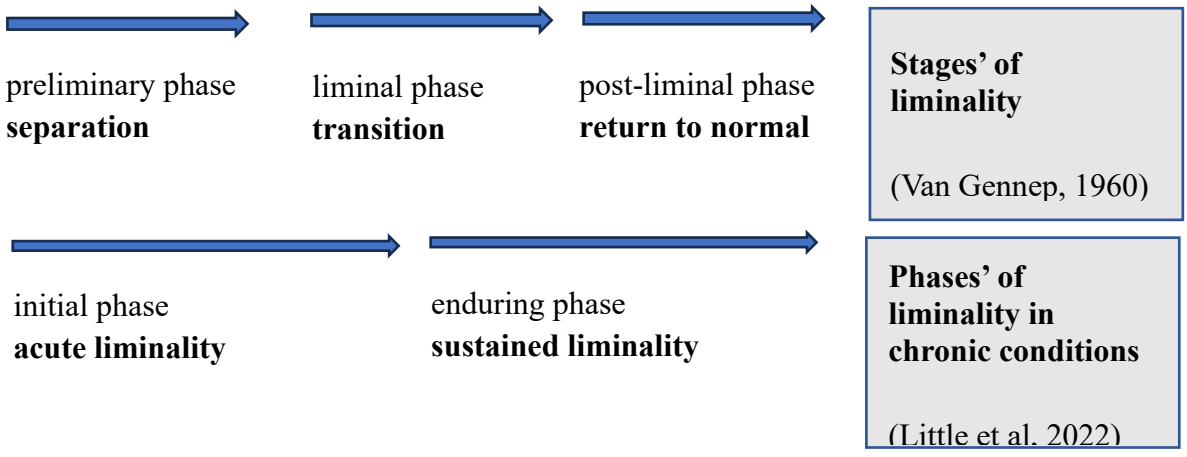
The initial phase of illness liminality with diagnosis and the short-after period is viewed as an inherently liminal phase, characterised by waiting for surgery or test results, thus

facing uncertainties about decisions and the future. Many patients experience disorientation, oscillating between believing and rejecting what is happening around them. Participants have the common mental characteristics to set the disease aside and seek normality. They try to "put it out of my mind" and desire to live as normally as possible. Patients navigate between desiring to gather information but try to avoid knowing more to normalise the period between diagnosis and treatment or wait for test results (Bruce et al., 2014)

In this dissertation, the liminality concept for chronic health conditions is a crucial extension of liminality. Namely, the concept of liminality, particularly in the context of severe and chronic illness, manifests itself in a dual-stage process. The initial phase, known as acute liminality, is characterised by a brief transition state. This is followed up by an enduring phase, described as sustained liminality, which is identified by sustained liminality, which has the potential to extend throughout the entirety of the patient's life (Little et al., 2022).

The 1. Figure below illustrates the primary distinction between the original theory and its application to chronic or life-threatening illnesses.

1. Figure: Periodicity of Liminality in the Original Concept and the Chronic Concept



Source: edited by the author based on Van Gennep (1960) and Little et al. (2022)

3.1.1.2 Liminality Understanding in Diabetes

Diabetes, a chronic condition, requires lifelong management involving consistent blood sugar monitoring, medication adherence, balanced diet, physical activity, and lifestyle adjustments (Awah et al., 2009). Proactive disease management prevents complications from uncontrolled blood sugar levels (Gomes & Negrato, 2015).

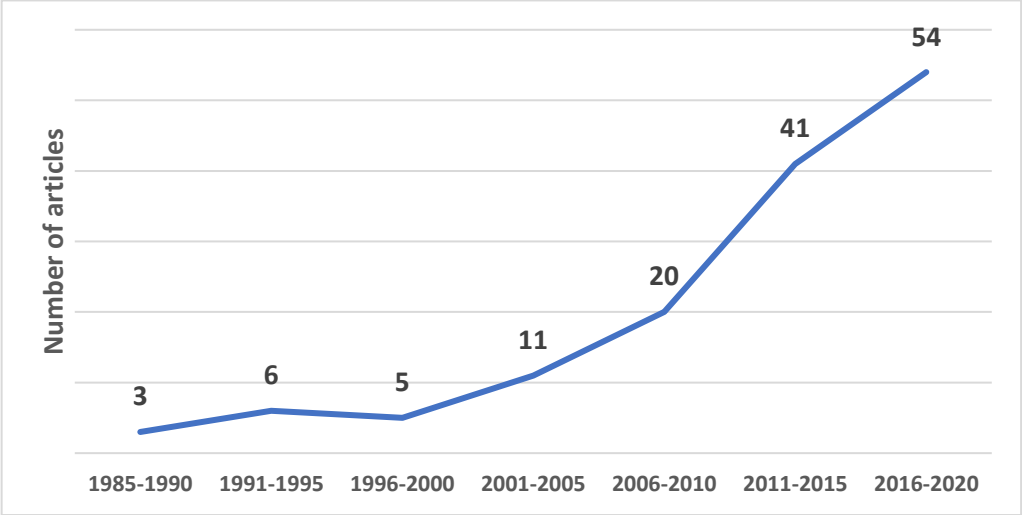
Living with diabetes is analogous to living in a state of liminality, as diabetes patients face the possibility that their blood sugar level will become dangerously low. People with diabetes face dual risks, such as the long-term risk of low blood sugar, which indicates loss of consciousness or seizures, and the long-term hazards of too high blood sugar, which may result in heart failure, eye problems or amputations. (Arduser et al., 2015).

Diabetes is characterised by its persistent nature, and although optimal management is desirable, achieving a resolution remains unrealistic. The efficacy of some strategies or approaches may vary over time as they may work some days but fail the next day. The concept of liminality in diabetes extends beyond the continuous process of self-management adaptations (Thulin, 2021).

3.1.2 Liminality in Consumption

Liminality might have been a lens in consumption research for almost forty years (Darveau & Cheikh-Ammar, 2021). The significance of this theoretical lens has grown within consumption research, evident from a nearly doubled frequency of related articles being published every five years (see 2. Figure).

2. Figure: Increase in the Quantity of Consumer Research Articles Incorporating Liminality



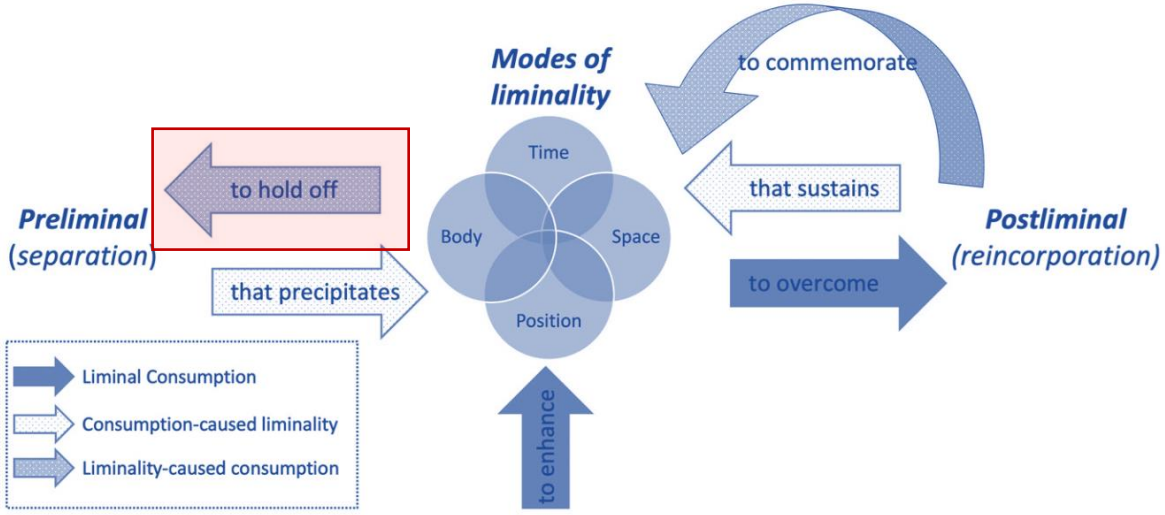
Source: (Darveau & Cheikh-Ammar, 2021)

Life transitions thrust individuals into new and unfamiliar situations (Altmaier, 2020). These shifts can profoundly impact consumer behaviour. Shifts and transformations in an individual's life are often mirrored in their behaviour as consumers (Hopkins et al., 2014). The expectations surrounding life transitions impact a person's quality of life ((Thyroff et al., 2018). This concept is relevant in understanding how trust in medication can predict health outcomes. If a patient has low trust or negative beliefs in medication, that can lead to worse health outcomes.

"liminal consumer" refers to an individual undergoing significant life-altering change. In this context, the concept of liminality has emerged as a framework for examining consumer behaviour and consumption practices during diverse phases of identity transitions (Darveau & Cheikh-Ammar, 2021). There is a broader frame, called *"liminal collective",* since the transition may affect an individual and a community, for example, a family (Pettigrew et al., 2014) or a company department. These two types of liminality can coexist simultaneously, as certain individual transformations may be shared with or impact a community (Darveau & Cheikh-Ammar, 2021). An illustrative instance of this concept could be when a woman becomes a mother; her transition into motherhood might also influence her family, and they collectively undergo a liminal phase during this transformation. Similarly, a chronic disease can also serve as an event that impacts the entire household.

The literature establishes a connection between liminality and consumption, yet these two phenomena' specific directions of influence remain diverse and contextually dependent. This parallel relationship appears logical, as no existing theory comprehensively addresses the interaction between consumption and liminality. In this regard, Darveau and Cheikh-Ammar (2021) propose a framework to elucidate the underlying dynamics of this interaction. Their conceptual framework centres around three distinct categories of consumption linked to liminality: (1) liminal consumption, (2) consumption-caused liminality, and (3) liminality-caused consumption (see 3. Figure). In the upcoming sections, these consumption patterns will be further explored based on the work of Darveau and Cheikh-Ammar (2021).

3. Figure: Liminality-related Consumption Categories



Source: (Darveau & Cheikh-Ammar, 2021)

3.1.2.1 Liminal Consumption:

Liminal consumption is defined as a renewing process related to transitional life experiences (Cody & Lawlor, 2011). Two interpretations might occur: "consumption to overcome liminality" and "consumption to enhance liminality."

Consumption to OVERCOME Liminality: Noble and Walker (1997) link consumption and liminality, suggesting symbolic consumption to make the transitions during identity changes easier. People use consumption to navigate liminality, often using meaningful

products to imply new roles while leaving behind old ones. This type of consumption aims to reduce discomfort and stress during changes. However, dependence on this form of consumption can result in an extended state of liminality.

Consumption to ENHANCE Liminality: Liminal consumption is not only about making the transition more accessible; it can also strengthen the liminal experience. Those items relevant only during the transition phase are referred to as “Sacra” because of their ritual position in the liminal phase. For example, motherhood or pregnancy products or services such as a nursing bra may enhance the experience of being a new mother (Tonner, 2016). In contrast, this differs from "consumption to overcome liminality," which seeks to reduce and control negative emotions, as it focuses on enhancing the positive aspects of the transition.

3.1.2.2 Consumption-Caused Liminality:

Consumption-caused liminality refers to liminal states indicated by consumption (Thomsen & Sørensen, 2006), yet the interpretations of this concept do not necessarily align. Two distinct perspectives on consumption-caused liminality are present: consumption that sustains liminality and consumption that precipitates liminality.

Consumption that SUSTAINS Liminality: Thomsen and Sørensen (2006) introduced consumption-caused liminality, highlighting products or activities commemorating liminal feelings. A subset termed "consumption that sustains liminality" is identified, intensifying liminal experiences. In a study about baby carriages and motherhood, Thomsen and Sørensen (2006) found that these four-wheeled equipment purchased during pre-pregnancy triggered memories of earlier liminal identities for mothers-to-be, frustrating transitional progress. This phenomenon is labelled "entrapped liminality" when individuals feel stagnant and return to past life stages (Yau & Christidi, 2018). Such consumption can delay escape from liminality, as seen in addictive consumer behaviours like gambling or drinking (Pettigrew et al., 2014).

Consumption that PRECIPATES Liminality: An alternative interpretation of consumption-caused liminality emphasises a distinct phenomenon. This perspective involves consumption that leads individuals into a liminal experience, differing from sustaining liminality. It prompts them to step across the threshold of liminality, prompting transitions. Tattoos, for instance, can shift identity into liminal zones between subject and

object (Patterson & Schroeder, 2010). Emerging adults are navigating a new landscape of workplace attire due to the pandemic's shift toward remote work, recognising the need for an updated wardrobe that balances professional and casual styles to express identity and maturity (V. Brown, 2023).

3.1.2.3 Liminality-Caused Consumption:

This approach reveals a distinctive and infrequently explored, thus existing link between consumption and liminality. Unlike prior discussions, this form of consumption involves an inverse causal relationship where liminality affects consumption. Liminality-caused consumption manifests in two ways: consumption to hold off liminality and consumption to commemorate liminality.

Consumption to HOLD OFF Liminality: Consumers may postpone inevitable liminal transitions through consumption, maintaining ties to preliminary identities and corresponding consumption habits. "Private passions," described by Cody and Lawlor (2011), illustrate this by allowing liminars to engage in former behaviours, even if socially unconventional. Such consumption, prevalent in the preliminal phase, ensures continuity in identity and resists full engagement with a new liminal state. Mothers-to-be, for instance, incorporate "private passions" not just for pleasure but to sustain a consistent female identity and avoid a singular "pregnant" identity. Transitions are a fragmented and nonlinear process, as seen in mothers-to-be refusing to identify with their pregnant bodies (Min & Peñaloza, 2019).

This new concept, "liminality-caused consumption," was introduced by Darveau & Cheikh-Ammar (2021), providing a counterpart to the idea of "consumption-caused liminality" originally proposed by Thomsen & Sørensen (2006). This concept opens avenues for future research to explore how preferences for specific products or consumption behaviours are influenced by liminality.

Consumption to COMMEMORATE Liminality: Liminality-caused consumption also commemorates liminal experiences, which can profoundly shape individuals and groups, influencing future consumption patterns. Commemorative consumption honours completed transitions through remembering, often involving cherished memories (Hirschman et al., 2012). Certain products and practices persist after liminal phases, while others are as fleeting as the liminal experience. Al-Abdin et al. (2016) show that post-

revolution, former liminars avoid products tied to political turbulence, showing how liminal experiences negatively impact consumption behaviour.

3.1.2.4 Liminality Caused Consumption in Empirical Research.

In the following chapter, due to the limited number of empirical studies highlighting consumption-caused liminality (Darveau & Cheikh-Ammar, 2021), the focus will be placed on investigating these articles. The objective is to understand the scenario better where liminality functions as the causal factor, resulting in distinct consumption patterns. Through the examination of these significant articles, an effort will be made to uncover the dynamic where liminality becomes the driving force behind specific consumption behaviours.

1st study: “Private passions” - Teenagers on the Borderline

This study by Cody and Lawlor (2011) targeted a transitional life phase—from primary to secondary education—a vivid liminal experience. The sample consisted of female tweens between 11 and 12 years old. The study was conducted across two Irish cities, covering primary and secondary education's final and initial months. Diverse data collection methods were employed, such as personal diaries, interviews, shopping trips, e-collages, and researcher diaries.

This in-between state creates tension for them in navigating consumption practices. These girls are split between being loyal to their childhood past and aligning with the teenage segment's consumption expectations.

Despite distancing themselves from childhood, they are unwilling to abandon familiar comforts completely. This leads to "*private passions*", where they occasionally privately satisfy their former selves. This creates a conflict between their private behaviour and the persona they must fulfil the expectations of the teen consumer segment.

Transitioning from childhood to the teen segment requires leaving childish associations behind. A quote from this qualitative study illustrates this, as the girl desires to engage in activities considered too young for her new teen identity. While expected to embrace teenage interests, she occasionally allows herself to play with "childish" toys privately, reducing the risk of public exclusion.

> *well, I used to love Barbies and Bratz and everything ... and then I was like I can't play with Bratz anymore ... but I want to ... so sometimes I do on my own ... but no I can't play with them anymore ... everyone else didn't like them so it was like okay I can't like these ... well my sister might beg me and I'd be like I don't want to and then I'd go oh fine ... I'll just do it to make you happy but I'd be there enjoying it like yeaaaa* (Cody & Lawlor, 2011, pp 215.)

When this girl is with her younger sister, she can freely enjoy child-like activities without facing social consequences. However, her hesitation to part with these markers underscores the tweens' unique position, straddling the realms of childhood and teenage identity. Despite this close proximity to both phases, societal expectations push them to keep these interests private. This is driven by the growing social pressure to conform to the norms of the teen segment.

2nd study: Enduring passions - Mother-to-be

Cody and Lawlor (2011) introduce the concept of "private passions," identifying a negative form of consumption where teens preserve behaviour from their pre-liminal identity.

Tonner's (2016) study focuses on women undergoing a transition from a non-mother identity to motherhood. Interviews were conducted among first-time mothers during pregnancy and the first year of their child's life. This paper discusses the persistence of consumption practices, including "public" leisure activities, as indicators of their pre-identity stage. A participant's narrative during her prenatal interview exemplifies this notion, as she emphasises her commitment to her fitness routine despite being pregnant.

> *I'd always been quite fit and you know going to the Gym was what I did before I got pregnant and I wanted to keep that. . . I wasn't going all yoga with the prego's [pregnant women] so I kept going to the gym and was still pounding away till quite late. . .* (Tonner, 2016. pp 111.)

For this participant, engaging in her interests before becoming a mother does not cause a conflict with her sense of identity. Instead, these activities seem to provide her with a sense of fulfilment by giving her control over her transition into motherhood and allowing her to maintain independence from societal norms related to motherhood.

Conclusion of the two studies

Chronic illness often places individuals in a liminal state—between health and illness or between their past healthy self and their current non-healthy self. Individuals with chronic diseases may employ consumption to maintain ties with their former, healthier selves and *hold off liminality*. They may engage in activities, products, or services that remind them of their life before the illness, attempting to resist fully accepting their current condition. Just as tweens struggle with the balance between childhood and teenage identities, those with chronic diseases might feel split between their past and present. They may secretly manifest their private passions in behaviours and consumptions that remind them of their healthier phase. Societal pressures and expectations can force individuals with chronic illnesses to hide certain behaviours or consumption patterns. The need to conform or appear "normal" might create a *public vs. private tension* as conflict with their inner desires, thus driving specific secret consumption patterns.

3.1.2.5 Liminality Concept on the Consumer Journey

Nakata et al. (2019) expanded the concept of liminality in the consumer journey, specifically highlighting long-term medication use for chronic diseases. As they noted, the consumer journey literature has collected significant knowledge in the past decades, but three gaps in understanding the customer experience have emerged.

(1) Many studies explored indirect measures like perceived value and service quality. A noted gap exists in understanding consumers' direct emotional and cognitive experiences during their consumption journey. This understanding is limited because researchers are trying to quantify the journey but have not yet realised a robust and validated method for this purpose (Nakata et al., 2019).

(2) The research spectrum is somewhat limited in the post-purchase phase of the consumer journey. However, this is a crucial phase of the journey since loyalty decisions happen here (Etkin & Sela, 2016).

(3) Research needs empirical studies on how consumers' context influences the journey (Kumar et al., 2010). Data collection in real-life settings is recommended for understanding journey experiences by highlighting the interplay between individuals and their daily circumstances.

To fill these gaps, Nakata et al. (2019) studied medication compliance in hypertension patients, a chronic condition requiring long-term management. According to their results, taking medicine is not a black-and-white process. Instead, it is a continuous balancing act where patients sometimes follow their doctor's regulations and at other times do not follow or do not follow correctly. This result is novel compared to the medical perspectives, which see patients binary as they either fully complying or not at all (Brannon & Brock, 2001). This balancing act is "liminality." In the context of medication and other treatment, this in-between state, or liminality, can linger. For example, medication might be skipped occasionally if a patient does not consistently feel clear symptoms of an illness. However, when symptoms are noticed, medication is likely to be resumed. What makes this even more complex is the life context affecting how someone approaches their medication. Maybe there are side effects they do not like, or perhaps the medication is expensive. All these factors play a part in the ongoing balancing act of medication taking (Nakata et al., 2019).

Nakata et al. (2019) emphasise liminality in understanding post-purchase experiences, suggesting that the customer journey needs to be more concise in current models. The unpredictable and variable nature of product or service usage is underscored through the lens of medication adherence in chronic illness. The traditional linear view of the customer journey is challenged and portrayed as fluctuating.

The concept of liminality helps to understand the complex and dynamic nature of the consumer journey, particularly in the context of long-term medication use for chronic diseases. Whether the purchased medication is taken or not illustrates real-life contexts within the consumer journey as a post-purchase phase.

3.1.2.6 Liminality Concept in Advertising

The liminoid approach in advertising is about creating and utilising spaces that allow consumers to explore different facets of their identity through engaging, voluntary, and emotionally charged transformative experiences. This approach can also be applied in health communications to promote behaviours and medication adherence by framing them as transformative experiences that enhance one's life and health (Hackley et al., 2021). Advertisements using a liminoid approach often depict a journey of change, promising consumers that they can transform their lives through the use of a product or

service. This aspect might be a key element in health communication while explaining the necessity of medication.

3.1.3 Measuring Liminality

In their literature review (139 journal articles focusing on the application of liminality in consumer contexts), Darveau and Cheikh-Ammar (2021) underscore that while the amount of such articles is steadily expanding, the majority of them (79.3%, n=111) adopt the qualitative approach. A less dominant portion of these research articles is about developing the conceptual frameworks (17.9%, n=25), whereas a small minority (2.9%, n=4) employs quantitative methodologies, such as regression or structural equation modelling. These statistical figures on methodological preferences suggest that the realm of liminality within consumption research is still in an exploratory phase, wherein qualitative approaches largely dominate the methodological landscape.

In medical research, fluctuating adherent behaviour and disease acceptance can be used as indicators of liminality. Disease acceptance refers to the psychological process of acknowledging and coming to terms with one's chronic illness (Hsieh et al., 2019). It is a crucial step in the management of chronic conditions, as it allows individuals to understand the necessity of medication and other treatment regimens. Scales in medical literature measure these concepts. For further understanding, see Chapter 3.2.5, Measuring Medication Adherence.

3.2 Medication Adherence

'Drugs don't work in patients who don't take them'

/ C. Everett Koop, a former US Surgeon General/ (Lindenfeld & Jessup, 2017)

This phenomenon relates to the connection and teamwork between a doctor and a patient. Understanding this process has evolved significantly over recent decades, adapting to shifts in the doctor-patient relationship paradigm (Simon, 2010). The upcoming chapter will focus on an overview of three phenomena to comprehend the evolution of the concepts in understanding the patient-doctor relationship.

The first assessment aimed to understand how well patients adhere to their medication, dietary, and exercise recommendations. Academic literature frequently uses the term

'compliance' to gauge how well patients cooperate with their medication and treatment plans. (Vermeire et al., 2001a) This scenario entails a one-way exchange in which the choices made by the physician take precedence, therefore neglecting the patient's viewpoint. Non-compliance is seen as a sign of inadequate understanding or unreasonable behaviours, indicative of a paternalistic standpoint that disregards the patient's perspective. This phrase has several limitations. The patient's viewpoint was neglected when evaluating medication adherence or illness management. The possible individual influencing factors might be, besides others, expenses related to treatment, concerns about social stigma, allocation of resources, and individual prioritisation of life goals. From a clinical perspective, compliance refers to showing expected behaviour, while non-compliance suggests displaying inappropriate behaviour. Nevertheless, non-compliance does not always result in negative consequences. For example, choosing not to follow the recommended medication may mitigate the potential side effects and reduce associated financial burdens. Thus, evaluating non-cooperative behaviour's appropriateness within the compliance framework relies on understanding its causal factors (Chakrabarti, 2014).

At the beginning of the century, the World Health Organization (WHO) suggested that the term 'compliance' placed excessive emphasis on the individual responsibilities of both the doctor and the patient. As a result, the concept of compliance underwent a transformation, leading to the need for a new definition: *'adherence*.' (Sabaté & World Health Organization, 2003). This approach concentrates more on the participants' cooperation, discussion and partnership in the healing process (Vermeire et al., 2001). It emphasises patient autonomy and responsibility for therapy failure due to non-adherence. The concept rejects paternalistic hierarchy, establishing a doctor-patient agreement characterised by cooperation rather than subordination. The definition underscores patient participation in selecting appropriate therapy. Unlike the compliance theory's dichotomy of non-cooperation versus cooperation, adherence theory perceives instead a continuum. Behaviour ranges from complete non-adherence to complete precision, with partial medication adherence in between (Chakrabarti, 2014). Scholars rely on this expression to convey the cooperation between doctors and patients (Tilson, 2004). This partnership is intricate to the extent that some authors either refrain from explicitly defining the concept of medication adherence or frequently employ it interchangeably with compliance (Vermeire et al., 2001).

As I write about healthcare cooperation, a third phenomenon must be introduced here. *'Persistence'* assesses the extent to which a patient adheres to the treatment at an appropriate level. Persistence is defined as the duration from the initiation of treatment until the point at which the patient discontinues the treatment. This is a form of "time-to-event" data, meaning that the primary interest is the length of time until a treatment discontinuation occurs (Vrijens et al., 2012). It represents the successful, extended collaboration between a doctor and a patient, making it particularly pertinent in the context of chronic diseases. Hence, it should be noted that persistence is not synonymous with medication adherence, nor does it replace the previously mentioned ideas. Instead, it serves as a complementary factor that clarifies medication intake, giving additional insights into the length of treatment (Cramer et al., 2008).

The topic is increasingly relevant, which is supported by the fact that the annual volume of scholarly articles differentiated by keyword ‘medication adherence’ or ‘patient compliance’, sourced from the PubMed online database, was four times greater in 2020 compared to the year 2000 (Kardas et al., 2023).

Factors of Non-adherent Behaviour

Non-adherence to treatment prescriptions can be attributed to several factors (Cameron, 1996; Sabaté & World Health Organization, 2003). However, the literature lacks consistency in categorising and grouping these reasons. Nevertheless, two primary clusters of non-adherent patients have been identified.

When patients are unable to take their medicine as directed due to outside circumstances such as financial barriers arising from inadequate medication budgets, physical or mental limitations, forgetfulness, limited access to therapy, a misunderstanding of the recommended regimen, language barriers, or medical issues like misusing an inhaler, this is known as *non-intentional non-adherence*. They fail to adhere to treatment due to factors they cannot personally influence. In this case, the cause of non-adherence is external and beyond their control.

Non-adherence could also result from patients' poor remembering of post-consultation medical advice. It is known as intentional non-adherence when people decide not to take their prescription medications as directed. For instance, they may reject dietary

restrictions, lack trust in prescribed drugs, or deviate from the recommended medication dosage by taking less. These patients consciously deny treatment recommendations; their reasons are internal and within their control. This usually entails individuals stopping therapy too soon or lowering their dose because they follow their ideas instead of their doctor's advice. (Chakrabarti, 2014; Lehane & McCarthy, 2007; Horne, 2006; Wroe, 2002).

The frontier between unintentional and intentional non-adherence is not entirely clear-cut, with some overlap between the two categories. (Horne, 2006). Besides these two non-adherence groups, five interconnected factors can influence non-adherence

- *Socio-economic factors*: These encompass elements such as family support, employment status, social stigma, the structure of the insurance system, and the overall cost of therapy.
- *Healthcare team and system-related factors* include communication between healthcare professionals and patients, the availability of medicines and medical supplies, and the adequacy of follow-up care.
- *Condition-related factors*: The severity of symptoms, illness duration, and the disease's overall seriousness fall into this category.
- *Under therapy-related factors*: Key sub-factors within this dimension are side effects, therapy duration, and medication type used.
- *Patient-related factors:* These encompass age, personal beliefs, demographic variables, knowledge levels, and the presence of multiple concurrent health conditions (multimorbidity) (Kardas et al., 2013; Sabaté & World Health Organization, 2003).

3.2.1 Medication Adherence from the Marketing Perspective

In addition to various analyses of healthcare marketing conducted by (Kotler et al., 2008 Kotler & Clrake, 1987; Simon, 2010), Stremersch and Van Dyck introduced a novel perspective in the Journal of Marketing, establishing a new framework and research agenda for marketing in the life sciences field. Within this framework, three key areas have been identified as crucial for marketing decision-making in healthcare:

(1) *Therapy Creation*: This encompasses the development of treatment strategies.

(2) *Therapy Launch*: Involves introducing and implementing these treatment strategies.
(3) *Therapy Promotion*: Focuses on strategies to enhance patient loyalty to the treatment plan.

The third area, therapy promotion, is particularly significant as it offers opportunities to improve patient adherence to treatment strategies. Optimal treatment programs should be designed to ensure that patients can and are willing to follow them (Stremersch & Dyck, 2009). These treatment strategies are pivotal in reducing intentional and non-intentional non-adherence. What sets this marketing-focused approach in healthcare apart is its emphasis on assessing the patient's ability and willingness to cooperate effectively for successful healing rather than assuming unconditional patient adherence. The ABC educational framework is designed to enhance the ability of health professionals to support patient adherence to medication, recognising that the decision to take medicine ultimately rests with the patient. This framework is particularly relevant for pharmacists, doctors, and nurses and consists of four key components: competency framework, curriculum, diagnostic tools to assess competence and guidance materials (White et al., 2013).

A similar perspective can also be found in the service-oriented view of healthcare. In this context, the success of healing processes relies on the collaboration between the service provider (doctor or therapist) and the client (the patient). The service value in healthcare is achieved through a process of co-creation between the healthcare service providers (including doctors, nurses, therapists, dietitians, and others) and the patients. In this approach, healthcare service providers do not take patient cooperation for granted but actively involve the patient's beliefs and capabilities when formulating and implementing treatment strategies (Nakata et al., 2019).

Marketing has a research stream on consumer compliance, and health-related compliance might be considered a substream for this research. This research stream investigates the factors influencing individuals' compliance with various directives, decisions, and recommendations within the consumer context. A natural extension of this stream is health-related compliance to unravel the complex interplay of psychological, behavioural, and situational factors that shape individuals' responses to medical guidance and interventions. This sub-stream delves into individuals adhering to health-related

instructions, treatments, and regimens (Nakata et al., 2019). Through this lens, the marketing discipline aims to contribute insights into enhancing medication adherence and fostering improved health outcomes.

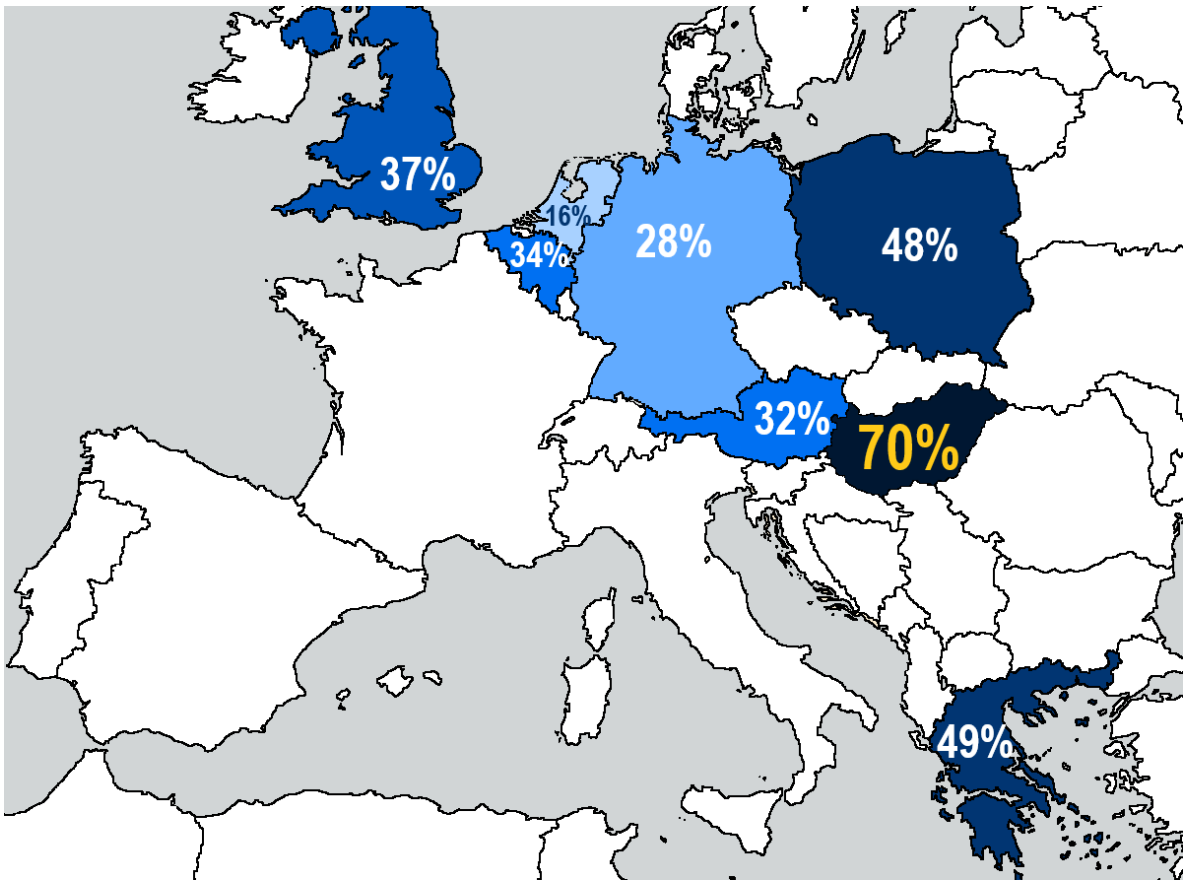
3.2.2 Characteristics of Medication Adherence

Non-medication adherence leads to approximately 200,000 deaths each year and costs the European Union between €80 billion and €125 billion annually (van Boven et al., 2021). The estimation of medication adherence levels can significantly vary across various factors, including the specific disease group under consideration, patient age, the type of treatment prescribed, the duration since the initial diagnosis, family status, economic factors such as affordability, and a range of sociodemographic variables. Some diabetes and/or Hungary-related statistics are detailed below.

A study included a cohort of 2,000 adults with diabetes who were taking multiple medications for hyperglycemia, diabetes-associated conditions, and other comorbidities found that the overall medication adherence rate was 68.5% (Kirkman et al., 2015). Satisfactory glycemic control is not achieved in at least 45% of patients diagnosed with type 2 diabetes (T2DM) (Polonsky & Henry, 2016).

Among the countries studied, Hungary exhibited the significantly highest levels of non-adherence (70.3%) in hypertension patients (see 4. Figure). Regarding intentional non-adherence, Wales and England had lower rates at 9.6% and 9.9%, respectively. Hungary had a somewhat higher intentional non-adherence rate of 12.7%. Austria recorded a 17.3% intentional non-adherence rate, while Poland had the highest rate at 25.7% (ABC Project Team, 2012).

4. Figure: Non-adherence rate in Eight European Countries for Hypertension Patients



Source: edited by the author, based on (ABC Project Team, 2012).

The research found no correlation between medication adherence and sociodemographic variables such as age, sex, or education (Schüz et al., 2011). That raises doubt on the existence of a definitive typical nonadherent patient and instead points to the possibility that various individual characteristics and attitudes might cause adherent behaviour. Even if correlations between sociodemographic factors and traits such as personality were identified, they would only help pinpoint "at-risk" groups for interventions, not define the treatments themselves. While these factors are not unimportant, their link to medication adherence is indirect. The best explanation for their influence is through effects on other relevant measures, such as financial status, which might affect the ability to afford medications (Horne, 2006).

3.2.3 Intentional Non-adherence

Patients sometimes feel disheartened about their treatment when they perceive a lack of positive perspective or unsatisfactory results. This can lead them to question the need for full medication adherence and consider interrupting their treatment temporarily. The temptation to interrupt the therapy is related to the desire to exert personal control over their life, even if they are aware of the negative consequences that may follow. Patients may rebel against the treatment regimen and want to do something they have decided for themselves to regain control (Huyard et al., 2016).

Based on the qualitative research of Huyard et al. (2016), some patients deliberately chose not to follow their treatment as prescribed. The reason for doing so is to maintain some level of authority and restriction over how the treatment influences their daily lives, schedules, and activities (Williams, 2000). Essentially, they wanted to keep the treatment from dominating or dictating every aspect of their lives. The treatment is described as overwhelming and occasionally too demanding. To manage, the most challenging parts of the restrictions are sometimes eliminated or skipped. Dietary restrictions, physical activities, or the personal monitoring of specific health metrics are identified as challenging tasks. Medication adherence is a less burdensome part of the treatment (Huyard et al., 2016).

As noted by Huyard et al. (2016), the primary burden patients experience is a perceived loss of autonomy over their lives. They yearn to regain the control they once had over their bodies, decisions, and time before being diagnosed with their illness. Patients with chronic conditions want to feel normal again (Williams, 2000). This sentiment resonates with the concept of "liminality," where consumption patterns, even those related to health, originate from liminality brought by chronic conditions.

Intentional non-adherence can be understood within the context of liminality. Patients with chronic conditions experience liminality between their past healthy selves and their lives dominated by illness. Acting nonadherent is like trying to regain bits of their old life and take back some control, especially when the treatment feels too burdening. Even though patients know several risks and consequences, some choose not to stick to the treatment plan. This opposition shows how much feeling normal is missed and how being entirely controlled by the chronic condition is rejected. These patients appear to be

trapped in a difficult position, trying to balance what doctors say with wanting to have some control over their lives while dealing with long-term health problems.

3.2.4 Financial Affordability and Medication Adherence

Based on Morisky's scores, it was found that in Hungary, factors such as employment status, ease of borrowing money, low self-efficacy, and a high number of perceived barriers to adherence had a significant impact on adherence. Three out of four are closely related to the financial status of the household (ABC Project Team, 2012).

There is evidence that patient non-adherence rises during recessions. Thirty per cent of senior patients in Portugal stopped buying their prescribed medicines during the 2010–2014 crisis. Additionally, almost 15% of patients started lowering their medicine or increasing the gap between doses to spare money (Costa et al., 2016).

Financial support and the cost of prescription pharmaceuticals are essential drivers of medication adherence among hypertension patients in disadvantaged rural locations (Mamaghani et al., 2020).

Implementing financial reinforcement strategies, such as providing monetary incentives for medication adherence, significantly enhances medication adherence rates for various health problems. Financial incentives enhance patients' probability of adhering to their prescribed prescription regimens, underscoring the importance of addressing financial barriers to improve medication adherence (Petry et al., 2012).

Almost one-third of patients in the US confess to not following their medication regimen because of financial barriers (Ganguli & Thakore, 2021). According to Mchorney and Spain (2011), 56% and 43% of respondents mentioned the cost of paying for medicine as a cause for non-fulfilment and non-persistence, respectively. To enhance medication adherence among people with chronic illnesses, this research highlights the need to address patients' worries about prescription expenses in addition to their perceived need for drugs and concerns about their medications. Similarly, adherence to the treatment regimens was shown to be significantly restricted by cost limitations for 68.3% of asthma and COPD patients in low-resource settings in Kyrgyzstan (Tabyshova et al., 2022).

According to Irish research, patients with a medication-related financial burden at baseline had significantly lower self-reported medication adherence based on the Morisky

scale (MMAS-8). Financial burden was correlated with indicators of lower socio-economic status, such as lower educational attainment and a lower proportion of private health insurance. Higher levels of co-morbidity, including chronic diseases like angina and stroke, were also more prevalent among those reporting financial burdens (Dillon et al., 2018).

Based on the results of a logistic regression conducted on a Greek sample during the debt crisis, those who had to face financial problems were more adherent than those who had no financial issues (Monokroussou et al., 2020).

Evidence from various global contexts consistently shows that economic constraints significantly impact patients' ability to procure and adequately administer their medications. Strategies such as providing financial support, reducing prescription costs, or implementing incentive-based programs have shown promise in improving medication adherence rates.

3.2.5 The Role of Time in Case of Medication Adherence

Several medication adherence statistics have limitations over time, especially in tracking dosing regimen changes. Methods like counting returned medications only offer rough estimates and fail to identify accurate discontinuation times (Vrijens et al., 2012). Consequently, there is a significant gap in research concerning long-term medication adherence. The lack of longitudinal or time-related data underscores the necessity for research in this area to develop effective interventions tailored to maintain medication adherence in the long run, especially for individuals managing chronic conditions (Zwikker et al., 2014). Most related papers suggest no direct effect of time on medication adherence.

Three components might define medication adherence according to ABC Taxonomy, a structured classification system that outlines the stages of medication adherence. *Initiation* is when a prescription is given, and the first dose of medication is actually taken; this is the beginning of a patient's medication adherence journey. It is an essential phase because if the patient never takes the first dose, there's no medication adherence to speak of. The *implementation* phase covers the management of the medication according to the regimen, from the first to the last dose. It focuses on how the patient continues taking their medication in the long run. *Persistence* captures the duration from the start of the medication until the discontinuation. It is an ongoing process, realising the length of time

a patient continues with the prescribed treatment before stopping (Vrijens et al., 2012). All of these components are time-related.

Examining young adults and children after a transplant at two time points (Time 1 at baseline and Time 2 approximately 1.5 years later), the study utilised self-reports from patients and their caregivers, levels of serum immunosuppressants, and a combined approach of these methods to measure medication adherence. The results suggested that overall non-adherence rates remained unchanged between the two times (Loiselle et al., 2015). Australian research highlighted similar results concerning the time effect. Research on Australian patients with rheumatoid arthritis from one given clinic offers insights into how time affects medication adherence throughout a one-year follow-up period. According to the research, the median Compliance Questionnaire on Rheumatology (CQR) score increased somewhat from 71% to 74% over time, indicating that overall self-reported medication adherence was pretty constant (Wabe et al., 2019).

Another study, which included a sample of 600 consecutive ischemic stroke patients recruited from three stroke centres across Korea, found that while medication persistence remained relatively stable over time, medication adherence rates declined significantly over the one-year follow-up period. 89.7% of the patients were adherent at the three-month follow-up, which dropped to 82.2% by the one-year follow-up (Yoo et al., 2023).

Some papers find that medication adherence changes over time. Some studies suggest that medication adherence improves over time, while others indicate it decreases.

An American study involved older patients aged 65 and above who took at least one prescription medication and were enrolled in an online survey. Regarding the effect of time on medication adherence, the study found that overall, medication adherence and beliefs about medication necessity and concerns showed no significant changes over the two years among the general cohort of respondents. However, for those with initially lower medication adherence levels, there was a statistically significant improvement in medication adherence over time (Unni et al., 2015).

Patients in New Zealand who had experienced their first hospitalisation for cardiovascular disease showed a significant improvement in medication adherence following the first hospitalisation. Medication adherence was assessed using the proportion of days covered (PDC) method, and the data showed that medication adherence rates were generally around 55% before hospitalisation but increased significantly afterwards. However,

despite this initial post-hospitalization improvement, there was a notable decreasing trend in medication adherence over the subsequent quarters, highlighting the challenges of maintaining high medication adherence levels over an extended period (F. Hu et al., 2020).

In summarising the chapter on the role of time within medication adherence, it becomes clear that understanding the long-term patterns of medication adherence is crucial but *currently under-researched*. The studies highlighted across various populations and conditions reveal mixed results regarding how medication adherence changes over time. These studies highlight that while some patterns can be discerned, such as initial improvements following significant health events or interventions, maintaining these gains remains challenging.

3.2.6 Measuring Medication Adherence

Assessing medication adherence is a contentious ongoing issue in research and practice, followed by numerous methodological challenges (Horne & Weinman, 1999). An ideal medication adherence measurement method should be easily applied, non-expensive, and offer insight into patients' attitudes, behaviours, and concerns. The patient's burden of participation should also be considered. The upcoming chapter will provide an overview of the most widely recognised measurement methods and discuss some of their research limitations.

Subjective and objective measures

The World Health Organization's prevalent classification of medication adherence assessment methods categorises them primarily into *subjective* and *objective* approaches.

Subjective methods rely on a patient's perception of their medication-taking behaviour. This approach is often facilitated by healthcare providers using tools such as questionnaires. However, biases frequently characterise this self-assessment (Anghel et al., 2019).

In contrast, *objective* methods— such as electronic monitoring of medication administration, assessing clinical outcomes, pill-count, and examining pharmacy records—offer a more accurate option to assess medication adherence. A deeper dive into this classification reveals direct and indirect assessment methods (Anghel et al., 2019).

Direct and indirect measures

Another approach to categorising measurement techniques is to differentiate between direct and indirect methods. Direct methods validate medication use through direct observation or by analysing biological markers. In contrast, indirect methods apply tools such as questionnaires and pill counts (Anghel et al., 2019).

Direct methods involve detecting drug concentrations in body fluids (blood or urine) or observing medication intake. While this approach offers definitive evidence of drug ingestion, there are also challenges. Individual metabolism variations and drug interactions can impact the body fluid method. An essential problem with this approach is the high cost of data collection. It provides a binary result of medication adherence or nonadherence without insights into patterns. Another branch of direct methods, the observation techniques, can be misleading as patients might overact to take their medicine, and patients may adhere only during observation. Another disadvantage is that it is mainly feasible in healthcare (Lam & Fresco, 2015; van den Bemt et al., 2012).

Indirect methods are favoured in medication adherence research because they are easier to apply and more cost-effective than direct ones. These methods include counting pills and electronic health records, employing electronic monitoring devices, and collecting self-reported data (Anghel et al., 2019).

Pill count: This method calculates doses missing between health care appointments against doses received. This cost-effective method might be applied to various formulations such as pills, inhalers, injections, etc. Two major disadvantages might be considered. Firstly, average medication adherence is provided, but the daily patterns are not detailed. Secondly, the fact that the pills are removed from the packages is not proof that the drug has been ingested (de Achaval & Suarez-Almazor, 2010; Lam & Fresco, 2015).

Electronic databases: This approach assumes that prescription refills reflect medication intake. A centralised electronic system is needed for a cost-effective medication adherence measure (Raebel et al., 2013; Sikka et al., 2005). Refill data possibly overestimate medication adherence, indicating only buying and not consuming the drugs (Lam & Fresco, 2015; Raebel et al., 2013). These electronic records might be inexpensive but do not capture individual medication adherence patterns (Anghel et al., 2019).

In 2017, Hungary introduced the National eHealth Infrastructure (EESZT), a cloud-based platform connecting healthcare providers and pharmacies. On November 1, 2017, it centralised medical data, including prescriptions. Although EESZT could bolster medication adherence monitoring, there is no current national funding or immediate plans for related initiatives in Hungary (Kardas et al., 2022).

Medication Event Monitoring System (MEMS) devices are integrated into medicine containers to record dosing histories. The opening of the container is assumed to represent medication ingestion. Their accuracy has been established in various studies, and they serve as a reference for other medication adherence methods (Checchi et al., 2014; Lam & Fresco, 2015). These tools provide detailed dosing information, but potential misuse of the storage might distort results (Checchi et al., 2014). The limit of the widespread use of this tool is mainly its high cost.

Self-reported methods are often used in research for medication adherence measurement due to their cost-effectiveness and simplicity (Forbes et al., 2018). The most crucial criticism of this method is that it tends to overestimate medication adherence because of possible mistakes in patient recall or biased reporting. The estimated ratio of underestimation is around 20% (Haynes et al., 1980), but as seen above, other indirect and direct measures have concerns regarding accuracy. Questionnaires, as self-reports, provide individual attitudes and behaviours and have been validated and correlated with objective measures in various patient groups (Nguyen et al., 2014).

There is no silver bullet in measuring medication adherence, as all the methods mentioned above have their pro and cons. The most widely used medication adherence measurement techniques are self-reported tools (Ágh et al., 2024). These measurement tools are prioritised for their distinct benefits in medication adherence assessment: they are economical, noninvasive, minimally burdensome for patients, and easy to administer (Stirratt et al., 2015). They are feasible for measuring medication adherence within clinics, providing early indicators of potential nonadherence before adverse clinical outcomes (Garfield et al., 2011). Besides capturing non-adherent behaviour, self-reports can capture the factors behind it, such as the patient's understanding of their treatment,

personal attitudes and beliefs towards medication, and other psychosocial variables (Garfield et al., 2011).

The main criticism of these tools is that they rely on the assessment that patients remember and report their medication-taking behaviours accurately, not being influenced by the desire to present themselves in a positive light. Therefore, these tools mostly overestimate medication adherence, which can lead to overreporting medication adherence (Wibowo et al., 2021).

Scales and questionnaires

In scientific medication adherence research, numerous scales have been developed and employed to measure medication adherence. Despite their prevalence, the literature documents the existence of more than 40 scientifically validated measurement scales. These scales can be categorised into five clusters based on their primary focus:

- The first group concentrates solely on medication-taking habits.
- The second group centres on medication-taking behaviour and identifying barriers to medication adherence.
- The third group of scales addresses questions related exclusively to the barriers to medication adherence.
- The fourth group gathers information about beliefs associated with medication adherence.
- The fifth group simultaneously explores barriers and beliefs related to medication adherence (Nguyen et al., 2014)

The fifth methodology is the most commonly used in the marketing-oriented approach to medication adherence, and it is occasionally combined with any of the other four measurement methods.

Using questionnaires in this dissertation to gain insights into patients' attitudes and behaviours regarding medication adherence is the required perspective from the consumption perspective. Cost-effectiveness ensures the feasibility of the data collection fieldwork. Validated scales are based on clearly defined concepts and structures. They can be applied appropriately across various diseases and diverse demographic groups. While surveys have biases (for example, respondents over-evaluate their medication adherence

in self-reports (Ágh et al., 2024)), as detailed above, their benefits outweigh the limitations.

In the next section, various medication adherence scales are presented. These are described based on their objectives, structural frameworks, alternate versions, and the specific dimensions they measure. Notably, the overview also includes the scales employed in this dissertation.

3.2.6.1 MARS-5

One frequently used medication adherence scale is the MARS5 scale (Horne, 2003), which originated from the Medication Adherence Questionnaire (MAQ) and initially comprised ten statements known as MARS10. The original scale has a long history in research.

In order to reduce the scale, the 10-item version was investigated on patients with hypertension, asthma, and diabetes. Based on a principal components analysis, the scale was shortened to a 5-item version called MARS-5. This compact version exhibits good reliability and validity in assessing medication adherence, significant associations with blood pressure control, and patients' beliefs about medicines. Thus, the MARS-5 is a proper self-report tool to assess medication adherence across various health conditions (Chan et al., 2020).

The question had a preface in a non-threatening manner to reduce the potential impact of social pressures that might push patients to report higher medication adherence. Respondents are also ensured that their responses would remain anonymous and confidential (Rand & Wise, 1994).

The five statements must be scored on a 5-point scale (from 5-never, 4-rarely, 3-sometimes, 2-often and 1-very often)

- I forgot to take the medicine
- I alter the dose of medicine
- I stopped taking the medicine for a while
- I decided to miss out on a dose
- I take less than instructed (Chan et al., 2020)

3.2.6.2 Beliefs About Medicines Questionnaire - BMQ

The history of this scale dates back almost 25 years from now. The creators of the scale, Horne et al., first published the series of statements in 1999. Their aim in creating this was to be able to assess the cognitive and belief background of patients related to medication. To construct the scale, they involved 524 patients in the study struggling with multiple chronic conditions such as asthma, diabetes, kidney problems, cardiovascular diseases, psychiatric conditions, or other chronic medical conditions (Horne et al., 2013).

The scale's popularity over the past 20 years is due to its ease and simplicity. In addition, it is universally applicable (and can be adapted if needed) for almost any patient group, has been customised for multiple languages and cultures, and has been successfully validated in light of the results. The advantage of the scale is that it can be applied universally to most patient groups. However, for specific health conditions, it is necessary to adapt some questions, such as replacing the term “medication” with “treatment” (Llewellyn et al., 2007).

The BMQ scale comprises 19 statement items. Each is individually evaluated on a Likert scale, where a value of “1” indicates “strong disagreement,” while a value of “5” represents “strong agreement.”

Two main types of BMQ scales have been developed, each consisting of 2 sub-scales; thus, altogether, four BMQ subscales exist (see 4. Table):

The “General BMQ” scale captures the general opinions of respondents about medication using two distinct sub-scales.

The first sub-scale, *“General BMQ – Overuse”*, includes 3 statement items and focuses on the potential risks associated with the beliefs about excessive medication use for patients.

The second, the *“General BMQ – Harm”* sub-scale, contains five statements and concentrates on the beliefs about the adverse side effects of medications (Horne & Weinman, 1999).

The General BMQ scale was also tested longitudinally. After four years, no statistically significant differences were found regarding the general attitudes of the same respondents towards medication. This suggests that the general views on medication use and its associated risks and concerns remain stable over time (Porteous et al., 2010).

The purpose of the “Specific BMQ” scale is to measure the opinion of individual patients regarding their medications and treatment. It is composed of two additional sub-scales as follows:

The *“Specific BMQ – Necessity”* sub-scale measures beliefs about the effectiveness of the treatment with five statements.

The “Specific BMQ – Concerns” sub-scale uses 6 statement items to measure potential fears associated with the treatment that each patient should follow patients (Horne et al., 1999).

No correlation was identified between the two Specific BMQ sub-scales. However, it was demonstrated that they relate differently to perceptions about the disease. These findings suggest that these two beliefs might be interpreted as two distinct phenomena rather than two opposing poles of attitudes towards prescribed medications(Horne & Weinman, 2002).

Related to the BMQ scale, it is necessary to define another measurement tool, namely the so-called necessity-concerns differential, which is calculated from the two Specific BMQ scales. This differential reveals whether the respondent perceives the necessity of the medications to be more dominant or if concerns about them are more critical. It is calculated by subtracting the values given for BMQ - Concerns from the values of BMQ - Necessity. If the result is negative, it means that concerns dominate the respondent's beliefs and the opposite if the result is positive, that the feeling of necessity is the main domain that regulates the patient’s beliefs (Bondesson et al., 2009; Horne & Weinman, 2002).

4. Table: Structure of BMQ Scale

BMQ - General		BMQ - Special	
O	Doctors use too many medicines	N	My health, at present, depends on medicines
H	People who take medicines should stop their treatment for a while now and again.	C	Having to take this medicine worries mc
H	Most medicines are addictive	N	My life would be impossible without medicine
O	Natural remedies are safer than medicine	C	I sometimes worry about the long-term effects
H	Medicines do more harm than good	N	Without medicines, I would be very ill
H	All medicines are poisons	C	My medicines are a mystery to me
O	Doctors place too much trust in medicine	N	My health. In the future. I will depend on my medicines.
O	If doctors had more time, they would prescribe fewer medicines.	C	My medicines disrupt my life
		C	I sometimes worry about becoming too dependent on my medicines.
		N	My medicines protect me from becoming worse.
		C	These medicines give me unpleasant side effects.
O = overuse, H = Harms		*N = Necessity, C = Concerns*	
(1) Completely agree (2) Somewhat agree (3) I am unsure (4) Somewhat not agree (5) Completely not agree			

Source: edited by the author, based on Horne et al. (1999)

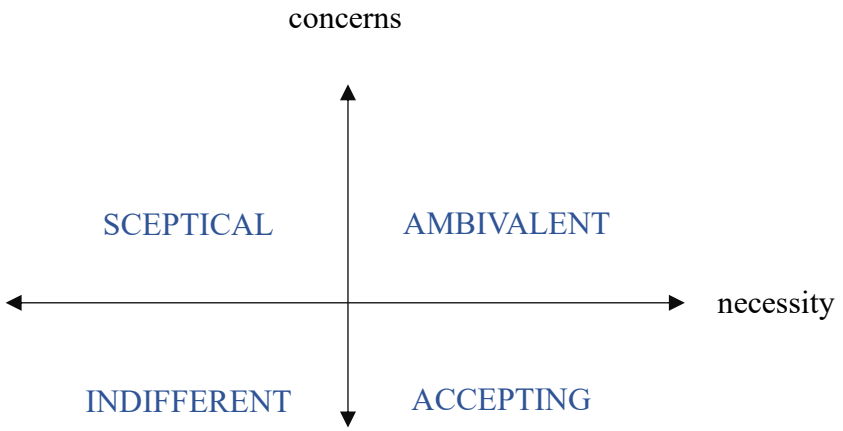
In the field of medication adherence in the case of chronic disease, the Specific BMQ scale is essential. This tool has demonstrated a correlation with the level of self-reported medication adherence measurements. The relationship between medication adherence and beliefs about medication/treatment is defined by the so-called *"necessity-concerns framework"*. This framework posits that the initiation and later maintenance of

medication or therapy are related to the patient's belief about how necessary they feel the treatment is and how robust their concerns about the potential negative consequences are (Horne, 2003).

This framework is supported by numerous publications using the BMQ. Among various chronic disease patients, those who, based on their responses, intentionally follow medical prescriptions less strictly perceive their treatment as less crucial. This evidence is highlighted by their lower scores on the "BMQ – Necessity" subscale (Clifford et al., 2008). Similar findings were realised in a study examining patients dependent on regular dialysis (Wileman et al., 2011). These results might be well summarised by the following classification created on a sample of asthma patients. Using the BMQ necessity-concern dimensions, a coordinate system can be established, allowing patients to be categorised into four segments (see

5. **Figure**).

5. Figure: The Necessity-Concern Matrix



Forrás: Cai et al., (2020), pp 6.

The established four segments showed a significant relationship with adherence. The least adherent group is the sceptical segment, which sees little treatment need and expresses serious concerns about it. The highest medication adherence can be observed in the accepting group, which understands the treatment necessary and is less worried about potential adverse effects (Cai et al., 2020).

The BMQ scale was originally designed for use in British English by its developers (Horne et al., 1999). However, over the past 25 years of its application, it has been translated into numerous foreign languages. The complete scale (all four subscales) or, in some cases, specific subscales are available in major languages, depending on the field of application. During its use in the US, a Spanish version was introduced due to many Spanish-speaking patients (McInerney et al., 2020). In Germany, it was used to study kidney transplant recipients (Bünemann et al., 2020). The "Specific BMQ" scale was validated in Italian for four patient groups (Tibaldi et al., 2009). For the Chinese, the 'Specific BMQ' subscales were adapted for studies on patients with asthma, showing suitable internal consistency indicators (Cronbach-alpha for concerns being 0.698 and for necessity being 0.784) (Cai et al., 2020).

There have been many publications on its adaptation to more minor languages. In Swedish, it was used to study hospital patients (Bondesson et al., 2009). The Latvian version was used to measure the beliefs of asthmatics across various medication adherence projections, including using the 'Specific BMQ - Treatment Necessity' scale (Smits et al., 2020). In the Netherlands, it was used to study the attitudes of pharmacy clients (Menckeberg et al., 2008). Among the most recent BMQ publications is the Polish adaptation of the scale, which was filled out by patients with circulatory disorders and medical students to ascertain the scale's validity (Karbownik et al., 2020).

This literature review covers one Hungarian application of the "Specific BMQ" scale. The so-called ABC research was part of a multi-country medication adherence study in twelve EU member states, including Hungary. ABC project focused on the medication adherence of patients taking anti-hypertension drugs. If unavailable, the scales were translated into each participant's country's language, including Hungarian. The back-and-forth translation of the self-report questionnaire into Hungarian was done, but the Hungarian version of the scale and its validation results were not published separately (ABC Project Team, 2012)

3.2.6.3 Intentional Non-Adherence Scale – INAS

A new scale assessing medication adherence was formulated by moving away from existing theoretical frameworks to focus on understanding barriers from the patients' perspective. This approach was rooted in two primary sources: insights derived from prior studies and findings from qualitative research literature (Weinman et al., 2018). Non-

adherence was conceptualised as a desire to reduce medicine intake and labelled as "resisting medicines" (Pound et al., 2005). Medicines often serve as undesired reminders of illness, thus violating one's self-identity.

Based on this insight, Weinman et al. (2018) selected items to represent various reasons for intentional non-adherence. Initially, 30 items were selected, but due to duplication issues, eight items were removed. The data was collected and analysed on a multimorbidity sample from three outpatient clinics: 175 hypertension patients in London, 115 oncology patients in London, and 196 gout patients in Auckland.

Similarly to MARS, this scale also focuses on anonymity and eliminating social pressure by prefacing the following: "*People have different experiences when taking medication and use their medications in ways which suit them. Sometimes, people forget or decide not to take their medication for various reasons. We are interested in your personal views and experiences of your prescribed medication regime and the way you use your medications. All of the information you provide is confidential. There are no right or wrong answers to these questions – an answer is correct if it is true. We are most interested in your own opinion. Please choose the response that best fits your circumstances. Listed below are some reasons why people sometimes stop taking their medications. We would like to know how often each of the following statements is true for you in the past six months."* (Weinman et al., 2018 pp. 111). The items' answers were measured on a five-point Likert scale (1 = strongly disagree, 2 = disagree, 3 = neutral, 4 = agree, 5 = strongly agree).

Following its initial publication, the scale was validated across various cultures and diseases based on the original structure of 22 items. In Portugal, the validation was conducted on a sample of 133 participants with chronic pain. Four intentional non-adherence factors were extracted. Resisting Illness and Testing Treatment were identified in alignment with the original scale, albeit with fewer items. Additionally, two new factors, Mistrust Treatment and Resisting Treatment, emerged. However, four items were omitted due to low factor loadings (Sampaio et al., 2021).

This scale has also been tested in New Zealand on a gout sample where two different factors have emerged besides the original intentional non-adherence scale, such as Drug Specific Concerns and Medicine Sensitivity. Patients who did not reach the target SU level (objective urinary measurement for comparison) reported more reasons on the INAS

scales for not taking their medication than those who achieved the target. Primary motivations for not taking the gout medications are the desire to maintain a normal lifestyle and to perceive themselves as healthy again (Emad et al., 2022).

5. Table: INAS Factor Structure in Literature.

	Number of items		
FACTORS	Weinman et al., 2018	Sampaio et al., 2021	Emad et al. 2022
Resisting Illness	**8**	**6**	**7**
Testing treatment	**5**	**3**	**4**
Mistrust Treatment	-	2	-
Resisting Treatment	-	7	-
Drug Specific Concerns	-	-	6
Medicine Sensitivity	-	-	5
Total number of items involved	13	18	22
Deleted items compared to the initial 22	Nine items were deleted (high skewness and similar factor loadings)	Four items were deleted (low factor loadings)	No items were deleted.
Sampled diseases	Hypertension, oncology and gout patients	Chronic pain: oncologic, musculoskeletal, neuropathic, and post-surgical or post-traumatic .	Gout

Source: edited by the author based on Weinman et al., 2018; Sampaio et al., 2021; Emad et al., 2022.

As summarised in 5. Table while there are different versions of the INAS factor structures across samples, the "Resisting Illness" and "Testing Treatment" factors consistently emerge in each despite varying item counts. This consistency underscores the universality and importance of these themes across cultures. Given the absence of a validated Hungarian scale version, this dissertation will initially survey all 22 items, primarily focusing on replicating the original two-factor structure.

From a liminality lens, the resisting illness factor must be further elaborated. This factor consisted of the following items:

- Because my body is sensitive to the effects of medicine
- Because I worry about becoming dependent on my medicine

- Because I want to think of myself as a healthy person again
- Because it reminds me that I have an illness
- Because I want to lead an everyday life again
- Because it is good not to have to remember
- Because it is inconvenient to take all the time
- Because the drug schedule does not fit with my lifestyle
  (See question preface wording above in this paragraph.) (Weinman et al., 2018).

For several reasons, the "Resisting Illness" subscale of INAS appears to be an effective tool for capturing the concept of liminality in medication adherence.

Firstly, the scale highlights medication-taking's psychological and emotional aspects, such as how it may threaten one's identity or evoke discomfort through memories or thoughts about illness (Weinman et al., 2018). This aligns well with the concept of liminality, which involves a state of being "in-between" or transitional, often accompanied by a sense of ambiguity or disorientation. In the context of medication adherence, this could mean being caught between accepting and resisting one's identity as a person with a chronic condition.

Secondly, the scale's focus on non-adherence's emotional and cognitive aspects allows for more nuanced interventions. For example, if the scale indicates that non-adherence stems from difficulty tolerating discomfort, techniques from Acceptance and Commitment Therapy (ACT) could be applied. ACT employs mindfulness and behaviour change methods to help individuals become aware of unhelpful thoughts and make more effective decisions. This is particularly useful in addressing the liminal state where patients may struggle with their identities and the emotional complexities of medication adherence (Weinman et al., 2018).

3.2.6.4 Acceptance and Action Diabetes Questionnaire (AADQ)

The AADQ is a tool designed to assess how individuals accept thoughts and feelings related to diabetes and how much these thoughts and feelings hinder meaningful actions. It uses an 11-item scale, where responses range from '1-never true' to '7-always true'. Higher scores on this scale represent greater acceptance (Gregg et al., 2007).

There are no subscales covered in the item structure. The following items are strictly focusing on disease acceptance.

- I try to avoid reminders of my diabetes.
- I do not take care of my diabetes because it reminds me that I have diabetes.
- I avoid taking or forget to take my medication because it reminds me that I have diabetes.
- I often deny to myself what diabetes can do to my body.
- I avoid thinking about what diabetes can do to me. (Gregg et al., 2007)

3.2.6.5 Financial Affordability - AFF

The barriers to medication adherence encompass various elements, including the patient's cognitive function, forgetfulness, and the social support network. However, a small portion of the typical medication adherence scales grounded in literature concentrate on the financial aspects of non-adherence, although affordability could potentially be a significant determinant of medication adherence (Atella et al., 2005; Sunny et al., 2020).

Although financial affordability is relevant regarding medication adherence, self-reported measurement tools are rare in the literature. Two exact scales were covered that directly address the financial aspect of medication adherence.

The first of these scales is specifically tailored for families with a child suffering from a severe illness, serving as a subscale of the IoFS (Impact on Family Scale). This scale was developed in 1980 to quantify the effect of children's illnesses on family life. The foundation for the development of the scale was based on interviews, with the families included in the sample varying in terms of the children's age, diagnosis, severity of the illness, and the demographic status of the family. The scale consists of 24 items grouped around four factors. Three factors reflected negative impacts, namely (1) Financial Burden, (2) Familial/Social Impact, and (3) Personal Strain. Additionally, they identified a factor reflecting positive impacts, named (4) Mastery, which captures positive elements exerted on family and social relationships. The items were rated by the respondents from 1 to 4, where 1 represented "completely agree" and four indicated "completely disagree" (Stein & Riessman, 1980).

The other self-reported financial measurement tool focuses on the financial feasibility of medication adherence. Despite being introduced 15 years ago, the Affordability scale is not extensively documented in scholarly literature. While it has been utilised in several studies to assess medication affordability, there have been no subsequent reports of its

reliability through Cronbach's alpha coefficient (ABC Project Team, 2012; Morrison et al., 2015). The scale comprises six statements assessed using a 5-point scale, ranging from 5 (always) to 1 (never). The statements are as follows:

- If I am worried about money, I take less of my medicine to make it last longer
- I have to leave getting my prescription dispensed until I get paid
- If I have a number of different items on my prescription, I do not get them all dispensed because I cannot afford them all at once
- I have in the past borrowed money to pay for my prescription medicines
- Knowing that I will not be able to afford the prescription stops me from going to see my doctor
- If I cannot afford my prescription, I do not get my medicine dispensed at all (Schafheutle et al., 2010)

This second Affordability scale will be employed in the current research for two reasons. First, it is designed for adults, making it more aligned with our target demographic. Second, it is characterised by a greater emphasis on barriers to medication adherence rather than merely focusing on the financial burden, which is seen as a more fitting approach to meeting the objectives of our study.

3.2.6.6 Concluding Medication Adherence Measurements

The MARS5 is a reliable self-reporting tool that assesses the extent to which patients adhere to their prescribed treatments, providing essential insight into their medication adherence behaviours.

Similarly, the BMQ is vital for comprehending the motivations behind intentional non-adherence. The necessity-concern framework facilitates the analysis of how patients evaluate the cost-and-benefit before deciding to follow or disregard the prescribed treatment.

Upon analysing the items within the INAS Resisting Illness scale and the Acceptance and Action Diabetes scale, it becomes evident that they reflect a discomfort with the current state of illness and the longing to return to the pre-illness phase. These scales can

potentially be viewed as a marker of 'liminality' - representing a transitional or 'in-between' state where individuals do not fully accept their current health conditions and resist integrating their illness into their identity. Consequently, non-adherent behaviour can be perceived as a manifestation of this liminal state, where individuals are postponing the full acceptance of their new health reality.

Given that existing research lacks dedicated scales for evaluating liminality, the INAS Resisting Illness scale and Acceptance and Action Diabetes Questionnaire present promising tools for measuring this concept. They help gauge the extent to which patients have accepted their present health condition or dreamed of their previous "normal" state prior to the onset of the illness.

These arguments encourage the researcher to apply INAS Resisting Illness or AADQ as potential measurements for liminality while understanding medication consumption.

4 CONCEPTUAL FRAMEWORK

Based on the literature review detailed above, the following conceptual framework might be drawn for this dissertation.

Chronic illness creates a complex dynamic for patients, challenging them to balance their current quality of life with an uncertain future (Allen et al., 2015). This state can be seen as a liminal experience, marked by an absence of normalcy (Honkasalo, 2001). Over time, patients often long for a return to everyday life, where illness does not define them but rather integrates into their existence while preserving their individuality (Bruce et al., 2014).

This dissertation focuses on the liminal transition occurring in chronic conditions based on the framework introduced by Little et al. (2022). Understanding liminality within chronic conditions provides insight into individuals' transitional experiences as they adjust to long-term health changes. In chronic illness, liminality unfolds in two stages. The first is acute liminality, a brief transition as patients come to terms with diagnosis and treatment. Then, sustained liminality follows, an enduring state of uncertainty influencing their choices and behaviours (Little et al., 2022). The initial phase represents the realisation of their diagnosis. The enduring, long-term phase is when individuals learn to live with their condition over a long period. It involves the sustained experience of being in a liminal state, where adaptation processes are continuous, and individuals navigate the complexities of integrating the condition into their daily lives and identities (Little et al., 2022)

Within the consumption realm exists a phenomenon known as "Consumption to Hold-off Liminality." This strategy comes into play when "liminal consumers" seek to reconnect with aspects of their past life or identity (Darveau & Cheikh-Ammar, 2021). It involves indulging in "private passions," where these individuals engage in activities or behaviours reminiscent of their previous phase, thus resisting a complete transition into their new liminal state (Min & Peñaloza, 2019).

The individual living with a chronic disease can be likened to the concept of a "liminal consumer" (Nakata et al., 2019). Furthermore, their state of liminality can be viewed as an ongoing and potentially lifelong journey, often spanning their entire illness duration (Bruce et al., 2014).

Individuals with multiple restrictions due to their health condition may experience what is referred to as a "private passion." This term describes moments when they intentionally deviate from their restrictions by not adhering to medication regimens to regain a sense of normalcy.

The primary objective of this dissertation is to explore and understand the initial, acute liminal phase in depth. This liminality is characterised by the level of illness resistance, which terminates over time.

Based on this conceptual frame, this research will work with the following research question:

> **How do patients' initial reactions to a chronic condition diagnosis during the liminal phase influence their development of long-term medication adherence?**

5 RESEARCH METHODOLOGY

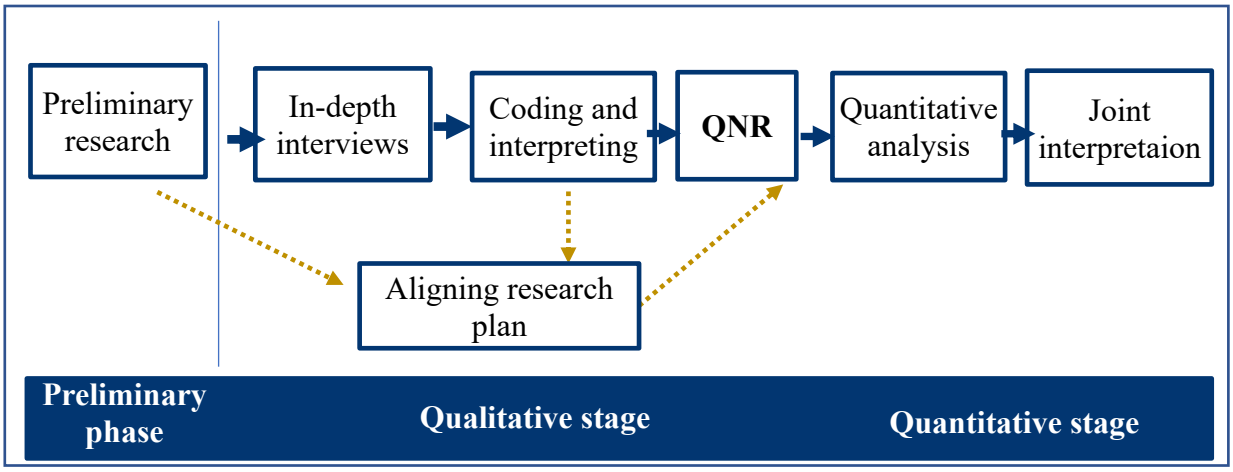
This section details the methodology applied in this dissertation in components. This dissertation applies a mixed-method approach. *Methods* refer to the particular steps to carry out research—for example, sampling and data collection or data analysis (Clark & Ivankova, 2016). *Mixed methods research* means purposefully combining quantitative and qualitative approaches to address a research problem (Clark & Ivankova, 2016). This means the research combines at least one quantitative and one qualitative approach (Johnson & Onwuegbuzie, 2004). This dual-pronged approach enriches the comprehensiveness and depth of the research insights.

The methodology of this dissertation unfolds a tripartite structure (1+2). The first phase is an initial *preliminary phase,* which serves as the foundational inquiry conducted within the dissertation's planned scope framework. This preliminary phase adopts a quantitative modelling approach, anchoring on the principal structural concept that examines liminality's impact on medication adherence. This phase has utilised a former existing database, which presents certain limitations, notably the absence of temporal data on the duration since diagnosis. Consequently, the quantitative model could not incorporate the duration of the disease state, a factor which may bear significance in understanding the full scope of the liminal effect.

Under the *primary phase*, data has been directly collected to explore and model the role of liminality. This primary phase starts with a *qualitative stage*, aiming to build theory (Horváth & Mitev, 2015) and uncover connections between various phenomena. The qualitative methodology was *in-depth interviews* followed by thematic content analysis. The second stage of the primary phase is the *quantitative stage*, a questionnaire-based process built on the literature and the findings of the preliminary and qualitative stages. Its goal is quantifying and generalising the relationships in the literature, as well as the initial phase and the qualitative stage.

These three parts are sequential, meaning they build on each other (Clark & Ivankova, 2016), as the experiences from the first preliminary phase were necessary for constructing the second phase, formulating precise hypotheses for the quantitative stage, strengthening the model to be tested, choosing the proper measurement scales (see 6. Figure**: Research Process**).

6. Figure: Research Process



source: edited by the author

In the upcoming subchapters, the main methodological issues for each phase will be explained, such as the strategies employed for sampling and the procedures for collecting data. The models and hypotheses will be introduced and explained in Chapter 6, titled 'Analysis and Results.' As each phase builds upon the findings of the previous one, it is necessary to create each phase's model to understand the previous phase's conclusions and limitations. The main summary of the methodological framework is demonstrated in 6. Table.

6. Table: Methodological Summary For Research Steps

		Preliminary phase	Primary phase	
			qualitative stage	quantitative stage
Goal		Evaluate the role of liminality within the concept of medication adherence.	Building upon insights from the preliminary phase, investigate patient experiences for model building in the primary quantitative stage.	Validate and quantify the influence of liminal phases on medication adherence and measure the impacts.
Data collection	**Date**	January 2020	January-March 2024	March 2024
	Fieldwork	Market research agency	The PhD researcher	Market research agency
	Tool	Online questionnaire	Interview guide	Online questionnaire
Sample	**Sampling**	Selected from a representative sample of 1,000 individuals based on inclusion criteria	Participants were recruited through personal networks with an emphasis on diversity.	Recruitment through an online panel specialising in chronic diseases.
	Inlcusion criteria	- age above 30, - taking medication daily, - diagnosed with any chronic disease	- age above 18, - taking medication day, - diagnosed with diabetes / high blood pressure/ musculoskeletal disease/ high cholesterol / cardiovascular disease - diagnosed at least a year ago	- age above 18, - taking medication daily, - diagnosed with diabetes / high blood pressure/ musculoskeletal disease/ high cholesterol / cardiovascular disease
	Sample size	482 (from 1000 rep) patients	16 patients	500 patients
Data		database	voice record transcripts	database

source: edited by the author

5.1 The Preliminary Quantitative Phase

5.1.1 Questionnaire and Sampling

As an initial phase of this research, a survey was conducted in Hungary to gather data. This online survey was executed in collaboration with a market research agency. The data collection took place in January 2020.

This research focused on understanding how intentional non-adherence (INAS), belief about medication (BMQ) and financial affordability of medications (AFF) can predict adherent behaviour (MARS5).

I want to express my greatest gratitude to my supervisor, Judit Simon, who made this data collection possible and inspired me to use these findings to shape the focus of my dissertation and incorporate the data within it.

In medication adherence research, it is uncommon to find studies collecting representative samples. More often, research relies on concentrated samples, such as clients from a single pharmacy or patients from a specific hospital, and typically focuses on one or a few disease groups like asthma or diabetes. However, our data sample stands out in medication adherence research, encompassing a diverse representation of the Hungarian population. The sample is representative in Hungary regarding age, gender and region.

The data was collected from Hungarian citizens aged 30 and above. Of the 1000 individuals surveyed, 482 have chronic diseases and regularly take medication. In the preliminary part, this chronic disease sample was the focus of the research.

5.1.2 Data Analysis

Initially, demographic and health condition information is presented using a demographic approach. SPSS v.29 software (IBM, 2022) was used for demographic analysis. Subsequently, a preliminary PLS-SEM model was applied to examine the liminal effect on medication adherence within this multimorbidity sample. The PLS-SEM is employed through the ADANCO 2.3.4 version (Henseler & Dijkstra, 2015).

Since the late 20th century, nearly every significant scientific journal in the marketing field has featured at least one publication using Structural Equation Modelling (SEM) (Babin et al., 2008). Within the top 30 marketing-themed journals, there is an increasing trend of publications employing the SEM methodology. This implies that both

covariance- and variance-based structural modelling methods are versatile and adaptable (Hair et al., 2012).

A study examining the publication process explored if using Structural Equation Modelling (SEM) benefits marketing researchers. Their findings showed that SEM usage has some advantages. However, these benefits are not extraordinary and primarily result from the fact that publications using SEM tend to have more stable theoretical foundations. This theoretical stability is due to the necessity of complex theoretical underpinnings for constructing models (Babin et al., 2008).

In the Hungarian context, it is evident that higher-tier journals tend to feature publications employing Structural Equation Modelling (SEM) more frequently. These publications often address various marketing issues. Notably, domestic research has a greater prevalence of PLS-SEM approaches (Kemény et al., 2023).

Two primary types of SEM are applied in the research methodology. CB-SEM minimises the difference between estimated and sample covariance matrices, while PLS-SEM maximises explained variance in endogenous latent variables through iterative OLS regressions. PLS-SEM calculates latent variable scores precisely as linear combinations of related manifest variables, treating them as perfect substitutes (Fornell & Bookstein, 1982), while CB-SEM treat them as the asymptotic representation of the population (Henseler et al., 2015). PLS-SEM development makes consistent PLSc suitable for models with reflective constructs (Kemény et al., 2023). Further advantages of the PLS approach are that no distributional assumptions are set for the investigated variables (Henseler, 2021), and the model can work well with smaller sample sizes (Hair et al., 2016).

The research model is assessed by ADANCO (Henseler & Dijkstra, 2015), created for PLS-SEM modelling, while other statistics will be supported by SPSS version 29 (IBM, 2022).

5.2 The Primary Qualitative Research Stage

Qualitative research is not about measuring but rather about deeper understanding. This approach is not about strictly standardised processes but a sequence of iterative, flexible steps (Horváth & Mitev, 2015).

A narrative approach, which is more flexible than many other qualitative methods, was employed during the qualitative phase. This method's essence is centred around storytelling. In the narrative approach, the focus is not only on the story itself but also the manner and person narrating it. Through this method, a specific aspect of people's lives relevant to the research is understood, and insights into certain realities are provided (Squire et al., 2013).

Tools such as observations, written records, and interviews can be used for data collection. Among these, interviews are prominently used. Within these interviews, a series of interconnected questions are presented. The interviewee is supported by being listened to carefully, and the interviewer makes minimal interjections. The primary aim is not to receive direct answers but to ensure that the participant's personal stories related to the research topic are shared (Allen et al., 2015).

The approach is resource-intensive and requires a high degree of expertise from the researcher to create ethically acceptable processes and interpret complicated, sometimes disorganised data (Osborne & Grant-Smith, 2021). In fields like health services research and health technology evaluation, in-depth interviews have grown in popularity, leading to an increase in the publication of qualitative research findings in medical and affiliated publications (Mays & Pope, 2000).

In the qualitative stage, *in-depth interviews* were conducted with patients. The sections below elaborate on further details regarding the sampling, data collection tools, and other aspects.

5.2.1 In-depth Interviews

In the case of the in-depth interviews, it was necessary to consider that the topic is extremely sensitive since participants were expected to discuss very personal and sensitive areas, specifically their health. The goal was for the interviewee to narrate their health journey during the narrative interview from the onset of their illness to the moment of the interview and even the period before the diagnosis if they considered it essential

(e.g., as a contrast). The interview process followed a semi-structured guideline, where I asked the subject to recall and describe from the beginning how the illness impacted their everyday life, with particular attention to the initial stages.

Testing the interview guide to ensure it was "working," meaning whether it "went deep enough," was essential for the interviews. If necessary, modifications to the initial questions or the entire plan were required to encourage respondents to open up during the discussion. In this research, the guide was tested with two interviewees, and their discussions also formed part of the analysed conversation data. During the test interviews, it became evident that the first few warm-up questions naturally led the partners to discuss most of the earlier questions freely. Accordingly, the main task of the interviewer was to encourage the interlocutors to elaborate further on the topics raised. As a result, the interviews were indeed realised as semi-structured. Due to the test responses, an additional question was added to the guide: "If you had to rate yourself from 1 to 10, where 1 means you do not follow your doctor's prescriptions at all, and 10 means you do everything according to your doctor's prescriptions, what score would you give yourself? Why?"

The guide for in-depth interviews is included in the appendices of this dissertation plan (see 2. Appendix: Qualitative Interview Guide). The interviews followed this predefined and focused structure, which helped to minimise the potential for bias due to the responses received from different subjects.

Building trust at the start of the interview was crucial. The interviewer's role was significant in creating an environment that allowed participants to comfortably immerse themselves in their stories, recall details, and confidently share their insights on the effects of their illness. Thus, the interviews were effectively realised as semi-structured, allowing for a comprehensive and profound exploration of the participants' experiences.

5.2.2 Sampling and Data Collection

Sampling: The criterion for inclusion in the sample is that the person is above 18, must be undergoing treatment and taking medication daily for any of the following illnesses: diabetes, high blood pressure, musculoskeletal disease (back problems, joint inflammation, rheumatism, etc.), high cholesterol, cardiovascular disease. This diagnosis should have been received at least a year ago, ensuring participants have significant experience dealing with the initial shock of the diagnosis and the subsequent phase of

constant liminality. The sample is diverse in gender, settlement size, region, age, diagnosis, occupation and family life cycle (see Table 15. **Table**. The original sample size was 16 patients, but one participant must have been excluded due to a technical problem with the recording and transcript (his voice was so deep that the recorder did not identify it as a human voice). The final and analysed sample is 15 individuals.

Recruitment for this study was strategically executed via personal networks, leveraging statistical data highlighting a high prevalence of chronic diseases. This prevalence suggests a significant probability that most individuals, or their close relatives or friends, are potentially impacted by such chronic conditions. Based on this premise, initial contact with potential participants was facilitated through acquaintances. An associate of each prospective participant first approached them, presenting the opportunity to engage in the research. Upon receiving a positive response, their contact details were forwarded to the researcher. Subsequently, I contacted the subjects to explain the objectives and methodology of the interview more comprehensively. This discussion included detailed explanations of the research conditions, such as anonymity guarantees, voluntary participation, expected duration, and communication medium to be utilised. If the participants expressed their willingness to proceed, the interview was scheduled. Only one potential participant, unreachable by phone after multiple attempts, withdrew from the recruitment process. All other individuals who were contacted consented to participate and were duly included in the study. This method ensured a thoughtful and ethical approach to participant recruitment, aligning with the study's aim to maintain high research integrity and participant confidentiality standards.

Tools for data collection:

Channels: Data collection was conducted through multiple channels, tailored to the preferences of each interviewee. The methods were face-to-face discussions, online calls (via Microsoft Teams), and telephone conversations. It can be conclusively stated that the channel choice did not influence the depth of the conversations; participants could open up and engage in meaningful dialogue even during telephone or online interviews. At the closing part of the discussions, several participants expressed that they found the conversations very fulfilling, noting that they had never before been listened to so thoroughly regarding their medication experiences.

Data recording: The interviews were recorded digitally during the interviews, with the consent of the participants. A digital transcript (with the Microsoft Teams transcript app) was created parallel with the recorded audio, serving as one qualitative analysis source. A second transcript was also conducted after the research with the help of amara.org. The text transcribed by artificial intelligence must be cross-checked with the original interview for accuracy and adjusted for proper punctuation. Even with these modification efforts, using these applications greatly helps the research process, saving time and money.

Data storage and ethics: It was essential to clarify for both parties that the participant voluntarily participated in the research. The participant voluntarily joined the research and permitted their shared information to be used and analysed for the study. While their statements can be quoted directly, they will always be kept anonymous.

The interviewer guarantees that all recorded content will be treated with anonymity. After recording, a unique code is assigned to each interview. This code is used in later analyses and quoting directly to maintain participant anonymity. Once the interview is completed, the participants are informed that any of their statements or even the complete interview might be withdrawn at any time if they specify any parts they wish to be excluded from further analysis or publication. (Additional ethical considerations can be found in Chapter Ethical Considerations "Ethical Considerations").

5.2.3 Data Analysis

The foundation of data analysis is based on digital and printed interview texts, which can be regarded as raw data. In narrative analysis, two pillars stand out: "what" the participant says and "how" they express it (Frey, 2018).

An inductive approach was employed during the analysis, as no preexisting codes exist. Codes are developed through an open-minded reading process. Reading the interviews repeatedly achieves a closer understanding of the texts, and codes that best-fit parts of the text can be identified. Similar or related codes were then grouped into categories. Patterns were formed from these categories, and the main themes of the raw material emerged from these categories.

Conelly and Clandinin's (1990) three-fold tool helps this process. First, "broadening" provides an understanding of the broader context of the case by examining the characters in general, considering their values and social and historical circumstances. On the other hand, "deepening" focuses on the minor details of the data, highlighting aspects such as respondents' feelings, dilemmas, understandings, or the impacts of an event. After utilising both the broad and deep tools, storytelling and retelling happen, revealing the logical connections of the investigated case.

Taking notes is closely connected to coding and interpreting the interviews (Boeije, 2010). A brief memo was noted after each interview. This memo describes the conversation and captures essential contexts, the interviewer's impressions, and new ideas. It also helps navigate between the stories.

5.3 The Primary Quantitative Research Stage

The quantitative stage of the research is strategically built upon the insights and findings garnered from both the preliminary and qualitative stages. It was meticulously designed to leverage the foundational data and nuanced understandings developed earlier in the study. The main objective of this phase was to apply statistical methods to quantify and validate the relationships and patterns identified in the earlier phases and supported by the literature review.

5.3.1 Sampling and Data Collection

Sampling:

Given that a specific population is aimed to be studied, the most apparent method of sampling in the primary quantitative phase for data collection is a panel sample. (Malhotra & Simon, 2009). I collaborated with a market research agency to assist with fieldwork. This agency maintains a specialised and regularly updated panel of individuals with chronic diseases.

Panel data is commonly associated with longitudinal research. However, it is beneficial not only for time-related studies but also for dealing with a unique target group that's challenging to access. If such a group is commercially valuable, agencies might establish specialised panels. The chronic disease sample exemplifies this, as numerous medical

industry studies rely on this group. Members of offline and online panels receive some incentives for their participation. As a member joins the panel, a detailed psychographic report is built on the individual. A common bias in panel studies is that new panel members may answer questions more favourably, aiming to align with what they perceive as the researcher's expectations (Malhotra & Simon, 2009).

The research aimed to gather data from a demographically and medically relevant population to ensure the validity and applicability of the research findings. The inclusion criteria for the study were designed to identify participants most relevant to the research objectives. Participants must be aged 18 or older. Participants are required to take medication daily, including individuals who routinely manage their medication. Eligible participants must have been diagnosed with one or more of the following chronic conditions: diabetes, high blood pressure, musculoskeletal disease, high cholesterol, or cardiovascular disease. These conditions are chosen because they typically require ongoing medical management and can significantly impact an individual's health and quality of life, as these are the most frequent chronic diseases in Hungary (KSH, 2024).

Tools for Data Collection:

The data was collected through a questionnaire. The questionnaire included the following scales: INAS Resisting Illness, INAS Testing Treatment, BMQ Necessity, BMQ Concerns, Financial AFFordability, MARS5, and AADQ. Specific sections of the questionnaire were devoted to gathering information on demographic details and health condition characteristics. The applied scales are detailed in the Literature Review (Chapter 3.2.6) and summarised in 7. Table.

7. Table: Scales Applied in the Primary Quantitative Stage

Phenomenon	Scale	Dimensions	Abbrev.	Nr. of items	Likert	Reference
MEDICATION ADHERENCE	Medication Adherence Report Scale	unidimensional	**MARS5**	5	1-5	Horne, 2003
	Beliefs About Medicines Questionnaire	Necessity	**BMQ_N**	5	1-5	Horne et al., 2013
		Concerns	**BMQ_C**	6		
	Intentional Non-Adherence Scale	Testing Treatment	**INAS_RI**	5	1-5	Weinman et al., 2018
LIMINALITY		Resisting Illness	**INAS_RI**	8		
	Acceptance and Action Diabetes Questionnaire	unidimensional	**AADQ**	11	1-7	Gregg et al., 2007
FINANCIAL AFFORDABILITY	Financial affordability	unidimensional	**AFF**	6	1-5	Schafheutle et al., 2010

Source: edited by the author

The MARS, INAS, BMQ, and AFF scales were borrowed from the ABC project on medication adherence, which aimed to achieve two primary goals. The first was to create a standardised European consensus on terms associated with non-adherence, and the second aimed to delve into patient beliefs and actions regarding medication adherence. Data for this study was gathered from multiple European nations, including Hungary. All scales used in the research were either in a validated language format or underwent a back-and-forth translation specifically for the ABC survey (ABC Project Team, 2012).

The AADQ questionnaire, originally designed for diabetes patients, was adapted in this dissertation research to apply to patients with any chronic disease. Consequently, the term 'diabetes' in the items was replaced with 'disease' to generalise its relevance. The AADQ scale is not validated in the Hungarian language; thus, the items were translated and tested in the pilot testing. The AADQ scale is reported as unidimensional (Gregg et al., 2007; Rajaeiramsheh et al., 2021), but further in this analysis (Chapter 6.3.4), a three-factor structure will be extracted.

The final data collection process was facilitated using an online survey tool operated by the market research agency. The researcher responsible for this dissertation provided the

content and structure of the online survey. Subsequently, the questionnaire was programmed and tested to identify any inconsistencies.

The questionnaire underwent a pilot phase involving 2 participants with a target age of 65. These patients were tasked with completing the programmed questionnaire in real time. The researcher followed the procedure via Team call (assisted by their younger relatives). This process offered feedback regarding clarity, potential repetitions, or issues such as unclear wording. Based on the memo protocol developed after the test completion, the agency finalised the questionnaire. The correction list is available in Hungarian because of the wording refinement in 3. Appendix: Modification List After Questionnaire Pilot Test (Hungarian).

5.3.2 Data Analysis

This thesis aims to assess a model that investigates the relationships among multiple latent structures. For this purpose, establishing and testing a Structural Equation Model (SEM) is considered appropriate. All the used scales are reflective scales in the model.

Similarly previously detailed in 5.1.2. The data chapter analysed the demographic and health condition data using SPSS v.29 (IBM, 2022). The PLS-SEM model, implemented via ADANCO 2.3.4 (Dijkstra & Henseler, 2015), explored the liminal effects on medication adherence among individuals with multimorbidity. The application of PLS-SEM, a method increasingly recognised in top-tier marketing journals for its adaptability and versatility in handling complex models, echoes the growing trend of its use in addressing intricate research questions (Hair et al., 2012; Kemény et al., 2023). Details of SEM and PLS-SEM methodology are detailed in the 5.1.2 chapter, as the preliminary methodology has applied the same modelling approach.

This methodological consistency between the preliminary and primary quantitative phases not only strengthens the theoretical underpinnings of our study but also aligns with the broader academic discourse on the efficacy and precision of SEM approaches in effectively capturing latent constructs.

Besides PLS-SEM, the primary quantitative research stage also employs Exploratory Factor analysis (EFA) in the case of AADQ and Confirmatory Factor Analysis (CFA) in the case of INAS and AADQ scales. SPSS v.29 was employed for Exploratory Factor

Analysis, and JASP 0.18.1.0 software was utilised for Confirmatory Factor Analysis. Confirmatory Factor Analysis (CFA) is a statistical technique used primarily in social sciences to test if the relationships between observed variables and their underlying latent constructs fit a structure based on a previously introduced theory (T. A. Brown, 2015). This method assesses the construct validity of a measurement model—whether the data fit the hypothesised measurement model (Bollen, 1989). Key aspects of CFA include the specification of the factor model, estimation of the parameters, evaluation of the model fit, and considerations of model modifications. Models are evaluated based on various fit indices, such as the Comparative Fit Index (CFI), Tucker-Lewis Index (TLI), and the Root Mean Square Error of Approximation (RMSEA), which provide measures of how well the hypothesised model is represented by the given sample data (L. Hu & Bentler, 1999). To investigate one moderating effect more deeply, moderation analysis is run by JAMOVI 2.3.28.

5.4 Ethical Considerations

During my decade-long involvement in the civil sector, I witnessed a recurring scenario in which thesis writers or researchers preparing dissertations collaborate with organisations. They use the organisation's resources, including the time of colleagues, volunteers, and their network. They then analyse the information they gather through their unique perspectives, and in the best-case scenario, they share their findings before or after completing their work. However, in the worst-case scenario, they vanish and never return.

This is precisely why I believe research must contribute value. To accomplish this, it is essential to view the partner as a research setting and actively integrate their well-being, interest and privacy into the research process.

Beyond personal experiences, ethical considerations are indispensable, especially during qualitative research, particularly in cases as sensitive as people's health and expenditures (Bailey, 2018).

Ethical compliance was ensured through an independent entity. The *Research Ethics Committee* of the Corvinus University of Budapest offered this opportunity in Hungary. The Committee has released *ethical approval* for the primary research phase of this

dissertation (nr: KRH/118/202, see 1. Appendix). This additional layer of validation ensured a rigorous adherence to ethical standards.

I considered the ethics principles already in the earliest phases of the research and continue to reflect on these principles and their associated implementation plans in later stages. This approach ensures responsible research thanks to the following considerations and the guarantees to meet the expectations:

*Respect the Vulnerable Participants: D*iabetes patients with chronic health conditions might be vulnerable. Their physical and emotional vulnerabilities must be considered in each research step.

Guarantee: The participants, diagnosed with chronic diseases, are invited to share their personal experiences and habits, mainly focusing on their medication-taking practices. This approach is vital for research to delve into these habits in depth. The formulation of the data collection instrument has been created to avoid causing any embarrassment to the participants. Throughout the entire process, their autonomy and potential obstacles are considered. Additionally, they are assured they can recall their statements at any point, ensuring a respectful and considerate engagement.

Volunteer Participation: Ethical research emphasises that participants are not obligated to be involved. The planned dissertation research respects their autonomy and freedom of choice.

Guarantee: During the recruitment process, it was highlighted that data collection and research were voluntary and anonymous. Participants were informed that they had the right to withdraw their statements and retract their consent at any time. In the quantitative phase, using the agency's online panel served as evidence that participation was entirely voluntary, with the agency employing its standard motivational tools to manage respondents as usual. The researcher recruited participants through personal and professional networks in the qualitative phase. They were not offered incentives for their participation and were informed in advance about the study's voluntary nature and the anonymity of their responses. The circumstances were also clarified in advance: the interview topic, available platforms, and the interview length.

Informed Consent: The researcher takes the initiative to educate participants thoroughly about the research process, objectives, and potential risks before deciding.

Guarantee: A written consent form was impossible due to geographical distances and the online nature of the interviews. Instead, each participant was thoroughly briefed on their anonymity and voluntariness before verbally agreeing to participate and consenting to the recording. They repeated this agreement at the beginning of the recording as proof of their consent. By obtaining oral consent (as detailed in Interview Guide 2. Appendix: Qualitative Interview Guide), a proactive approach is presented to transparency and safeguarding participants' rights.

Anonymity and Data Security: Data handling is solely the responsibility of the researcher, who takes measures to maintain the anonymity and security of the collected data.

Guarantee: In the quantitative phase, data management was undertaken by a market research agency. However, the questionnaires were designed so that they did not collect any personal information. As a result, neither the agency nor the researcher could identify any of the participants. During the qualitative phase, interviews were meticulously catalogued using unique ID codes assigned to each participant. When compiling the research report, participants were identified solely by their ID, age, gender, diagnosis, and county and occupation. The process did not involve additional researchers in roles such as data collection or analysis, ensuring a streamlined and focused approach. The recordings were stored separately from the identifiers and password-protected.

Confidentiality: Maintaining the privacy and confidentiality of participants' health information is an ethical obligation and essential for building trust among participants.

Transparency in Sharing Results: The researcher commits to sharing results with qualitative participants upon request.

Guarantee: The analysis and findings contributed to my dissertation, which the Doctoral School made publicly available online. At the closing of the qualitative interviews, participants were allowed to request a copy of the final report. Those

who expressed interest received the research findings they contributed to, ensuring they were informed of the study outcomes they participated in.

6 ANALYSIS AND RESULTS

6.1 Preliminary Quantitative Phase

The preliminary questionnaire employed several medication adherence-related scales, including INAS Resisting Illness, INAS Testing Treatment, BMQ Necessity, BMQ Concerns, Financial AFFordability, and MARS5. All the employed questionnaires were applied using the Hungarian version of these scales (see 7. Table). It must be noted that the AADQ questionnaire and the time since diagnoses variable were not included in this database.

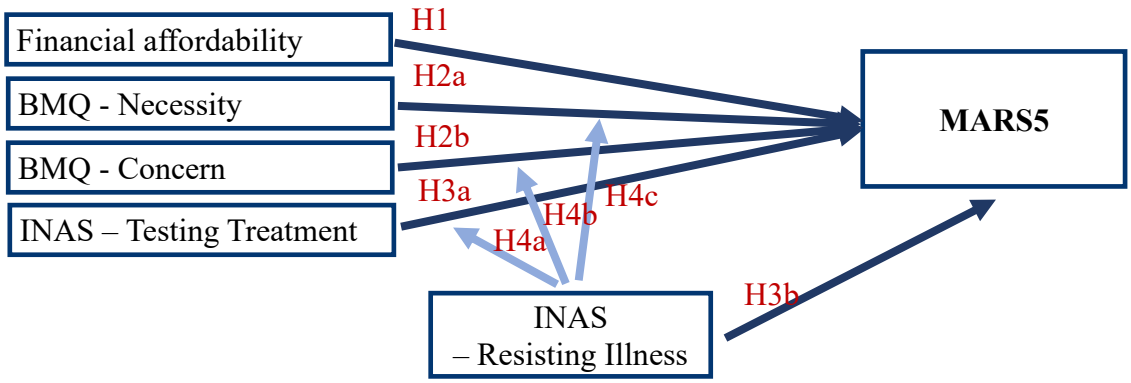
6.1.1 Preliminary Research Model

Before formulating hypotheses and interpreting results, it is essential to understand the scoring interpretations for the scales used according to the applied data collecting questionnaire:

- in MARS5, higher scores indicate more non-adherent behaviour
- in AFF, higher scores signify more significant financial challenges related to treatment.
- in BMQ Necessity, higher scores reflect stronger beliefs in the necessity of medication.
- in BMQ Concern, higher scores denote increased concerns about medication.
- in INAS Testing Treatment, higher scores represent a higher level of testing.
- in INAS Resisting Illness, higher scores suggest a more decisive rejection of the current state, indicating a higher degree of liminality.

The 7. Figure depicts the research model of the preliminary study, and the subsequent subchapter details the formulated hypotheses along with their literature backgrounds. Hypotheses H1-H3 focus on the direct effects within the model, whereas H4 and its sub-hypotheses explore the moderating effect of illness resistance.

7. Figure: The Research Model of the Preliminary Study



Source: edited by the author

6.1.1.1 Effect of Financial Affordability on Medication Adherence

Financial affordability might be a pretty strong predictor for medication adherence. Medication-related concerns, including cost-related concerns, can drive patients' medication adherence behaviour. Out-of-pocket costs for medication can make it hard for diabetic patients to stick to their treatment plan. Some might skip the medicine because it is too expensive (Piette, 2009). Sunny et al. (2020) found in their epilepsy-related research that the average family per capita income (PCI) for the non-adherent group was 30% less than for the adherent group, indicating potential financial challenges in medication adherence. Affordability, as depicted by family per capita income and the financial burden of drug costs, is essential in influencing medication adherence, especially among those facing financial constraints. Atella et al. (2005) conducted their study in England and Italy. Patients with financial challenges in both countries often choose cost reduction over following the prescribed treatment. Their study realised that affordability challenges push patients to apply cost-saving strategies, such as postponing medication purchases, not procuring prescribed drugs, or changing for cheaper options, such as over-the-counter alternatives. These strategies directly lead to a deviation from the prescribed schedule and portions. A study in Uganda (Cathbert, 2019) considered treatment medication adherence as the dependent variable, while financial affordability was an independent variable in a hospital diabetic sample. According to the results, those spending less on the treatment were less adherent to the treatment. Also, the higher the income, the more the patient could follow the restrictions.

Thus, financial affordability is a critical determinant of medication adherence, with numerous studies highlighting its influence on patient behaviour. Those patients facing financial barriers often deviate from prescribed treatments, underscoring the role of affordability in ensuring consistent medication adherence.

> *H1: A worse financial situation (affordability) has a positive impact on medical non-adherence*

6.1.1.2 Effect of Beliefs about Medication on Medical Adherent Behaviour

Improving the doctor-patient relationship depends on understanding each patient's unique beliefs about treatments and medications. By recognising these beliefs, a treatment plan can be developed that the patient and doctor can agree upon. This mutual agreement can improve health outcomes thanks to increased medication adherence levels (Vermeire et al., 2001a). Understanding, evaluating, and measuring patients' views on medication and treatment is vital in medication adherence research.

Accordingly, the idea behind this hypothesis is not new in research. Health science has long recognised this direct relationship. The creation of the BMQ (Beliefs on Medication Questionnaire) was primarily to offer a reliable tool for predicting medication adherence based on this established connection.

A person's beliefs about their medication are more vital in determining if they will take their medication as prescribed than other factors like age, health condition, or background. While most patients think their medication is essential for their health, about one-third worry about the side effects. These concerns can lead to them taking their medication less than they should. Patients seem to weigh the benefits of their medication (how necessary it is for their health) against their worries about it (like side effects). This "pros vs. cons" thinking significantly affects how well they stick to their treatment. Patients who worry more about side effects than the medication's benefits tend to be less consistent in taking their medication (Horne & Weinman, 1999).

A meta-analysis of the BMQ framework has strengthened that both "necessity beliefs" and "concern beliefs" were significantly linked to medication adherence. Individuals who believe in the importance of their medication for health are more adherent than those who do not. On the contrary, those with solid concerns about side effects and potential

dependence were less adherent (Foot et al., 2016). If older individuals with several health conditions believe that their medications are tailored to meet their specific needs, they are more likely to remain committed to their treatment regimen; as beliefs about the necessity of medications increase, intentional medication adherence improves (Schüz et al., 2011). Elderly individuals with lower levels of medication adherence consistently displayed stronger beliefs about the concerns associated with their medications than beliefs about the necessity of taking them. A significant relationship was found between concerns regarding medications and non-adherence, suggesting that higher levels of medication-related concerns were associated with poorer medication adherence behaviours (Unni et al., 2015). It must be noted that contradictional findings are also present in the literature, such as specific concerns that do not predict the level of non-adherence in the case of elderly patients (Schüz et al., 2011).

The expectations surrounding life transitions impact a person's quality of life (Thyroff et al., 2018). This concept is relevant in understanding how trust in medication can predict health outcomes. If a patient has low trust or negative beliefs in medication, that can lead to worse health outcomes.

Beliefs about medication are essential in determining a patient's adherence to treatment. Studies consistently demonstrate that patients who perceive their treatment as necessary are more likely to adhere. At the same time, those with higher concerns about side effects or potential dependence are less consistent in their medication intake.

> *H2a: A stronger belief in the necessity of prescribed medications decreases non-adherence to the medication regimen.*
>
> *H2b: Increased concerns about prescribed medications result in higher levels of non-adherent behaviour.*

6.1.1.3 Effect of Intentional Non-Adherence Factors on Adherent Behaviour

Both INAS subscales significantly correlate with MARS scores in hypertension and oncology samples. This means that higher scores on the INAS (indicating more intentional non-adherence due to emotional or psychological factors) were associated with lower self-reported medication adherence scores on the MARS. The correlation was

slightly more potent in the oncology sample than in the hypertension sample (Weinman et al., 2018).

Similar findings were observed in a study conducted on a chronic pain sample in Portugal. Although this study extracted four dimensions of the Intentional Non-Adherence Scale (INAS) as opposed to the original two, all four dimensions were found to correlate significantly with self-reported medication adherence as measured by the Medication Adherence Report Scale (MARS). Higher scores in the intentional non-adherence dimensions were associated with poorer medication adherence behaviour (Sampaio et al., 2021).

> *H3a: Increased questioning of treatment results in a higher level of non-adherent behaviour*
>
> *H3b: Increased level of illness rejection results in a higher level of non-adherent behaviour*

6.1.1.4 Moderating the Role of Resisting Illness in Medication Adherence

Based on the qualitative study by Huyard et al. (2016), some patients intentionally deviate from their prescribed treatment. They do this to retain control over how the treatment affects their daily routines and activities (Williams, 2000).

Individuals who have accepted their illness and are motivated to use medication as part of their disease management are more likely to adhere to their prescribed regimens (Hsieh et al., 2019). A higher level of acceptance of diabetes has a significant correlation with less active coping and self-management (Schmitt et al., 2014). Also, measuring diabetes acceptance has significant potential advantages; incorporating it into a conceptual framework alongside related constructs like diabetes distress, self-efficacy, and medication belief might be beneficial (Schmitt et al., 2014).

Those who are more deeply engaged in the liminal phase and less accepting of their chronic condition are less influenced by the positive effects of treatment beliefs on medication adherence. Instead, their medication adherence is more affected by the negative adverse concerns regarding treatment.

H4a: Increased illness rejection negatively moderates the relationship between necessity beliefs and non-adherent behaviour.

H4b: Increased illness rejection positively moderates the relationship between concern beliefs and non-adherent behaviour.

H4c: Increased level of illness rejection positively moderates the relationship between treatment testing and non-adherent behaviour.Descriptive Analysis

First, the demographic features of the sample will be presented. Then, the analysis will introduce health-related factors, including medication-taking habits and diagnosed conditions.

6.1.2 Demographic Characteristics

The average age of these chronically diseased participants was 59.4 years, with 245 (50.8%) females. More than half of the sample (57.7%) is aged above 60 years. The sample had a balanced representation of Hungary's three main regions. About 19.5% hailed from Budapest, while 27.2% resided in a county seat. The predominant educational attainment was high school graduation, accounting for 41.7%. A majority, 67.4%, were either married or in a relationship. Regarding household composition, 62% did not have children under 18. When examining financial conditions, a mere 4.1% reported a very high status, and only 2.5% indicated a very low status. For further demographic details of the sample, please follow 8. Table.

8. Table: Frequencies for Demographic Variables

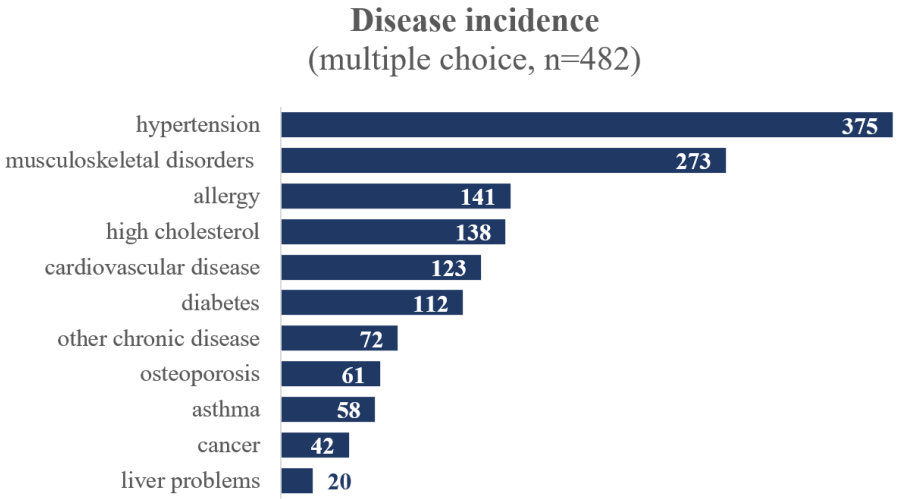
DEMOGRAPHIC FACTORS			
		n	**%**
Gender	male	237	49,2
	female	245	50,8
Multimorbidity	single diseases	156	32,4
	multimorbidity	326	67,6
Age group	30-44 years	64	13,3
	45-59 years	140	29,0
	60 years or older	278	57,7
Region (NUTS1)	Central-Hungary	135	28,0
	Western-Hungary	148	30,7
	Eastern-Hungary	199	41,3
Settlement	Budapest	94	19,5
	county seat	131	27,2
	other town	161	33,4
	village	96	19,9
Education	elementary school	18	3,7
	vocational training school	58	12,0
	high school without graduation	20	4,1
	high school with graduation	201	41,7
	MsC/BsC/postgraduate	185	38,4
Family status	single	42	8,7
	in a relationship / married	325	67,4
	divorced	63	13,1
	widow	52	10,8
Children under 18 years in the household	one	57	11,8
	two	18	3,7
	three	5	1,0
	four or more	1	0,2
	there is no child under 18 years	299	62,0
Income status	we live without worries, and we can regularly save money	20	4,1
	we manage well with our income, and occasionally, we can save money	116	24,1
	we have no living problems, but we cannot save money	176	36,5
	we barely get by on our monthly income	121	25,1
	we have financial problems month after month	37	7,7
	we must make sacrifices to get by.	12	2,5

source: edited by author

6.1.3 Health-related Characteristics

Notably, 81% (n=391) of those with chronic diseases live with multimorbidity, meaning they suffer from more than one disease. The most common problem among them is hypertension (n=375), but musculoskeletal disorders are also prevalent (n=273). To see the disease structure of the sample, see 8. Figure.

8. Figure: Number of Disease Incidences in the Sample



source: edited by author

The data provides insights into the respondents' medication habits and financial considerations concerning health conditions. One in five respondents (21,4%) takes only one type of medicine daily, while 23,0% take two. Half of the participants (50.2%) administer their medication twice daily. A majority (72,0%) benefit from state subsidies, offsetting their medication costs. Over half of the respondents (54.4%) consider financial constraints when purchasing medicine. To see further details on health-related variables, see 9. Table.

9. Table: Frequencies for Health-related Variables

Health-related variables			
		n	**%**
Types of drugs	on type	103	21,4
	two types	111	23,0
	three types	77	16,0
	four types	65	13,5
	five or more types	126	26,1
Times/day	once a day	160	33,2
	twice a day	242	50,2
	three times a day	67	13,9
	four or more times a day	13	2,7
Cost	my medications are fully state-subsidized	16	3,3
	I pay for a portion of it	347	72,0
	I need to pay the total price	119	24,7
Balancing when purchasing medicine	yes	262	54,4
	no	220	45,6

source: edited by author

6.1.4 Evaluating Preliminary Model

Given that the phenomena under study are latent constructs, structural equation modelling was employed to determine whether the hypotheses can be accepted or rejected as planned in the dissertation. This method can examine the relationships of multiple latent variables simultaneously.

In structural modelling, two testing approaches are examined. The measurement model is initially tested to determine if the applied variable sets (scales) are reliable enough and represent the given constructs. Secondly, the focus shifts to examining the actual structure, specifically the hypothesised relationship between the latent constructs.

6.1.4.1 Measurement Model

This chapter provides a comprehensive overview of the methodological rigour in evaluating the measurement model. The initial step focuses on the reliability of the constructs through three indices: Dijkstra-Henseler's rho (ρA), Jöreskog's rho (ρc), and Cronbach's alpha (α). The next step is the validity assessment of the constructs. The first layer of this assessment is convergent validity, which illustrates if the latent variable explains at least 50% of the variance of its indicators, as indicated by the Average Variance Extracted (AVE). The next validity layer emphasises discriminant validity, ensuring that each construct is distinct and unique. The final layer of validity is content validity, which fundamentally depends on the rigour implemented during the scale development process.

For transparency, it is important to highlight that four items were excluded from the constructs for specific reasons:

- "Item 6" from Affordability was removed due to a mistranslation, which was reviewed and corrected in the primary quantitative research so that the mistranslated and original items were also included separately.
- "item1" and "item3" from the BMQ Necessity scale were removed because of the Heywood case (Farooq, 2022).
- "Item 3" from the BMQ Concern scale was excluded due to its loading being below 0.4.

Reliability

Three index numbers might be considered while deciding the reliability of the constructs. The most traditional is Cronbach's (α) alpha, which has a threshold above 0.6 (Malhotra & Simon, 2009). The other conventional index is Jöreskorg's rho (ρc), which might be above 0.7 (Jöreskog, 1971). The latest developed index is Dijkstra-Henseler's rho (ρA), which should be above 0,707 (Dijkstra & Henseler, 2015; Kemény et al., 2022).

The reliability indexes for each construct can be found in 10. Table. Based on these indexes, all constructs are deemed reliable. Thus, all the constructs in the study can be considered reliable for measuring the intended phenomena: non-adherent medical behaviour, financial affordability, concerns beliefs, necessity beliefs, testing-treatment, and resisting illness.

10. Table: Inner Reliability of Measurement Model

Construct	Dijkstra-Henseler's rho (ρA)	Jöreskog's rho (ρc)	Cronbach's alpha (α)
TRESHOLD	ρA>0,707	ρc>0,7	α>0,6
MARS5	0.8604	0.8437	0.8395
AFF	0.8965	0.8625	0.8650
BMQ_C	0.8228	0.7857	0.7909
BMQ_N	0.8568	0.8213	0.8309
INAS_TT	0.9308	0.9263	0.9276
INAS_RI	0.9488	0.9480	0.9484

source: edited by author

Convergent validity

Convergent validity evaluates the correlation or similarity among the indicators associated with a latent variable. The Average Variance Extracted (AVE) represents the proportion of these indicators' variance accounted for by the latent variable. Ideally, the AVE should be 0.5 or higher, meaning that the latent variable explains at least 50% of the variance of its indicators. This suggests that the factor is unidimensional (Kemény et al., 2022).

In these results (11. Table**10. Table**), MARS5, AFF, INAS_TT, INAS_RI and BMQ_C have AVE values higher than 0.5. This means that these constructs capture more than half of the variance of their respective indicators. Therefore, their convergent validity is good, suggesting that they are unidimensional constructs. On the other hand, BMQ Necessity

has AVE values below 0.5 (AVE=0,4928). This indicates that these constructs capture less than half of the variance of their indicators. This could suggest that the items within these constructs might not be as closely related in the sample as is predicted in the literature (Horne et al., 1999). For further evaluation, it is essential to highlight that while the AVE for Necessity is slightly below the threshold, the difference is minimal. Therefore, the researcher deems it sufficient and determines that the model possesses good convergent validity.

11. Table: Convergent validity of the constructs based on the AVE index

Convergent Validity	
Construct	The average variance extracted (AVE)
MARS5	0.5259
AFF	0.5685
BMQ_C	0.5586
BMQ_N	0.4928
INAS_TT	0.7166
INAS_RI	0.6952

source: edited by author

Discriminant validity

Discriminant validity assesses whether two latent variables representing distinct theoretical concepts are statistically different. Essentially, one latent variable should have a stronger correlation with its indicators than with the indicators of the other latent variable. This ensures that the constructs are distinct from each other. More approaches were utilised in the evaluation of discriminant validity. The HTMT (heterotrait-monotrait ratio of correlations) method will be employed in this preliminary research, as it is the most recently developed and accurate index (Henseler et al., 2015). The range of thresholds is cited in the literature for this assessment, including values below 1, 0.9, and 0.85.

As presented in 12. Table, the HTMT index for this research falls below the thresholds of 1, 0.90, and 0.85. This suggests that the constructs can be considered distinct.

12. Table: HTMT Indices for Discriminant Validity

Discriminant Validity: Heterotrait-Monotrait Ratio of Correlations (HTMT)									
Construct	**MARS 5**	**AFF**	**BMQ_ C_**	**BMQ _N_**	**INAS_ TT**	**INAS_ RI**	**INAS_ RI x BMQ_ C**	**INAS_ RI x BMQ_ N**	**INAS_ RI x INAS_ TT**
MARS5									
AFF_	0.5730								
BMQ_C_	0.1546	0.0791							
BMQ_N_	0.3456	0.3881	0.1029						
INAS_TT_	0.5235	0.3542	0.2330	0.2888					
INAS_RI_	0.4617	0.4000	0.1643	0.4559	0.8280				
INAS_RIxBMQ_ C	0.0357	0.0157	0.0499	0.0343	0.1832	0.1151			
INAS_RIxBMQ_ N	0.2171	0.1832	0.0291	0.0382	0.3145	0.4778	0.0064		
INAS_RIxINAS_ TT	0.3340	0.2430	0.1320	0.2432	0.7909	0.6481	0.2062	0.3365	

source: edited by author

Content validity

The primary goal is to ensure that items accurately represent the intended construct's content areas. Content validity arises from early scale development procedures that produce items mirroring the construct's domain. This validity is strengthened by efficiently creating an "item pool" and having it assessed by experts (G.Netemeyer et al., 2003). This preliminary study assumes content validity because all scales are from established literature. Each scale has undergone rigorous validation processes, as detailed in the literature review.

Since all the measurement fit criteria meet the required standards, it is appropriate to examine the structural model and evaluate the hypotheses.

6.1.4.2 Structural Model

The measurement model evaluation begins by assessing the model fit using the SRMR indicator from the structural model, focusing on the differences between observed and estimated values. Next, path coefficients are analysed by their significance and hypothesised impact. The effects are measured using Cohen's f2 to indicate practical

strength. Finally, the determination coefficient R^2 quantifies how much variance of the endogenous construct is explained by the exogenous constructs.

Model fit

The overall model fit measure is the SRMR index. The model fit examination measures discrepancies between the empirical and the estimated correlation matrix (Kemény et al., 2022). The optimal threshold for a good fit for this index is below 0.6 (Dijkstra & Henseler, 2015), but in most studies, a more tolerant 0.8 threshold value is accepted (Kemény et al., 2022).

This study's SRMR value of 0.0577 suggests a good fit between the empirical and the estimated model.

Path Coefficients

The path coefficient (β) between endogenous (dependent) and exogenous (independent) variables quantifies the expected change in the dependent variable for a one-unit change in the independent variable, ceteris paribus. Besides the path coefficients' direction and absolute value, their significance is assessed. Reporting the confidence intervals may highlight that if an effect is significant, zero is not included within the 95% confidence interval (2,5% and 97,5%) (Kemény et al., 2022).

In this initial study, most hypothesised effects are significant, with the sole exception being the moderating effect of INAS Resisting Illness on the relationship between BMQ Necessity and MARS5. It is also important to highlight that the moderating effect of INAS Resisting Illness on the BMQ Concern's impact on MARS5 is significant at the 10% level.

Effects

The strength of the effects is a crucial piece of information which can be quantified using Cohen's f^2. This indicator signifies the magnitude of effects independent of sample size, indicating their practical utility. The values might be categorised as follows:

a) < 0.02: negligible effect

b) 0.02–0.15: weak effect

c) 0.16–0.35: moderate effect

d) > 0.35: strong effect (Cohen, 1988)

Many researchers expect every effect to be strong, which is unrealistic since not all variables can fulfil this condition (Kemény et al., 2022).

The most prominent effect in the preliminary research model is moderate, where affordability (AFF) influences non-adherence (MARS5) with an f2 = 0.2793. The following significant effect, though weaker, is from INAS Testing Treatment (INAS_TT) on non-adherent behaviour (MARS5) with an f2 = 0.1376. All other significant effects on MARS5 are considered weak.

Explanatory power

In structural equation modelling, R^2 represents the proportion of variance in the endogenous construct that is explained by the exogenous constructs in the model. It provides a measure of the model's explanatory power. If $R^2 = 0$, the model does not explain any variance in the endogenous construct. If $R^2 = 1$, that indicates that the model explains all the variance in the endogenous latent variable. Values between 0 and 1 indicate the proportion of the variance in the dependent latent variable that is accounted for by the predictor latent variables (Henseler et al., 2009).

In the preliminary research, MARS5 is the only endogenous construct, and the involved exogenous constructs explain half of this non-adherent measurement (R2=0.502).

13. Table: Path coefficients and effect size

Effect		Original coefficient	Standard bootstrap results		Percentile bootstrap quantiles		Effect
			t-value	p-value	2.5%	97.5%	Cohen's f^2
Direct effects	AFF-> MARS5	0.4287	6.4999	0.0000	0.2948	0.5544	0.2793
	BMQ_C -> MARS5	-0.1109	-2.2921	0.0221	-0.2116	-0.0220	0.0222
	BMQ_N_> MARS5	0.1783	3.1393	0.0017	0.0768	0.3003	0.0419
	INAS_TT -> MARS5	0.6280	4.3392	0.0000	0.3701	0.9309	0.1376
	INAS_RI-> MARS5	-0.2598	-2.2081	0.0275	-0.4993	-0.0380	0.0273
Moderating effects	INAS_RIxBMQ_C -> MARS5	0.0143	0.2716	0.7860	-0.0905	0.1215	0.0004
	INAS_RIxBMQ_N -> MARS5	0.1109	1.8385	0.0663	-0.0039	0.2383	0.0164
	INAS_RIxINAS_TT -> MARS5	-0.1919	-2.1298	0.0334	-0.3852	-0.0220	0.0262

source: edited by author

To realise the results of the hypotheses, 13. Table and **1. Figure**9. Figure.

H1: Worst financial situation (affordability) has a positive impact on medical non-adherence

The hypothesis is confirmed (t=6.500, p<0.001), indicating that individuals facing financial challenges with their medication tend to adhere less to their treatment regimen. This is the most potent effect in the model (f^2=0.2783)

H2a: A stronger belief in the necessity of prescribed medications decreases non-adherence to the medication regimen.

The hypothesis is confirmed (t=-2.2921, p=0.0221), indicating that individuals with stronger beliefs about their medication necessity tend to be less non-adherent to their treatment regimen. This effect in the model is weak (f^2=0.0222)

H2b: Increased concerns about prescribed medications result in higher levels of non-adherent behaviour.

The hypothesis is confirmed (t=3.1393, p=0.0017), indicating that individuals with stronger concerns regarding their medication tend to be more non-

adherent to their treatment regimen. This effect in the model is weak (f^2=0.0419)

H3a: Increased questioning of treatment results in a higher level of non-adherent behaviour

The hypothesis is confirmed (t=4.3392, p<0.0000), indicating that individuals more suspicious about the treatment tend to be more non-adherent to their treatment regimen. This effect in the model is weak (f^2=0.1376)

H3b: Increased level of illness rejection results in a higher level of non-adherent behaviour

This hypothesis is rejected. Although there is a significant direct effect (t=-2,2081 p=0.0275), this effect has the opposite direction as it was accepted based on the literature. The effect size is weak (f^2=0.0273).

H4a: Increased illness rejection negatively moderates the relationship between necessity beliefs and non-adherent behaviour.

This hypothesis is rejected. There is no significant moderation effect (t=0.2716, p=0.7860)

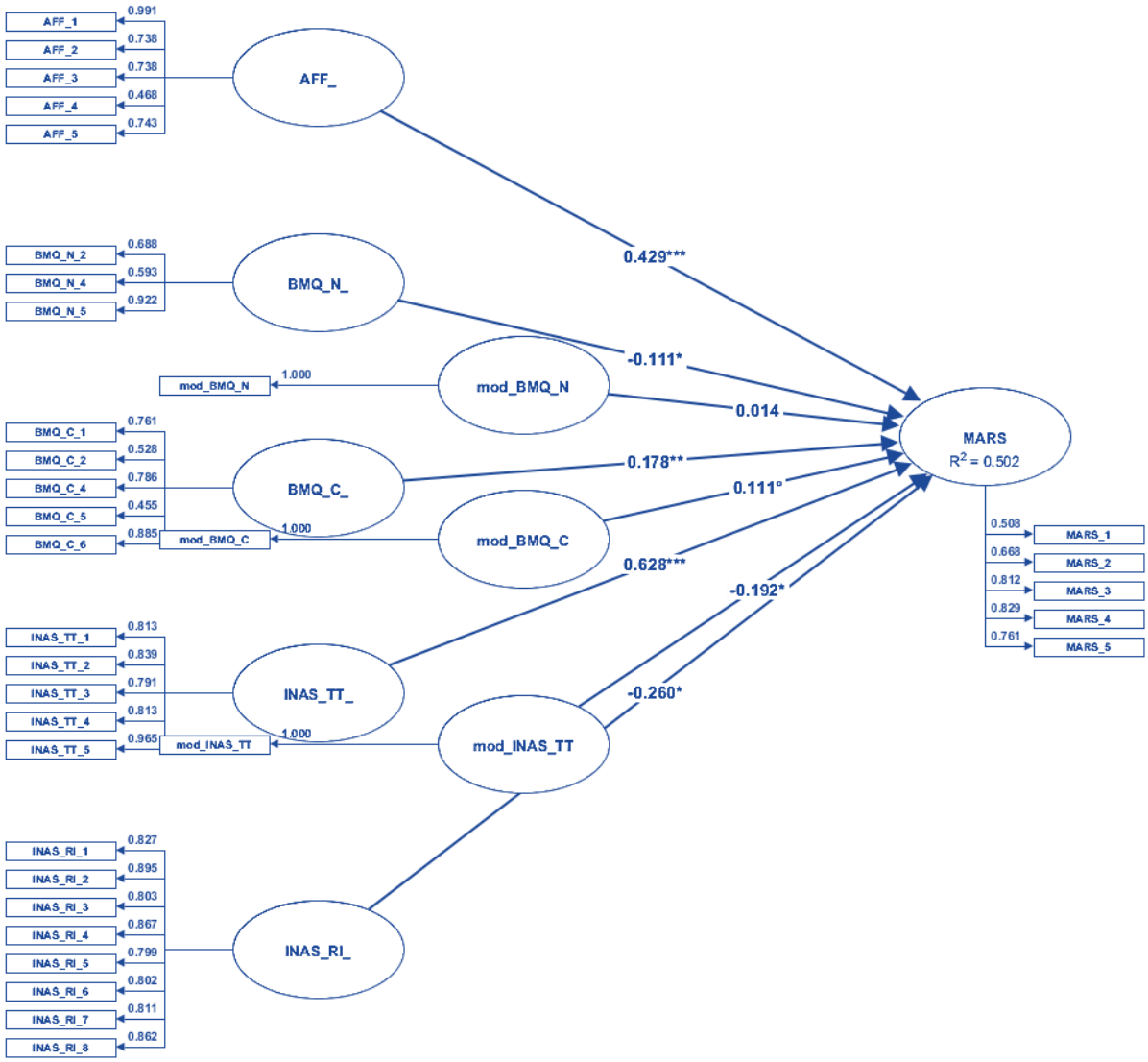
H4b: Increased illness rejection positively moderates the relationship between concern beliefs and non-adherent behaviour.

The hypothesis is confirmed at alpha=10% (t=1.8385, p=0.0663), indicating that individuals in liminality (resisting illness) are more affected by their illness concerns, which affect their non-adherent behaviour to their treatment regimen. This effect in the model is weak (f^2=0.0164).

H4c: Increased level of illness rejection positively moderates the relationship between treatment testing and non-adherent behaviour.

The hypothesis is rejected, although the path coefficient is significant (t=-2.1298, p=0.0334). However, the opposite is true since the moderation has a negative impact. This indicates that individuals more in liminality (resisting illness) are less affected by the testing treatment's effect on their non-adherent behaviour in their treatment regimen. This effect in the model is weak (f^2=0.0262).

9. Figure: Preliminary Empirical Research Model - Graphical Results



source: edited by author

6.1.4.3 Correlations Analysis

Given that the structural model yielded a contradictory relationship with the correlations found in the literature regarding the impact of INAS_RI on MARS5 and the moderating effect of INAS_RI on the relationship between INAS_TT and MARS5, additional correlation analysis was conducted on the construct variables using SPSS v.29.

14. Table: Correlation Coefficient Between MARS5 and its Predictor Constructs

Spearman correlations					
MARS5	**AFF**	**BMQ_N**	**BMQ_C**	**INAS_TT**	**INAS_RI**
Correlation Coefficient	,454**	-,170**	,302**	,456**	,434**
Sig. (2-tailed)	<0,001	<0,001	<0,001	<0,001	<0,001
N	482	482	482	482	482

**. Correlation is significant at the 0.01 level (2-tailed).

source: edited by author

As it is seen in 14. Table a medium positive correlation between MARS5 and both INAS_TT ($\rho(482)=0.456$, $p<0.001$) and INAS_RI ($\rho(482)=0.434$, $p<0.001$) exists. This implies that the findings in the database are consistent with previous research, indicating that a stronger tendency to undergo treatment testing and resist illness is associated with poorer medication adherence

6.1.4.4 Limitations and Conclusion for Further Research

This study has provided valuable insights into the moderation effect of Resisting Illness on various medication adherence scales and their impact on non-adherent behaviour, suggesting the significant role of liminality in medication adherence models. However, several limitations need to be acknowledged:

Moderating effect: Liminality (represented as INAS_RI) has a notable moderating effect, even within the medical aspect of the proposed research.

Haywood case: A Haywood case in the analysis indicates potential data or model issues. This underscores the importance of increasing the sample size in future studies to ensure more robust and reliable findings.

Contradictory Associations: The contradiction between correlation and SEM results may have several underlying reasons that require investigation. These reasons include the possibility of multicollinearity among exogenous variables, the need to control for other variables (e.g., time since diagnosis), and potential non-linearity within the model.

Another measure for liminality: The model should be evaluated using an alternative liminality predictor, the AADQ scale, or the time passed since the

diagnosis was received. This scale is anticipated to show weaker correlations with other predictors, so it should be applied in the primary questionnaire.

In conclusion, while this preliminary research has shed light on the relationship between liminality (Resisting Illness) and medication adherence behaviours, further studies with more targeted populations and other liminality measures are needed to provide more profound and nuanced insights into the dynamics of medication adherence.

6.2 Primary Qualitative Stage

6.2.1 Demographic characteristics

Altogether, 15 interviewees participated in the in-depth interview sequence. The participants are identified by gender, age, diagnosis, time since the first diagnosis, occupation, and county. According to the included criteria, the sample consisted of individuals diagnosed with at least one of the following diseases: diabetes, high blood pressure, musculoskeletal disease, high cholesterol, or cardiovascular disease. Other chronic conditions might have been present. All participants are above 18 years old, diagnosed at least a year ago, and take medication daily.

The sample includes 11 females and 5 males. The youngest participant is 43 years old, while the oldest is 75. Participants come from various counties in Hungary and have diverse occupational backgrounds, while six are retired.

The most common diagnoses are high blood pressure and diabetes. Nearly all participants are dealing with high blood pressure, often combined with other conditions. Many participants have diabetes, with some having lived with the condition for decades.

Several participants have multiple conditions, reflecting the complexity and interrelated nature of chronic conditions. The most recent diagnosis was 1,5 years ago, and the oldest diagnosis was received 47 years ago. The sample illustrates various stages of disease management, from recently diagnosed individuals to those with decades of experience.

Each participant received a code based on the gender (M – male, F – female) plus the age of the participants. For anonymity reasons, this ID code is used as a reference for each quote. For ID and demographic details, see 15. Table.

15. Table: Demographic Characteristics of the Interviewees

ID	Gender	Age	Diagnosis	First Diagnosis (years ago)	/Occupation	County
F43	Female	43	*High blood pressure*	1,5	An employee at a multinational company	Pest
F44	Female	44	*Diabetes, high blood pressure*	10	Social care	Budapest
M46	Male	46	*High blood pressure, high cholesterol, thyroid, joints*	30	IT professional	Budapest
M55	Male	55	*High blood pressure, diabetes*	10	Social care	Zala
F57	Female	57	*High blood pressure, Crohn's disease, lactose intolerance*	16	Office worker	Budapest
F58	Female	58	*High blood pressure and thyroid*	3	Freelancer trainer, coach	Budapest
M58	Male	58	*Diabetes, high blood pressure*	5-6	Hotel industry	Fejér
F65	Female	65	*Diabetes*	14	Retired, formerly a nurse	Budapest
F61	Female	61	*High blood pressure, diabetes*	22	Retired, former seamstress	Bács-Kiskun
M65	Male	65	*High blood pressure, stroke*	circa 30	Retired, former policeman	Bács-Kiskun
F66	Female	66	*High blood pressure, diabetes*	24	Retired, former family business worker	Hajdú-Bihar
M67	Male	67	*Various illnesses, high blood pressure, stroke*	8	Retired, former entrepreneur	Hajdú-Bihar
F74	Female	74	*High blood pressure*	15-16	Doctor (GP)	Pest
F75a	Female	75	*Various illnesses, high pulse, constriction*	47	Retired, former foreign trade administrator	Budapest
F75b	Female	75	*High blood pressure, high pulse, constriction*	25	Retired, former teacher	Jász-Nagykun-Szolnok

source: edited by the author

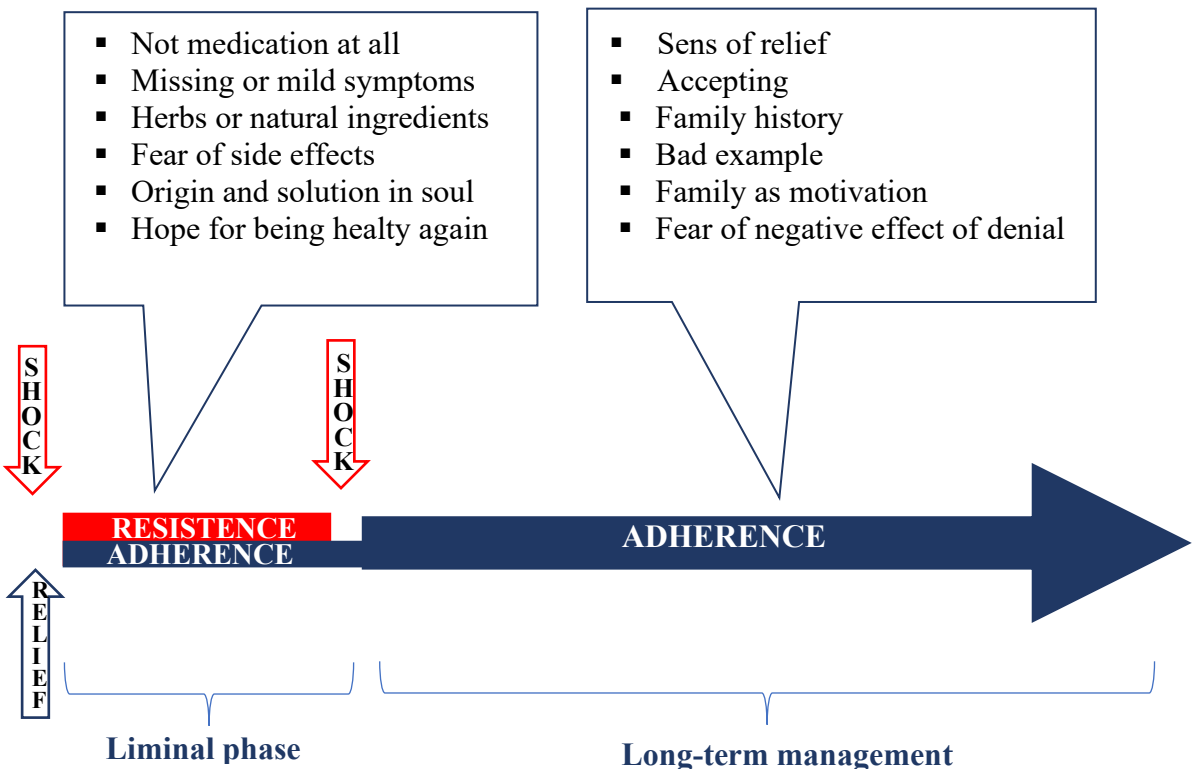
6.2.2 Life after the Diagnosis

The 10. Figure illustrates the timeline of medication adherence based on the qualitative research interviews. The process is depicted as a continuum, from resisting to medication adherence. It maps out the phases and factors influencing patients' medication adherence behaviour from initial diagnosis through long-term management. The first liminal phase might be twofold. Initially, if the diagnosis is unexpected, patients may exhibit resistance

to taking medication. Many times, a second shock, a significant health event, or increasing symptoms are needed to eventually push them towards accepting and adhering to their medication regimen. Some of the patients are adherent from the beginning with no denial phase. If the first reaction is a sense of relief since severe symptoms are experienced or diagnosis is expected, the patients would rather adhere to the treatment.

The following pages will discuss the factors covered in medication adherence. The screening will also examine the aspects and actions of patients who are in the denial phase at the beginning and what shock events can change their minds about resisting medication. As a final step, conclusions about long-term medication adherence will be discussed.

10. Figure: Timeline of Medication Adherence in Qualitative Research



source: edited by the author

6.2.2.1 First Reaction to Diagnosis

Receiving the first diagnosis can be very contrary for individuals. The first response to a diagnosis can be unexpected for patients who were before unconscious of any health problems. Still, it can be a comforting clarification for those who have long suffered without answers. Both answers greatly influence patients' attitudes to further treatment.

Shock

individuals who had no severe symptoms or prior medical problems, the receive of the diagnosis is a first shock. Unexpectedly realising the medical condition can be highly distressing and trigger resistance and treatment avoidance.

"I have already thought about registering on cripply.hu." M46 has experienced a profound emotional impact and a sense of sudden vulnerability.

"The belief that a person cannot be sick has been completely overturned for the entire family." (M67)

"It was hard to accept that I had a problem that required ongoing treatment and attention. I had never had any issues before, not even needing painkillers. It was challenging." (F65)

A Sense of Relief

The initial reaction to a diagnosis can sometimes be a kind of relief. For individuals who have been experiencing severe symptoms and suffering for a long time while searching for answers, the diagnosis can provide clarity and validation. Patients often perceive a direct benefit from taking their medication, as it offers tangible relief from discomfort or improves their quality of life. This immediate feedback can reinforce medication adherence behaviour, making it more likely that the patient will take their medication as prescribed. This situation results in a greater trust in the prescribed treatment associated with the diagnosis.

"I had reached a point where I didn't care what it was anymore; I just needed something because I wasn't feeling well at all. .... For me, it was actually a relief to get the prescription." (F44)

"At that point, there wasn't really an alternative for me because I was so desperate and lost that I didn't even start thinking about resisting." (F66)

6.2.2.2 Non-adherence as Part of Liminality

Receiving a diagnosis can be challenging, especially in the beginning. For some patients, it is difficult to accept that their body is not as strong as it once was. In particular, those diagnosed with high blood pressure often do not immediately grasp the seriousness of their condition. They might not understand the importance of elevated numbers or the necessity of taking medication. This initial lack of seriousness and understanding is particularly significant after the first diagnosis.

These accounts reflect a typical pattern of initial resistance to medication among patients. They often go through a phase of denial or downplay the severity of their condition, leading to inconsistent medication adherence. This resistance phase is a critical period that can delay effective management of their health condition.

No medications at all

Receiving a diagnosis often brings with it a period of uncertainty and resistance. Many patients, especially those diagnosed with high blood pressure, initially struggle to accept the necessity of medication. They often delay or completely avoid taking prescribed medicines, reflecting a phase of denial and underestimation of their condition.

Patients often receive a diagnosis but do not focus on it afterwards. They do not take the diagnosis seriously and do nothing to address it or stop taking medication by conscious decision.

During a medical examination, diabetes was discovered by chance, but for a while, F65 did not deal with it at all. *"I didn't really take it; let's say I didn't take it at all."* (F65)

"In high school, … in the third year, I suddenly felt very dizzy, and my blood pressure was measured at 180 in a lying position. Initially, I took medication, then I stopped and then restarted because of the military service requirements. Ever since university, I've been taking medication regularly for my blood pressure." (M46)

F43 provides a detailed account of her resistance: "*I strongly denied it; I did take the medication there because I had to, but then I stopped. … During the summer, my blood pressure would naturally go down. … For me, medication is a no-go zone, a necessary evil."* She elaborates on her conscious decision to avoid medication: *"I definitely made a decision that I don't need it because I can solve this on my own."*

The early resistance to begin therapy is typical of individuals who have just been diagnosed. As F58 expressed: *"Do I really need to medicate myself immediately?"*

Missing or mild symptoms

The level of medication adherence is influenced by the severity of symptoms, especially at the beginning of the treatment process. Accordingly, the reaction to constant medication taking might be very opposite. If symptoms are mild or absent (often with hypertension or high cholesterol), the motivation to adhere can be substantially weaker. Without experiencing direct discomfort from the condition itself, patients may not feel the urgency or need to take their medication regularly.

Without physical symptoms to act as constant reminders, sticking to a medication regimen can feel unnecessary or be easily forgotten. This inconsistency often persists until an event (shock) occurs that makes the consequences of non-adherence visible.

"Before, when they discovered by chance that my blood sugar was higher and that I should, or rather must, take medication, I didn't take it seriously and didn't really take the medication properly... because I had no symptoms. ... I wasn't hungry, my mouth wasn't dry, and I didn't need to urinate more." (F65)

"I remember thinking, okay, I felt bad once, but I've never really had any problems. So why is it such a big deal that this number is higher now?" (M46)

Herbs or natural ingredients

Many individuals choose herbal and natural cures after the diagnosis rather than starting prescribed drugs right away. A desire for natural treatments and worries about side effects from medications are two of the many things that affect this choice. Patients want to control their illnesses free from the supposed adverse effects of drugs. However, many eventually resort to prescription drugs under physician supervision when these approaches prove ineffective in managing their health problems.

"I was prescribed medication, but initially, I tried alternative treatments like various herbs. This approach worked for about a year because the side effects of medications are not easy to handle. ... However, after a year, I decided to start taking the medication because I continued to have problems." (F74)

"At first, I didn't want to take medication right away, so I found a solution in a garlic-hawthorn-mistletoe capsule available at a drugstore, which was said to be good for managing blood pressure. I managed my blood pressure with this for about two years, but eventually, it started to rise again despite increasing the dosage. At that point, I turned to my doctor." (M55)

"If I felt the need, I would take it for a while or supplement my medication with herbal remedies." (F66)

Natural herbs can also be an entryway when patients first refuse traditional medicine. This strategy decreases their worries about side effects and perceived disruption of medications, which can lead them to the concept of conventional treatment. They could become more open to the usage of regular medications since they see the limitations of herbal treatments over time and also get used to regular pill taking. Patients can gradually build trust in the treatment process by beginning with natural herbs.

"I hoped that using natural remedies would result in fewer side effects, but I soon realised they don't cure the issue but merely manage the symptoms, much like blood pressure medications do. Once I understood this, it wasn't as overwhelming to take the step of switching to standard medications because the natural substances were insufficient." (M55)

"The doctor explained that the thyroid medication contains the same hormone that my body naturally produces, just synthesised. So, it wasn't any different." (F58)

Fear of side effects

Patients delay back on or stop taking prescribed medications due to anxiety about adverse side effects. This is what motivates them to look for alternative therapies or skip traditional medicines.

"Based on the fact that all medications have side effects, ... if possible, I avoid taking them." (F58)

Patients worry that drugs could be more harmful than beneficial, also expecting an endless loop in which every new drug causes additional side effects that call for more medications.

"One issue is that there isn't a medication without side effects with chemicals. When chronic diseases start, a person begins taking medication for a particular condition, which might manage the symptoms, but the side effects create another problem, requiring additional medication. Over time, I found myself taking more and more medications over 4-5 years, and I didn't want to fall into that trap, starting with one medication and then taking more for the side effects of the first." (M55)

Moreover, the long list of possible side effects in pharmaceutical booklets might lead to hesitation in taking or reducing the medicine.

"When you open a medication and read the leaflet, there are doubts because it lists numerous potential side effects, from one in a hundred to one in a thousand, but it doesn't stress that I need to take it." (M67)

"I try to reduce my medication if I feel it's not that bad. For example, if my blood pressure is around 150, I start reducing the medication to minimise side effects." (F66)

Origin and solution in soul

Many patients feel that their mental mood greatly affects their physical health after receiving a diagnosis. People think that they can cure their physical problems by taking care of their mental and emotional issues. The fact that many of them got their diagnoses during or right after periods of extreme stress or emotional strain serves to support this viewpoint even more.

"We know that high blood pressure is closely related to stress, and I had hope that the various stress-reduction methods, which I seem to be very good at helping my clients with, would help me too." (M55)

"My basic approach to any organ-related problem is to find alternative ways to handle somatic complaints psychologically, identify their root causes, and address them somehow. Because I think medication often masks the symptoms." F58 received her diagnosis during a challenging period in her life. She resisted taking medicine for a long time. Instead, she preferred to treat her thyroid problem with natural remedies and stress-reduction approaches like autogenic training. She believes that physical problems have emotional causes.

"As a result, I didn't really deal with why I was feeling unwell. I always look for psychological reasons first, going to a psychologist before a doctor." (F43)

Hope to be healthy again

This reflects the liminal mindset, where the disease state is not fully accepted and where there is a belief that everything can return to how it was before the diagnosis. Patients maintain a strong conviction that they can overcome their condition without relying on medication or a freshly developed treatment in the future.

"I believe that I can reset myself and bring myself back. I have a strong inner force or resource I can connect to. If possible, I don't want to rely on medication." (F58)

"There is something I still need to work on, both physically and mentally, and I am trying to change this state in every possible way. … Maybe you won't be able to interview me in a year because I'll have stopped taking the stuff." (F43)

6.2.2.3 Second Shock is a Turning Point

This event characterises patients who initially resisted treatment, did not take their medication, or were inconsistent in their medication adherence. They often experience a pivotal health event that forces them to confront their condition seriously. These significant health crises, such as hospitalisations or severe health episodes, act as wake-up calls, compelling them to take their health more seriously.

"After I spent time in the intensive care unit and discovered I had high blood pressure, I fully cooperated with the medication afterwards." (F65)

"I had these symptoms but didn't address them because I had never had a serious illness before. I didn't prioritise them until I had a stroke. My general practitioner then told me that I had already had a minor stroke before this one. But it was this major stroke that made me realise the seriousness of my condition." (M67)

"These were complete collapses in terms of my energy level, capacity, and endurance. However, the truth is that this milder stroke brought such relief that I immediately accepted the medication. It didn't cause trauma that I now had to take medicine; I was actually relieved." (F43)

These quotes highlight how critical health events can dramatically change patients' attitudes toward their health. The shock of these episodes leads to a newfound acceptance and medication adherence to medical advice as patients realise the importance of managing their conditions to avoid further complications.

6.2.2.4 Elements of Medication Adherence

Acceptance

Some patients adhere to their treatment from the very beginning. This acceptance can stem from their personality, family upbringing, or a clear understanding of the necessity of cooperating with their therapy and following the doctor's instructions.

"From the very beginning, since 1980, I have known that I have to accept this. This is what life has dealt me, and I accept everything. ....I follow everything my doctor tells me to do." (F75a)

"It's completely natural in my family to take medications as prescribed. My mother-in-law is the prime example of this." (F74)

"Why would I question the doctor who is trying to help me live longer and with fewer problems?" (M58)

"I take my medication because I feel it helps me manage my stress and blood pressure. I know I need it." (F66)

Some patients are not as accepting of their diagnosis and treatment at the beginning, as discussed in the previous chapter (Chapter 6.2.2.1). However, over time, acceptance often develops as they come to terms with their condition and the necessity of ongoing treatment.

"It took a few years to reach the point of accepting my condition. I realised I had a choice: either accept it and find ways to live with it, or drive myself crazy. This applies to any illness – you must look ahead and figure out how to live a livable life alongside it." (F57)

"When I started taking medication, I felt significantly better within a week. The chronic fatigue lifted, and the early symptoms of neuropathy subsided." (M55)

The Influence of Family History

While initial reactions to a diagnosis can vary, the understanding that their condition may be hereditary can help patients accept their diagnosis more readily. Understanding that their illness may be inherited can ease the acceptance process, as they see it as part of their genetic and familial legacy.

"I can honestly say that I expected it. I expected it because there are diabetics in my family. It was a bit surprising, and it's never good to hear that you're not healthy, but I had an inkling that there would be something I might inherit." (F44)

"I understand, so it was in the package." (M58)

"I developed type 2 diabetes. I have to say, I wasn't surprised because, on my mother's side, my grandmother, both aunts and my mother all struggled with it. They all developed it around the same age I am now. We know it's partly a lifestyle disease, but there's also a genetic predisposition. And, of course, if we say it's a lifestyle disease, my lifestyle and eating habits were greatly influenced by my family." (M55)

"I asked if it was hereditary because my father, his only sibling, and their father and all of their siblings had either heart disease or stroke. It seems like everyone in the family passed away from either a stroke or a heart attack." (M68)

Bad examples

One's attitude to accepting and following medical treatment might be significantly influenced by family members' and acquaintances' health challenges and results. Accepting and following medical advice and treatment can be very motivating when one witnesses the harmful consequences of doing the opposite.

"Medication, nothing, my dear father... he passed away. It made me think a lot about health, his health journey, all his cancers, heart attacks, and other horrors, and the great similarities between him and me. ... My father was a walking, or rather a living example, of how to mess this up truly. And that's a path I will not follow." This realisation forced F43 to take her health more seriously to avoid a similar fate.

"I know someone who didn't accept their diagnosis, and it didn't end well. They also had cancer and chose a different path, which didn't turn out well." (M67)

Family as Motivation

The need to follow medical advice is often not just about urgent health issues. Many patients feel a strong sense of responsibility to their families and themselves, which motivates them to maintain their health. Personal promises, long-term goals, and the desire to be present for important family events serve as powerful motivators to adhere to prescribed treatments and take proactive steps in managing their health.

"So I feel that this is the minimum I can do for my health—to get the prescription, fill it, and take the medication. I believe I must do this for my own sake and obviously for the sake of my family, to take such good care of myself." (M67)

"Well, you're going to laugh, but my husband and I promised each other that we'd live for 300 years, which obliges us. It will be hard to reach 300 years with a weak thyroid, so... I feel a responsibility towards myself and my family. I want to be with them for a long time; I need to care for myself." (F58)

"I want to see my grandson graduate and see where he goes next, and I want to see my granddaughter get married." (F75b)

Fear of Complications without Medication

For many patients, the fear of serious complications from their condition is a significant motivator for adhering to their prescribed treatment. This fear is often rooted in personal or family experiences and is reinforced by awareness of the potential consequences of untreated illness.

"I know I have to take it, I need it. I have to take the medication. Otherwise, it could lead to a stroke or heart attack." (F44)

"Seeing stories on TV about people losing limbs suddenly makes you scared." (F66)

"My anxiety was strong because I know what diabetes can lead to, but it was a relief to know that the medication could stop this progression." (M55)

"I started taking the medication because I don't want to develop any problems, such as a stroke or anything else." (F74)

"It's somehow natural that I have to do this now because if I don't, my condition will worsen. Another thing that motivates me is the fear of becoming dependent on others. This pressure ensures that I take my medication." (F65)

6.2.2.5 Long-term Medication Management

Long-term medication adherence and treatment plans is essential for effectively managing chronic conditions.

Long-run Medication Adherence

Patients who maintain regular medication schedules and follow-up appointments are better able to stabilise their health and manage their symptoms. Once the routine is established, the patients adhere to the treatment plan with minimal mistakes. Having part of the daily schedule is an essential tool.

"Since then, I've been taking the medication, regularly going for control examinations, and measuring my blood pressure at home…. If I have any problems, I visit my cardiologist more frequently. This way, everything is pretty well adjusted." (F74)

"I take my medications regularly, without exception. I take them at the prescribed times and ensure I have enough supplies for travel or any unexpected situations. My priority is to make sure I have my medications on hand and accessible." (F65)

Flexibility in routine can be part of the routine itself for maintaining overall medication adherence: *"On weekends, I tend to be a bit lax and take my medication two or three hours later. But I think the amount of medication I have set for myself is okay because it works well for me."* (F44)

Over time, even those who initially resisted or were shocked by their diagnosis come to accept the necessity of medication. *"Now I live in peace, in harmony. I can accept that there are occasional difficulties. I don't fight against them anymore; if my heart acts up in the morning, I know what to do. I take my medication without hesitation because it helps me. This approach serves me well."* (F58)

Long-run Non-adherence

While many patients eventually accept and adhere to their prescribed treatment plans, long-term nonadherence remains a significant challenge for a few patients. Key drivers are the desire to minimise medication intake, scepticism about medical advice, and periodic reassessments of the necessity of their medication.

"Just yesterday, I decided not to take my medication. It was a conscious decision because I wanted to see what would happen. ... I plan to carry out similar actions if I don't experience any adverse effects in the coming weeks." (F58)

"I had been taking a sedative since 2002, and about a year and a half ago, I just stopped taking it for some reason, even though it wasn't a high dose. ... I feel that doctors, to some extent, overprescribe and experiment with medications." (F66)

Scepticism towards medical advice can also lead to nonadherence, as patients believe that doctors may overprescribe or experiment with treatments. Periodic nonadherence occurs when patients feel well and choose to take breaks from their medication, testing the necessity of their prescribed regimen. *"When I feel really good, I might not take it. This can go on for several days or even a few weeks."* (F66)

Medication Adherence in Sequental Diseases

After overcoming initial resistance and experiencing the benefits of medication adherence, patients are more likely to accept and comply with additional treatments for new conditions. Their previous experience helps them recognise the importance of medication in managing their health, leading to better medication adherence and health outcomes in the long run.

“Later, my cholesterol levels became very high, and I also took medication for that. At first, they gave me one drug, then another. I take two for blood pressure as well, so altogether, I take four medications continuously, and this has been going on for more than ten years." (M46)

Long-term Change

Over time, patients become more engaged in their treatment plans and tend to consult their doctors when they feel adjustments are necessary.

"It was a bit later when I mentioned that we should maybe re-evaluate and adjust my blood pressure medication because it started to rise again, reaching around 150-160. When they re-adjusted it, they switched me to [medication]." (M46)

"I worked out the amount that helps without causing harm. I told the doctor that I tried it this way. I thought he would give me a different medication, but he said if I feel better this way, I should take it like that." (F57)

"It's fine because I can adjust it. If needed, I increase my insulin by two units. We discussed that I should adjust between 30 and 36 units." (F75a)

"I might call the doctor to ask if I can take the morning medication in the evening as well because it seems to work better that way. Or I will ask for their opinion." (F43)

6.2.3 Summary and Conclusion for Model Building

This research explores the evolving nature of medication adherence among patients diagnosed with chronic conditions, highlighting significant differences between the initial, liminal phase and long-term management.

In the initial (liminal) phase, patients' first reaction to a diagnosis might be shock or resistance, particularly if they have no severe symptoms or prior health issues. This period is characterised by denial and a reluctance to start medication. Many patients do not immediately understand the seriousness of their condition if symptoms are mild or absent. The necessity of the treatment is not obvious under this condition. Thus, this initial phase is rather characterised by non-adherence and a conscious decision to avoid medication than the long-term, chronic phase, even if part of the patients are accepting from the very beginning of their disease history.

For non-adherent beginners, a second shock might be the gateway to medication adherence. Significant health events often act as wake-up calls, pushing patients towards acceptance and medication adherence.

In long-term management, patients come to terms with their condition and recognise the necessity of medication over time. They establish routines that integrate medication into their daily lives. Patients become more engaged in their treatment plans and consult their doctors for adjustments. This proactive approach helps them manage their condition more effectively.

The differences between the initial, liminal phase and long-term management in medication adherence highlight the importance of considering time since diagnosis in understanding medication adherence levels. Investigating these temporal dynamics can help healthcare providers better support patients in transitioning from initial resistance to long-term medication adherence, ultimately improving health outcomes.

6.3 Primary Quantitative Stage

6.3.1 Demographic Characteristics

The sample's demographic characteristics are presented at the beginning of the analysis. The sample consists of 500 individuals characterised by diverse demographic factors. The gender ratio is representative since, in 2022, 42% of the chronic disease patients were male and 58% female (KSH, 2022). Most respondents live with multimorbidity (n=415, 83.0%). Predominantly middle-aged and elderly patients are in the sample, but 15,8% of the respondents are below 35. Central Hungary hosts the largest sample segment (n=164, 32.8%), but each region is notably present in the research. Settlement size is diverse; the most significant proportion lives in towns (n=181, 36.2%), while Budapest is home to 105 participants (21%). Most participants have completed high school with graduation (n=234, 46.8%). A majority, 64,0%, were married or in a relationship (n=320). Most of the households comprise two members (n=218, 43.6%). Living problems are a characteristic of 28,2% (n=141). For further demographic details of the sample, please follow 16. Table.

16. Table: Frequencies for Demographic Variables

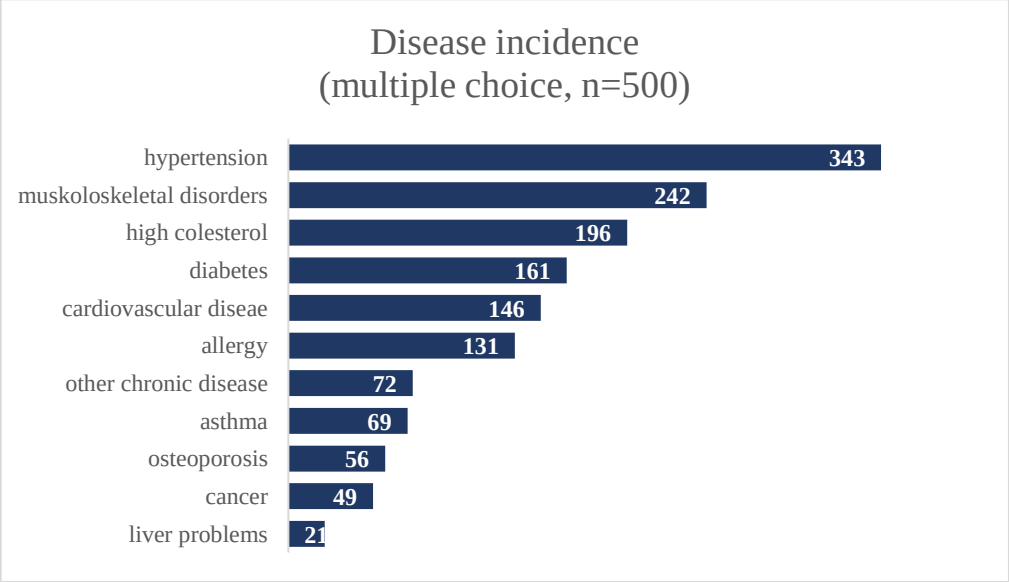
DEMOGRAPHIC FACTORS			
		n	**%**
Gender	male	209	41,8
	female	291	58,2
Multimorbidity	single diseases	85	17,0
	multimorbidity	415	83,0
Age category	under 25 years	13	2,6
	25 – 35 years	66	13,2
	36 – 45 years	71	14,2
	46 – 55 years	82	16,4
	56 – 65 years	101	20,2
	66 - 75 years	124	24,8
	over 75 years	43	8,6
Region	Southern Great Plain	62	12,4
	Southern Transdanubia	41	8,2
	Northern Great Plain	80	16
	Northern Hungary	60	12
	Central Transdanubia	63	12,6
	Central Hungary	164	32,8
	Western Transdanubia	30	6
Settlement	Budapest	105	21
	county seat	131	26,2
	other town	181	36,2
	village	83	16,6
Education	elementary school	16	3,2
	high school without graduation	61	12,2
	high school with graduation	234	46,8
	MsC/BsC/postgraduate	185	37
Family status	single	91	18,2
	in a relationship / married	320	64
	divorced /separated	49	9,8
	widow	39	7,8
Household members	1 person	115	23
	2 persons	218	43,6
	3 persons	84	16,8
	4 persons	59	11,8
	5 or more persons	24	4,8
Income status	we live without worries, and we can regularly save money	46	9,2
	we manage well with our income, and occasionally, we can save money	158	31,6
	we have no living problems, but we cannot save money	155	31
	we barely get by on our monthly income	102	20,4
	we have financial problems month after month	39	7,8

source: edited by author

6.3.2 Health-related Characteristics

The most common problem is hypertension, which affects 343 (68,6%) participants. Musculoskeletal disorders also present a high incidence, with 242 patients. Other notable conditions are high cholesterol and diabetes, which affect 196 and 161 participants, respectively. The sample further includes data on different problems, indicating diverse health challenges. This distribution highlights common and severe health issues to provide insight into the complex health landscape. To see the disease structure of the sample, see 11. Figure.

11. Figure: Number of Disease Incidences in the Sample



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Patients' general health condition is self-rated at an average of 5,57 on a scale from 1 to 10 (SD=2,12). The perceived severity of the most severe illness is relatively high (M=5,70, SD=2,34). As future considerations, participants anticipate that their health will worsen over time due to illness (M=6,32, SD=2,64). Patients report taking medication approximately 2,08 times per day on average (SD = 0,95). The unpleasantness of taking medication on an average day is rated at 3,44 (SD=2,51), indicating a moderate experience with the medication treatment. On average, a patient takes 3,98 different types of medication daily (SD=3,10). The mean of the total number of medications taken per day is 5,12 (SD=4,72). The form of the medication is mainly oral (472 cases), and 472 of

them are taking care of their medicines for themselves. To see further details on health-related variables, see 17. Table.

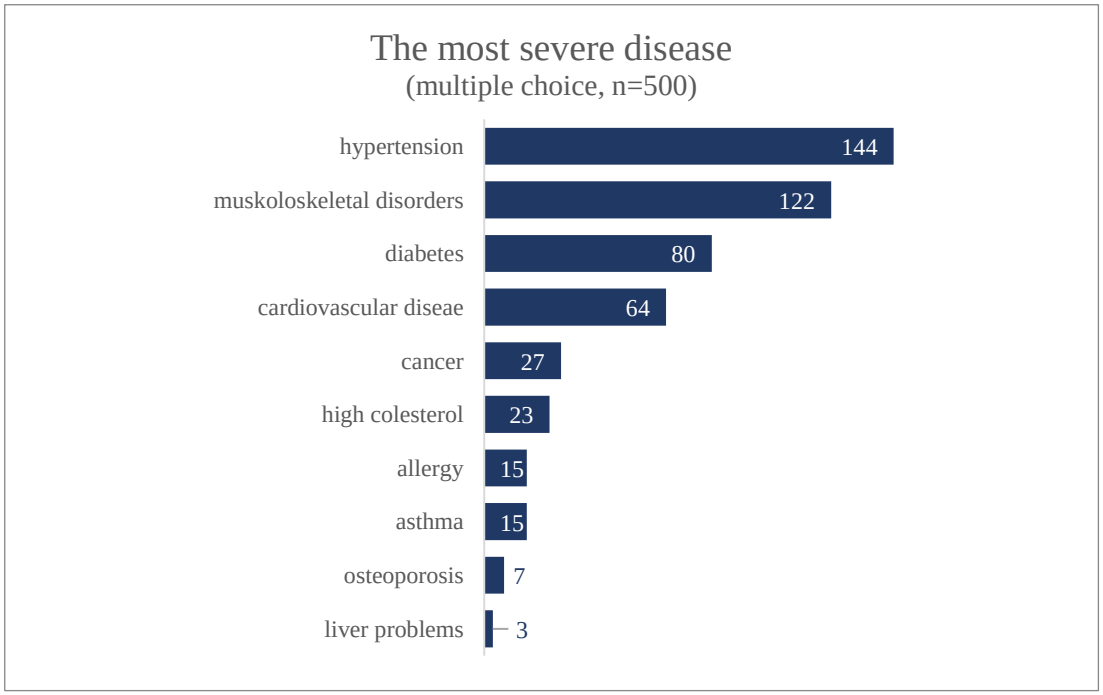
17. Table: Frequencies for Health-related Variables

Health-related variables	M	SD
General health-condition (1-10)	5,570	2,117
How unpleasant is taking medication on an average day? (1-10)	3,440	2,512
How severe do you feel your most serious illness? (1-10)	5,698	2,339
As time progresses, how your health condition will change due to illness (1-10)	6,322	2,636
How many times per day do you need to take your medication?	2,080	0,953
Number of types of medication taken a day	3,978	3,095
Number of medications taken a day	5,116	4,719

source: edited by author

Hypertension is perceived as the most severe condition (n=144). Musculoskeletal disorders follow closely (n=122), while diabetes (n=80) and cardiovascular diseases (n=64) are also significant (12. Figure).

12. Figure: Frequencies for Perceived Most Severe Disease



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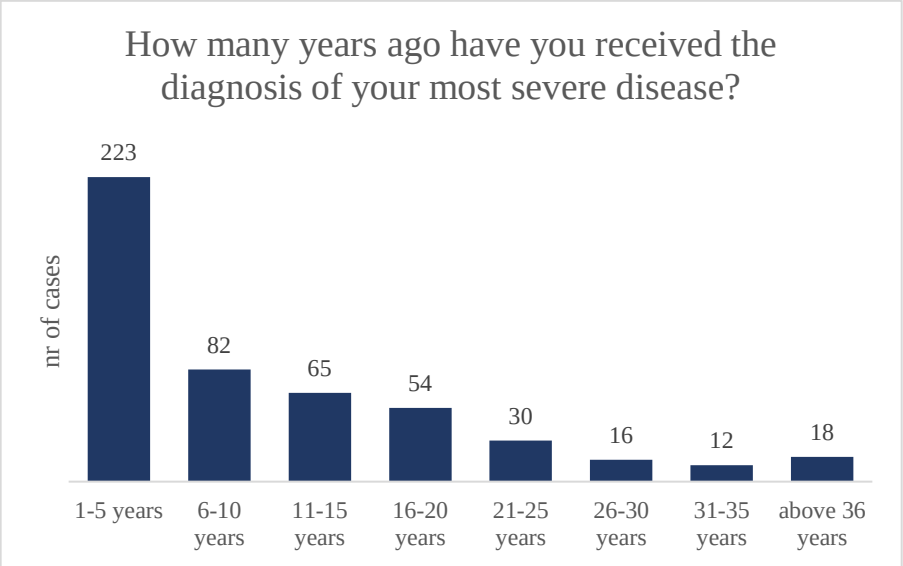
The patients received their diagnosis on average 11,29 years ago (SD=11,11). The distribution of the diagnosis time is illustrated in 13. Figure.

13. Figure: Frequencies for Disease Length



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6.3.3 Primary Quantitative Study

The primary quantitative questionnaire used medication adherence-related scales that were employed in preliminary research. Additionally, the AADQ scale was incorporated as an alternative method to measure liminality through the phenomenon of disease acceptance (see applied scales in 7. Table). The survey also included questions related to disease, treatment, and nursing (e.g., determining responsibility for or assistance with medication). Time-related measures were also included to account for the years with diagnosis. All the employed questionnaires were applied using the Hungarian version of these scales.

Similar to the preliminary phase, before starting with the analysis, formulating hypotheses, and interpreting results, the scoring interpretations for the scales employed in the primary data collection questionnaire are detailed:

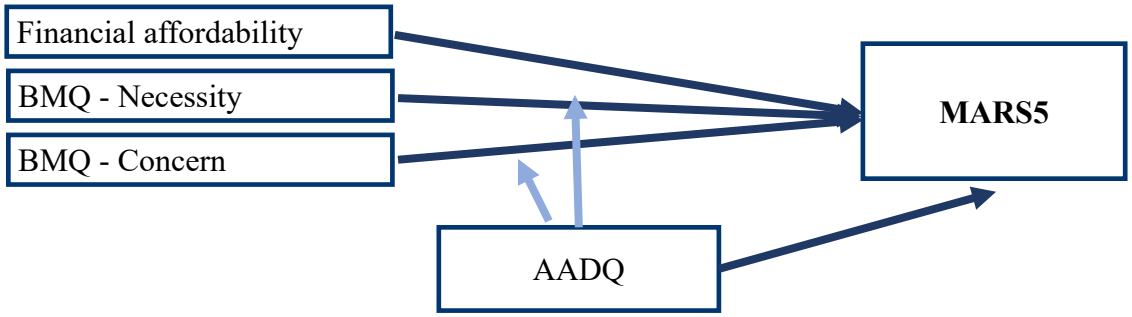
- MARS: Higher scores indicate greater non-adherence to prescribed medications.
- AFF: Higher scores measure increased financial challenges associated with treatment.
- BMQ Necessity: Higher scores reflect a stronger belief in the necessity of medication for health management.

- BMQ Concern: Higher scores indicate more concerns about medication's potential side effects or other adverse effects.
- INAS Testing Treatment: Higher scores represent a higher level of testing.
- INAS Resisting Illness: Higher scores suggest a more robust rejection of the diagnosed illness.
- AADQ: Higher scores signify a greater rejection of the disease diagnosis.

6.3.4 Indtorducing AADQ as a Potential Liminality Measure

An alternative scale for measuring liminality was proposed to conclude the preliminary research phase. The AADQ scale was selected for this role because it measures the level of acceptance of having a disease. This scale may help us understand how the stage of the transition from healthy to ill influences medication adherence. The literature review indicated that the AADQ scale is unidimensional. Therefore, the initial step of the research involved applying the AADQ scale as a potential moderator in the model introduced during the preliminary phase (see 14. Figure**: Model with AADQ Moderator**).

14. Figure: Model with AADQ Moderator



Source: edited by the author

Although the model demonstrated moderate explanatory power ($R^2 = 0.395$), several concerns warrant attention. The primary issues pertained to the AADQ scale, which exhibited suboptimal reliability as indicated by Jöreskog's rho ($\rho_c = 0.4965$) and Cronbach's alpha ($\alpha = 0.6918$). Additionally, the Average Variance Extracted (AVE) was exceptionally low at 0.1554, with three item loadings falling below 0.1 and four others

below 0.4. (Details of the model are found in 5. Appendix: ADDQ Moderated Model Results)

Based on these low AVE metric and item loading values and in light of the relevant literature, the AADQ scale may have more than one dimension, which could explain the observed deficiencies in the model's performance (Hair et al., 2010).

Therefore, the next step in the analysis involved randomly dividing the sample in half. An exploratory factor analysis (EFA) was conducted on the first half of the sample to identify the underlying factor structure. Subsequently, this extracted factor structure was validated through a confirmatory factor analysis (CFA) on the second half of the sample to ensure its robustness and replicability (Boateng et al., 2018).

The **exploratory factor analysis** (n=250) identified a three-dimensional factor structure, as outlined in 18. Table, employing Promax rotation. The analysis accounted for 53% of the total variance, with a KMO of 0.672.

Disease Denial captures behaviours where patients actively avoid confronting the reality of their disease. The items associated with this factor involve denying the potential harm the disease can cause and not acknowledging the existence of the disease as a self-protection mechanism. The loadings for these items are relatively high, indicating a strong association with the factor.

Liminal Disengagement reflects behaviours indicative of patients navigating the threshold (or liminal space) between health and disease. These items highlight coping strategies used when dealing with overwhelming feelings related to the disease, such as emotional eating or medication avoidance when reminded of their condition. The loadings vary; some items show moderate to strong association with the factor.

Controlled Illness Consciousness involves actively managing and controlling thoughts and reminders about one's illness. It shows how individuals either suppress or control their emotional responses to avoid being overwhelmed by the disease.

18. Table: Factor Structure and Loadings of AADQ Scale

FACTOR	Item	Loadings
Disease Denial	10. I avoid thinking about what the disease can do to me.	0,784
	8. I often deny to myself what the disease can do to my body.	0,696
	11. I avoid thinking about the disease because someone I knew died from the same disease.	0,677
	3. I do not take care of my disease because it reminds me that I have the disease.	0,635
Liminal Disengagement	7. I avoid stress or try to get rid of it by eating what I know I shouldn't eat.	0,828
	2. I have thoughts and feelings about having this disease that are distressing.	0,720
	4. I eat things I shouldn't eat when the urge to eat them is overwhelming.	0,622
	6. I avoid taking or forget to take my medication because it reminds me that I have disease.	0,531
	9. I don't exercise regularly because it reminds me that I have the disease.	0,459
Controlled Illness Consciousness	5. When I have an upsetting feeling or thought about my disease, I try to get rid of that feeling or thought.	0,791
	1. I try to avoid reminders of my disease.	0,523

source: edited by author

The next step involved validating this factor structure with a confirmatory factor analysis on the second random sample (n=250). The CFA results (see 19. Table) indicate a moderate fit of the model to the data. The RMSEA value is 0.087 (CI90% [0.068; 0.106], which suggests a moderate fit. The SRMR value is 0.073, which points to a satisfactory fit. The chi-square to Degrees of Freedom Ratio (χ^2/df) is 2.871, which indicates a good fit. The CFI and TLI values suggest that the model's fit could benefit from further improvement. These results indicate that the model fits reasonably well, although it is approaching the limit of acceptability. Further details of the CFA analysis are demonstrated in 6. Appendix.

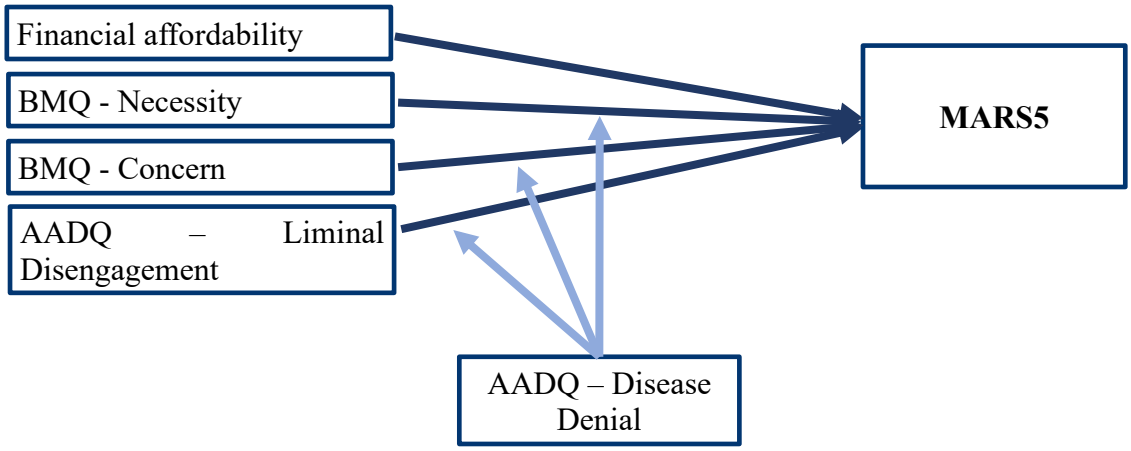
19. Table: CFA Fit Measures for ADDQ 3 Factor Structure

Fit Measures	
Metric	**Value**
Root mean square error of approximation (RMSEA)	0.087 CI90% [0.068; 0.106]
Standardised root mean square residual (SRMR)	0.073
X^2/df	2,871
Comparative Fit Index (CFI)	0.862
Tucker-Lewis Index (TLI)	0.800

source: edited by author

The three-factor AADQ structure was further integrated into a tailored PLS-SEM model (see 15. Figure). The Liminal Disengagement and Disease Denial dimensions were employed. Given its content similar to the INAS Resisting Illness, the Disease Denial Dimension was incorporated to capture the impact of liminality as a moderator effectively. Two items must have been deleted from Disease Denial and one from Liminal Disengagement due to their factor loadings below 0.4. The AVE for AADQ – Liminal Disengagement was 0.4413, Cronbach alfa 0.6476 and Jöreskog's rho 0.6711. The detailed results of the model can be seen in 5. Appendix. The overall explained variance of MARS5 was 0.391. Due to poor fit, convergent validity and reliability, another moderator was introduced in 6.3.5.1 chapter.

15. Figure: The Research Model of the Primary Study



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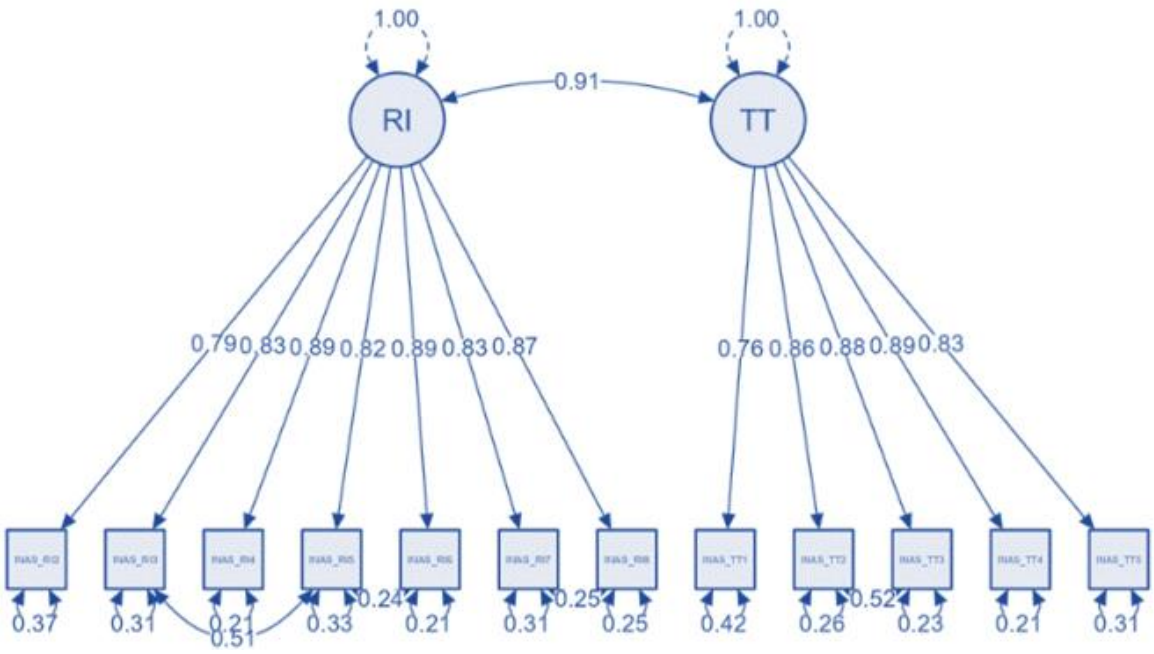
6.3.5 Building the Primary Research Model

6.3.5.1 Inventing INAS as a Potential Liminality Measure

As the AADQ scale was not proven reliable enough through the modelling procedure detailed in Chapter 6.3.4, the original starting point, the Intentional Non-Adherence Scale (INAS), was further employed as an illness acceptance measurement tool while modelling. Although several publications reference the INAS scale with various factor structures (see Chapter 3.2.6.3), none use a scale validation method. Therefore, the INAS scale was further investigated before initiating the primary modelling.

The dissertation uses the original factor dimensions (see 16. Figure) of intentional non-adherence, such as Resisting Illness and Testing Treatment. These two factors were strong enough through all factor studies covered in the literature structures (see Chapter 3.2.6.3). This structure was validated by a Confirmatory Factor Analysis as detailed below.

16. Figure CFA Factor structure of INAS scale



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The RMSEA value (0.078) (CI90% [0.067; 0.090]) suggests an acceptable fit, while the SRMR indicates a very good fit of the model (SRMR=0.025). The χ^2/df ratio is 4.055,

suggesting a moderate fit (between 3 and 5). The CFI (0.976) and TLI (0,967) values indicate a very good fit of the hypothesised model to the observed data. The model fit is good enough based on the most important fit measures (see 20. Table).

20. Table: CFA Fit Measures for INAS Factor Structure

Fit Measures	
Metric	**Value**
Root mean square error of approximation (RMSEA)	0.078 CI90% [0.067; 0.090]
Standardised root mean square residual (SRMR)	0.025
X^2/df	4,055
Comparative Fit Index (CFI)	0.976
Tucker-Lewis Index (TLI)	0.967

source: edited by author

The item loadings (see 21. Table) are above 0.7, ranging from 0,920 to 1,122, indicating an excellent fit to the tested model. This suggests that each item is a good measure of the underlying factor. Residual covariances are in 8. Appendix.

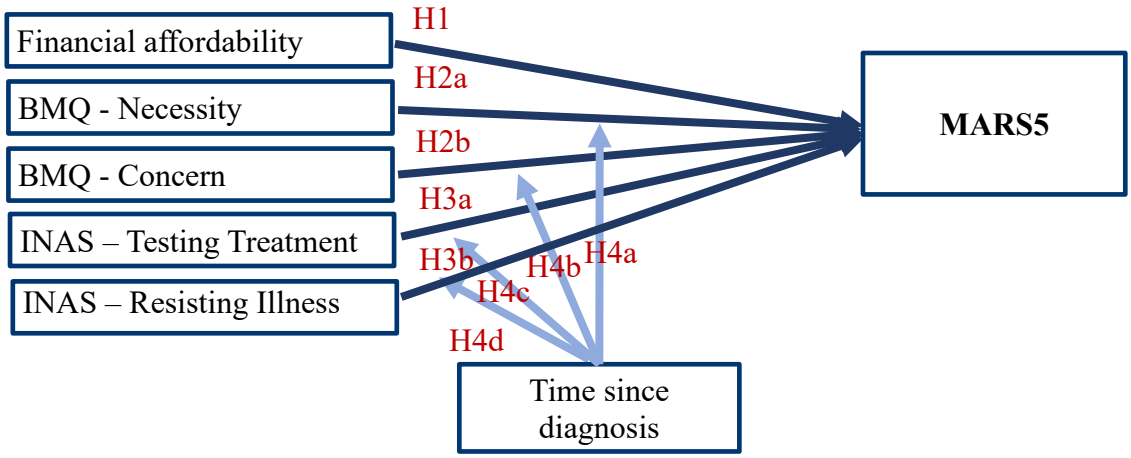
21. Table: CFA loadings for INAS Factor Structure

Factor loadings							
Factor	**Indicator**	**Estimate**	**Std. Error**	**z-value**	**p**	**95% Confidence Interval**	
						Lower	**Upper**
Resisting Illness	INAS_RI2	0.972	0.046	21.018	< .001	0.882	1.063
	INAS_RI3	1.099	0.049	22.533	< .001	1.003	1.195
	INAS_RI4	1.050	0.042	25.277	< .001	0.969	1.132
	INAS_RI5	1.122	0.051	21.959	< .001	1.022	1.223
	INAS_RI6	1.120	0.044	25.225	< .001	1.033	1.207
	INAS_RI7	1.031	0.046	22.429	< .001	0.941	1.121
	INAS_RI8	1.006	0.042	24.093	< .001	0.925	1.088
Testing Treatment	INAS_TT1	0.920	0.046	19.797	< .001	0.829	1.011
	INAS_TT2	1.014	0.043	23.720	< .001	0.930	1.097
	INAS_TT3	1.020	0.042	24.352	< .001	0.938	1.103
	INAS_TT4	1.015	0.040	25.057	< .001	0.935	1.094
	INAS_TT5	0.992	0.044	22.358	< .001	0.905	1.079

source: edited by author

A new variable, based on the qualitative findings, was introduced to the preliminary model to further develop it. As explained in qualitative findings, the time since diagnosis captures the liminal phase in the primary quantitative model (see 17. Figure).

17. Figure: The Research Model of the Primary Study



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6.3.5.2 Direct Effects on Medication Adherence

The direct effects observed in the primary quantitative model remain consistent with those identified in the preliminary model; thus, detailed literature support for the following five hypotheses can be found in Chapter 6.1.1.1, Chapter 6.1.1.2 and Chapter 6.1.1.3. These investigated direct effects are as follows:

> *H1: A worse financial situation (affordability) has a positive impact on medical non-adherence*
>
> *H2a: A stronger belief in the necessity of prescribed medications decreases non-adherence to the medication regimen.*
>
> *H2b: Increased concerns about prescribed medications result in higher levels of non-adherent behaviour.*
>
> *H3a: Increased questioning of treatment results in a higher level of non-adherent behaviour*
>
> *H3b: Increased level of illness rejection results in a higher level of non-adherent behaviour*

6.3.5.3 Moderating the Role of Time in Medication Adherence

Research demonstrates varied findings: some studies observe stable medication adherence rates over time, while others note significant fluctuations. For example, post-transplant studies on young adults and children reported unchanged medication adherence rates over 1.5 years (Loiselle et al., 2015). In contrast, another study on patients with ischemic stroke saw a notable decline in medication adherence rates over a year (Yoo et al., 2023).

Numerous studies suggest that the direct impact of time on medication adherence is either negligible or inconsistent. If not the direct effect but the influencing factors are examined, changes in medication beliefs over time can predict changes in medication adherence behaviours. Time influences medication adherence indirectly by altering patients' beliefs and attitudes towards their treatment (Schüz et al., 2011).

As demonstrated in the qualitative research (Chapter 6.2), the time passed since diagnosis helps in understanding how attitudes towards the disease and medications influence medication adherence. Over time, even those patients who initially resisted their condition and treatment tend to accept the necessity of medication and adhere more fully to their prescribed regimens.

> *H4a: The time since diagnosis positively moderates the effect of necessity beliefs on non-adherent behaviour.*
>
> *H4b: The time since diagnosis negatively moderates the effect of concern beliefs on non-adherent behaviour.*
>
> *H4c: The time since diagnosis negatively moderates the relationship of treatment testing on non-adherent behaviour.*
>
> *H4d: The time since diagnosis negatively moderates the effect of resisting illness on non-adherent behaviour.*

6.3.6 Evaluating Primary Model

Similar to the preliminary phase, the research's phenomena are latent constructs. Thus, structural equation modelling was employed to examine whether the hypotheses were accepted or rejected. PLS-SEM can explore the relationships of multiple latent variables.

In the primary modelling, two testing approaches are also examined: the measurement model is initially investigated to determine if the scales are reliable enough and represent the given constructs. The structural model helps to analyse the given structure and the direct and indirect effects concerning the hypothesised relationship between the latent constructs.

Since the methodological background is identical in the preliminary model and the primary model (PLS-SEM with ADANCO), the upcoming sections of the dissertation do not detail the methodological issues as they do in the detailed…. chapters. To avoid content duplication, the forthcoming chapters focus on the results and their meanings regarding the model and the hypothesis.

6.3.6.1 Measurement Model

For transparency, it is important to highlight that four items were excluded from the constructs for specific reasons:

- 'Item 6' from Affordability was removed due to the mistranslation covered in the preliminary phase. Instead, a new translation was realised in the primary phase, and item 7 was employed in the affordability construct. This item was reviewed and corrected in the primary quantitative research in a way that was mistranslated, and the original item was also included in the questionnaire separately.
- 'Item 3' and "Item 4' from the BMQ Necessity scale and 'Item 2' from the BMQ Concerns scale were removed because their loadings were below 0.4.

Reliability

The reliability indexes for each construct can be found in 22. Table. Based on these indexes, all constructs are deemed reliable. Each Cronbach's (α) alpha coefficient is above the 0.6 threshold (Malhotra & Simon, 2009), such as Jöreskorg's rho (ρc) is 0.7 (Jöreskog, 1971). Dijkstra-Henseler's rho (ρA) indexes are above the required 0,707 (Dijkstra & Henseler, 2015; Kemény et al., 2022).

Thus, all the constructs in the primary research can be considered reliable for measuring the intended phenomena: non-adherent medical behaviour (MARS5), financial affordability (AFF), concerns beliefs (BMQ_C), necessity beliefs (BMQ_N), testing-treatment (INAS_TT), and resisting illness (INAS_RI).

22. Table: Inner Reliability of Measurement Model

Construct	Dijkstra-Henseler's rho (ρA)	Jöreskog's rho (ρc)	Cronbach's alpha (α)
TRESHOLD	ρA>0,707	ρc>0,7	α>0,6
MARS	0.8742	0.8589	0.8551
AFF	0.9254	0.9200	0.9209
INAS_TT	0.9385	0.9288	0.9297
INAS_RI	0.9515	0.9499	0.9499
BMQ_N	0.7846	0.7469	0.7506
BMQ_C	0.8451	0.8295	0.8256

source: edited by author

Convergent validity

The measure of convergent validity, the Average Variance Extracted (AVE), represents the proportion of these indicators' variance accounted for by the latent variable. The threshold is 0.5, meaning the latent variable is unidimensional (Kemény et al., 2022).

MARS5, AFF, INAS_TT, INAS_RI, and BMQ_N capture the dimension as AVE values are higher than 0.5. This means that these constructs capture more than half of the variance of their respective indicators. BMQ Necessity has AVE values slightly below 0.5 (AVE=0,4986) (see 23. Table). It is essential to highlight that while the AVE for Necessity is slightly below the threshold, the difference is minimal. Therefore, the researcher evaluates it sufficiently. It is concluded that the model realises good convergent validity.

23. Table: Convergent Validity of the Constructs Based on the AVE Index

Convergent Validity	
Construct	The average variance extracted (AVE)
MARS	0.5549
AFF	0.6591
INAS_TT	0.7260
INAS_RI	0.7037
BMQ_N	0.5068
BMQ_C	*0.4986*

source: edited by author

Discriminant validity

Latent variables should represent distinct theoretical concepts. Discriminant validity measures whether a latent variable has a stronger relationship with its indicators than with the indicators of another latent variable (Henseler et al., 2015). The literature cites a range of thresholds for this assessment, including values below 1, 0.9, and 0.85.

As presented in 24. Table, the HTMT index for BMQ_C and BMQ_N is slightly above the 0,9 threshold (Franke & Sarstedt, 2018); all other latent construct pairs have sufficient HTMT values. This suggests that the constructs can be considered distinct, but the results concerning the two INAS scales might have limitations.

24. Table: HTMT Indices for Discriminant Validity

Discriminant Validity: Heterotrait-Monotrait Ratio of Correlations (HTMT)									
Construct	**MARS5**	**AFF**	**INAS_TT**	**INAS_RI**	**BMQ_N**	**BMQ_C**	**INAS_TT x time**	**INAS_RI x time**	**BMQ_N x time**
AFF	0,554								
INAS_TT	0,569	0,617							
INAS_RI	0,546	0,602	*0,907*						
BMQ_N	0,184	0,210	0,292	0,259					
BMQ_C	0,396	0,550	0,591	0,673	0,011				
mod_INASTTXyears	0,195	0,053	0,111	0,118	0,013	0,099			
mod_INASRIXyears	0,160	0,069	0,112	0,143	0,029	0,128	0,832		
mod_BMQNXyears	0,133	0,114	0,003	0,018	0,140	0,051	0,259	0,209	
mod_BMQCXyears	0,095	0,029	0,093	0,125	0,073	0,042	0,528	0,574	0,087

source: edited by author

Content validity

This preliminary study, like the preliminary study, assumes content validity since all applied scales originate from established literature.

Examining the structural model and assessing the hypotheses is suitable since all measurement fit criteria satisfy the requirements.

6.3.6.2 Structural Model

Using the SRMR indicator from the structural model, the measurement model evaluation starts by evaluating the model fit and concentrating on the variations between the

estimated and observed values. Path coefficients are next examined in terms of their significance and predicted effects. Cohen's f^2 quantifies the effects and shows their practical power. Lastly, the amount by which the exogenous constructs account for the variance of the endogenous construct is measured by the determination coefficient R^2 (For detailed results, see 25. Table).

Model fit

The study's SRMR value of 0.0446 suggests a good fit between the empirical and the estimated model (Dijkstra & Henseler, 2015; Kemény et al., 2022).

Path Coefficients

The path coefficient (β) between endogenous (dependent) and exogenous (independent) variables assesses the expected change in the dependent variable for a one-unit change in the independent variable, ceteris paribus. (Kemény et al., 2022). In the current model, two direct effects are significant, as Affordability and INAS Testing Treatment have a significant, positive impact on MARS5. Two moderation effects are also significant as time significantly decreases the effect of INAS Testing Treatment on MARS5 while time significantly increases the impact of BMQ necessity on MARS5.

Effects

The strength of the effects can be quantified using Cohen's f^2. The values might be categorised as follows:

a) < 0.02: negligible effect

b) 0.02–0.15: weak effect

c) 0.16–0.35: moderate effect

d) > 0.35: strong effect (Cohen, 1988)

The most substantial effect in the preliminary research model is weak: affordability (AFF) affects non-adherence (MARS5) with an f2 = 0.1233. The next most significant effect is the moderation effect of time on BMQ Necessity's impact on MARS5, with an f^2 = 0.0363. All other significant effects in the model are rather low.

Explanatory power

The model's explanatory power is represented by R^2, the proportion of variance in the endogenous construct explained by the exogenous constructs in the model. (Henseler et al., 2009). In the primary research model, MARS5 is the only endogenous latent, and the involved exogenous constructs explain 43,6% of non-adherent behaviour.

25. Table: Path Coefficients and Effect Size

Effect		Original coefficient	Standard bootstrap results		Percentile bootstrap quantiles		Effect
			t-value	p-value	2.5%	97.5%	Cohen's f^2
Direct effects	**AFF -> MARS**	0.3573	4.5823	0.0000	0.2184	0.5230	0.1233
	INAS_TT -> MARS	0.2612	1.8984	0.0579	-0.0030	0.5321	0.0200
	INAS_RI -> MARS	0.0946	0.5694	0.5692	-0.2525	0.3802	0.0023
	BMQ_N -> MARS	-0.0196	-0.4386	0.6610	-0.1161	0.0606	0.0006
	BMQ_C -> MARS	-0.0165	-0.1943	0.8460	-0.1578	0.1845	0.0002
Moderating effects	**INASTT_Xyears -> MARS**	-0.1443	-1.7724	0.0766	-0.3029	0.0129	0.0108
	INASRI_Xyears -> MARS	0.0707	0.7682	0.4426	-0.1155	0.2606	0.0025
	BMQN_Xyears -> MARS	0.1522	3.1206	0.0019	0.0488	0.2421	0.0363
	BMQC_Xyears -> MARS	-0.0235	-0.3071	0.7589	-0.1610	0.1379	0.0006

source: edited by author

To realise the results of the hypotheses, see 25. Table**13. Table** and 18. Figure**: Primary Quantitative Research Model - Graphical Results**.

H1: Worst financial situation (affordability) has a positive impact on medical non-adherence

The hypothesis is confirmed (t=4.582, p<0.001), indicating that individuals facing financial challenges with their medication tend to adhere less to their treatment regimen. This is the strongest effect in the model (f^2=0.123)

H2a: A stronger belief in the necessity of prescribed medications decreases non-adherence to the medication regimen.

The hypothesis is rejected (t=-0.439, p=0.661); beliefs about medication necessity have no proven effect on the level of non-adherence.

H2b: Increased concerns about prescribed medications result in higher levels of non-adherent behaviour.

The hypothesis is rejected (t=-0.194, p=0.846); more substantial concerns regarding the medication have no proven effect on the level of non-adherence.

H3a: Increased questioning of treatment results in a higher level of non-adherent behaviour

The hypothesis is confirmed at alpha=10% (t=1.898, p=0.058), indicating that patients who are more suspicious about their treatment tend to be more non-adherent to their treatment regimen. This effect in the model is weak (f^2=0.020)

H3b: Increased level of illness rejection results in a higher level of non-adherent behaviour

This hypothesis is rejected. Rejecting illness has no significant direct effect (t=-0,569, p=0.569) on the level of non-adherence.

H4a: The time since diagnosis positively moderates the effect of necessity beliefs on non-adherent behaviour.

This hypothesis is confirmed. There is a significant, positive moderation effect (t=3.1206, p=0.002), but the effect is weak (f^2=0.036). This indicates that patients who have been aware of their disease for a longer time have a more substantial decreasing effect of necessity beliefs on non-adherent behaviour compared to those who have a shorter disease history.

H4b: The time since diagnosis negatively moderates the effect of concern beliefs on non-adherent behaviour.

The hypothesis is rejected (t=-0.307, p=0.759), and there is no moderation effect.

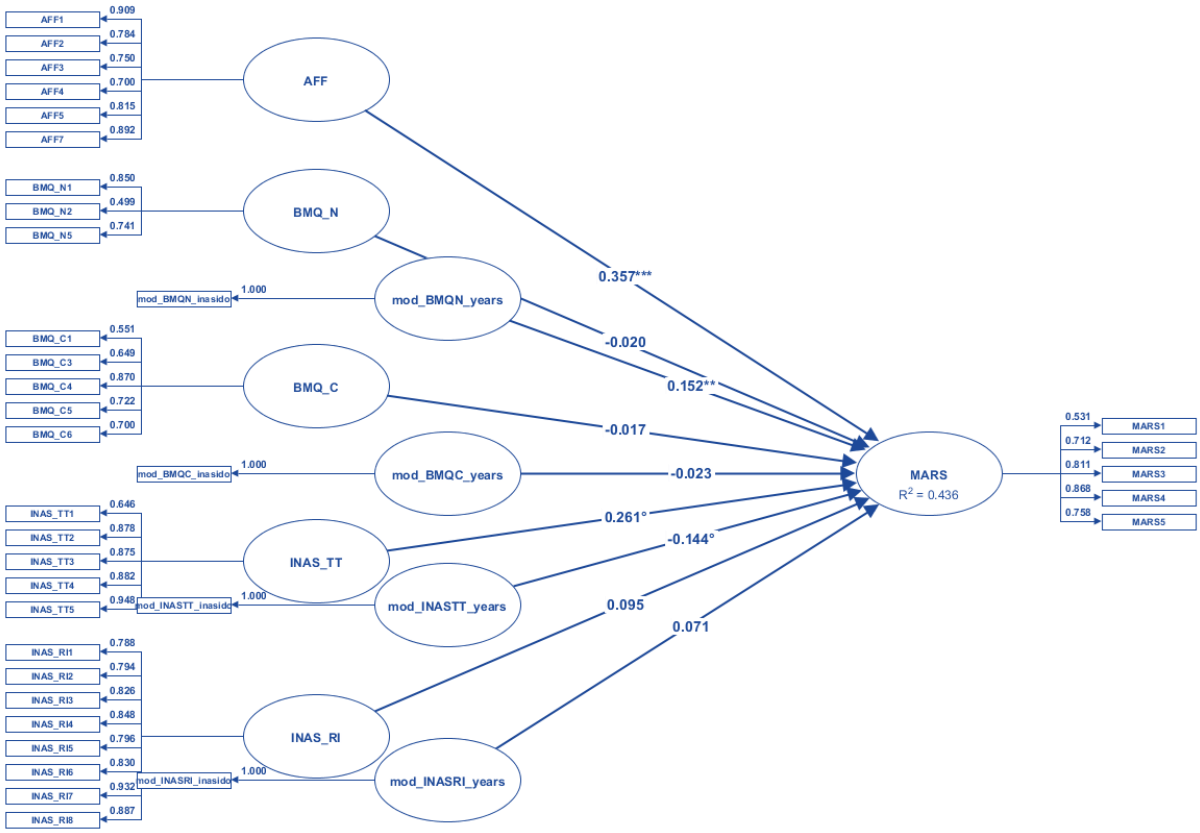
H4c: The time since diagnosis negatively moderates the relationship of treatment testing on non-adherent behaviour.

The hypothesis is confirmed (t=-1.772, p=0.0334) that there is a weak negative moderation effect of time (f^2=0,011). This indicates that patients who have been aware of their disease for a longer time have a stronger decreasing effect of necessity beliefs on non-adherent behaviour compared to those who have a shorter disease history.

H4d: The time since diagnosis negatively moderates the effect of resisting illness on non-adherent behaviour.

The hypothesis is rejected (t=0,768, p=0.443), and no moderation effect is proven.

18. Figure: Primary Quantitative Research Model - Graphical Results



source: edited by author

6.3.6.3 Moderation Analysis

To gain a deeper understanding of the effect of necessity beliefs on non-adherent behaviour and to analyse its non-significant direct effect, it is crucial to consider how time since diagnosis significantly and positively moderates this relationship. An insignificant direct effect suggests that, on average, across the sample, the belief in the necessity of medication does not significantly predict or influence medication adherence behaviour. However, the significant moderating effect indicates that the impact of necessity beliefs on medication adherence behaviour is not consistent across all conditions but varies depending on the time elapsed since diagnosis. This significant moderating effect implies that the influence of necessity beliefs on medication adherence behaviour does not uniformly manifest under all circumstances. Instead, it changes with the duration since diagnosis.

This variation highlights the importance of considering the time factor when assessing the impact of patient beliefs on medication adherence. The moderation analysis was conducted with JAMOVI software, with MARS5 as the dependent variable, BMQ Necessity as the independent variable, and time since diagnosis serving as the moderator (see 26. Table).

The direct effect of BMQ_N on non-adherent behaviour is significant. The negative estimate (-0,071) indicates that a firmer belief in the necessity of medications is associated with less non-adherent behaviour. Time has no direct effect on MARS5 (p=0,246). The interaction is statistically significant (p= 0.003), indicating that the effect of necessity beliefs on medication adherence behaviours is moderated by how long the patient has been diagnosed.

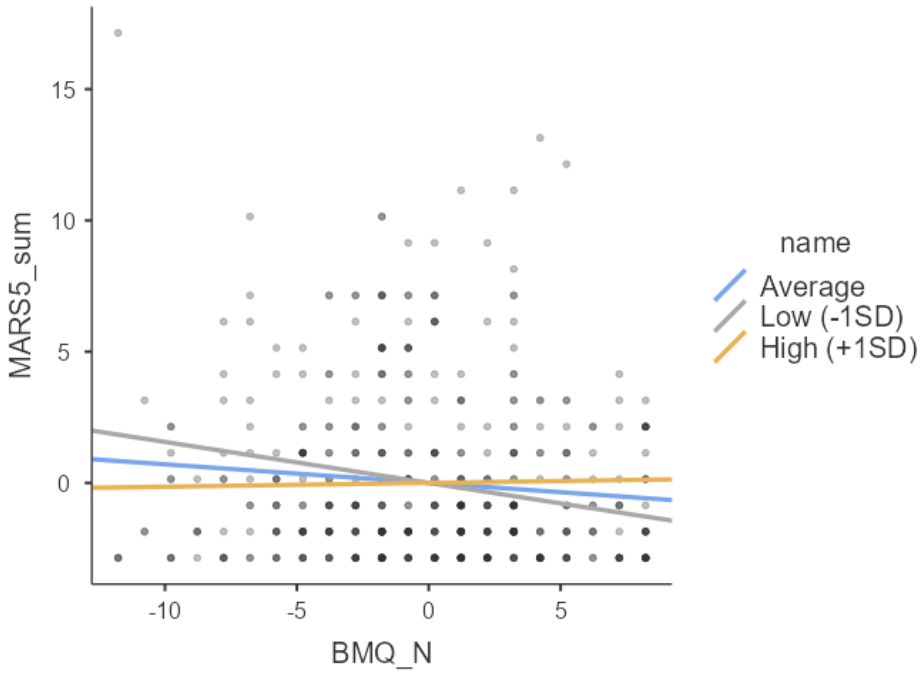
26. Table: Moderation Analysis in Case of BMQ_N

Moderation analysis			
dependent: MARS5	**B**	**Z**	**p**
BMQ_N	-0.071	-2.23	0.026
YEARS	-0.015	-1.16	0.246
BMQ_N ✻ YEARS	0.008	2.99	0.003

Source: edited by the author from JAMOVI output

Simple Slope analysis helps with further interpretation (see 19. Figure). The yellow line represents the slope of the relationship between necessity beliefs and non-adherence for patients who have been diagnosed for a longer time. The line is relatively flat, suggesting that increases in the belief in medication necessity have a minor impact on reducing non-adherence for these patients. The blue line represents the average time since diagnosis. The slope is slightly steeper, indicating a somewhat stronger relationship between necessity beliefs and non-adherence. The grey line represents patients more recently diagnosed with the steepest slope. This suggests that closer to diagnosis, the necessity beliefs have a more substantial protecting role against non-adherence. As a conclusion closer to the diagnosis, the impact of necessity beliefs on non-adherence is more pronounced, but this effect disappears over time.

19. Figure: Slope Analysis of the Moderating Effect of Time



Source: JAMOVI output

6.3.6.4 Summary and Conclusion

The research presents several findings related to medication adherence in chronic disease management:. The Acceptance and Action Diabetes Questionnaire (AADQ) was found to be not stable enough to serve as a mediator in the studied context. This instability suggests that the AADQ may require further refinement or validation for use in similar research settings.

The Intentional Non-Adherence Scale (INAS) was validated through Confirmatory Factor Analysis (CFA), confirming its reliability. However, the distinction between the two constructs measured by INAS can create challenges in interpretation.

Affordability was identified as a significant factor influencing non-adherence. The time elapsed since diagnosis was found to moderate the relationship between BMQ Necessity, non-adherence, and Testing Treatment vs. non-adherence.

7 INTERPRETATIONS AND CONCLUSIONS

7.1 Theoretical Contributions

In this concluding section, the findings from the empirical research phases are summarised and concluded, focusing on four main areas of measurement tools: direct effect on medication adherence, liminal moderators and pathways toward medication adherence. For summary of hypothesis also see 27. Table.

Measurement Tool Results

The Acceptance and Action Diabetes Questionnaire (AADQ), initially reported as unidimensional (Gregg et al., 2007), has revealed a more complex structure in this research. The AADQ scale was applied in general chronic disease wording instead of diabetes focus, and it was determined to have a three-dimensional factor structure through exploratory and confirmatory factor analyses. This result enhances understanding of patient medication adherence behaviours and the psychological processes underlying disease acceptance. The three identified dimensions are: ‘Disease Denial’ – capturing when patients actively avoid acknowledging their disease and its potential harm; ‘Liminal Disengagement’ - reflecting behaviours indicative when patients navigating the transitional space between health and disease, including coping strategies for dealing with overwhelming feelings related to the disease; ‘Controlled Illness Consciousness’ dimension shows how individuals either suppress or control their emotional responses to avoid being overwhelmed by the disease.

Validation of the Intentional Non-Adherence Scale (INAS) through Confirmatory Factor Analysis (CFA) based on the original framework (Weinman et al., 2018) not only confirms the INAS's reliability and structural integrity but also reinforces its applicability in assessing intentional non-adherence behaviours among patients with chronic illnesses. Understanding the nuances of intentional non-adherence can inform targeted interventions by adding depth to the theoretical understanding of intentional non-adherence.

Direct Effects on Non-adherence

Financial constraints significantly impact non-adherent behaviour in both model among patients with chronic diseases, underscored by the role of economic factors in patient medication adherence (ABC Project Team, 2012). Financial burdens can limit patients' ability to buy necessary medications, attend regular follow-up visits, or maintain a consistent

treatment regimen, directly leading to non-adherence (Ganguli & Thakore, 2021; ABC Project Team, 2012; McHorney & Spain, 2011). This result shifts the focus from purely medical or psychological models of non-adherence to include socio-economic factors similar to the research models of this dissertation.

The intentional Non-Adherence Scale (INAS) and the Beliefs about Medicines Questionnaire (BMQ) have different impacts on non-adherent behaviours since the INAS is a stronger predictor of non-adherence than the BMQ. Testing Treatment has a coherent increasing effect on non-adherent behaviour in both models (see Table 27). The INAS focuses on the intentional aspects of non-adherence, which suggests that non-adherence is often a conscious decision rather than merely a passive response influenced by beliefs. This finding challenges the traditional emphasis on patient beliefs (Horne, 2003) and underscores the importance of addressing patient intentions in medication adherence interventions. This result urges a shift in medication adherence models from a belief-centric framework to those that incorporate intentional behaviours.

Moderating Effects Capturing Liminality

"Resisting Illness" has a complex role in the context of medication adherence. Although the direct effect of resisting illness on non-adherence is ambivalent in the two models, its moderating effects are significant, decreasing the impact of "Testing Treatment" on non-adherence and strengthening the effect of "Concern" on non-adherence. This indicates that individuals who deny their illness are less likely to be non-adherent due to questioning their treatment. On the contrary, resisting illness intensifies the effect of concerns about medication on non-adherence. This could mean that patients who resist their illness yet have more concerns about their medication are more likely to exhibit non-adherent behaviours. This interaction highlights how resistance can exacerbate fears and worries about treatment, leading to avoidance of medication. This gave evidence that patient resistance to illness does not operate in isolation but interacts with other psychological factors to influence behaviour.

The moderating effects of time elapsed since diagnosis on non-adherence behaviours mainly focus on how these effects shape the impact of 'Testing Treatment' and the acceptance of treatment necessity. The findings highlight a dynamic aspect of patient medication adherence behaviour over time, showing a decrease in the influence of testing treatments on non-adherence while an increase in the acceptance of treatment necessity significantly mitigates non-adherence. As more time passes since a patient's diagnosis, the likelihood of engaging

in testing treatment behaviours—which involve experimenting with or questioning the efficacy of the prescribed treatment—decreases. This indicates that over time, patients develop a deeper understanding of the importance of their treatment, leading to better medication adherence. The decreasing effect of necessity on non-adherence is significantly closer to the diagnosis; as time progresses, this effect is eliminated. This is partially in line with Schüz et al., 2011 as time influences medication adherence indirectly by altering patients' beliefs and attitudes towards their treatment in case of necessity, but concern beliefs are not proven by primary quantitative research.

Path Toward Medication Adherence

The dissertation explores dual pathways to medication adherence. The first pathway involves patients who are naturally adherent from the beginning, either due to their nature or a deep understanding of their condition and the necessity of treatment. The second pathway involves those who initially resist treatment (Huyard et al., 2016) but become adherent following a significant health crisis or stronger symptoms. This reshapes their perception of their illness and the necessity of the treatment. It highlights how shock events can transform patient behaviour from non-adherence to adherence, which helps understand patient psychology.

There is a 'threshold' of medication denial represented by the initial resistance to starting any medication regimen. Overcoming this threshold involves a significant psychological adjustment where patients move from denial to acceptance. After this turning point, patients tend to accept additional medications more readily; therefore, the initial resistance to medication is a pivotal barrier that must be mainly only once crossed.

27. Table: Summary Table of Preliminary and Primary Quantitative Research

H		PATH		HYPOTHESIS		DECISION	
		PRELIMINARY (mod: INAS Resisting Illness)	PRIMARY (mod: Time since diagnosis)	PRELIMINARY	PRIMARY	PRELIMINARY	PRIMARY
DIRECT EFFECTS	**H1**	**AFF-> MARS5**		Worst financial situation (affordability) has a **positive** impact on medical non-adherence		**CONFIRMED**	**CONFIRMED**
	H2a	**BMQ_N_> MARS5**		A stronger belief in the necessity of prescribed medications **decreases** non-adherence to the medication regimen.		CONFIRMED	REJECTED
	H2b	**BMQ_C -> MARS5**		Increased concerns about prescribed medications result in **higher** levels of non-adherent behaviour.		CONFIRMED	REJECTED
	H3a	**INAS_TT -> MARS5**		Increased questioning of treatment results in a **higher** level of non-adherent behaviour		**CONFIRMED**	**CONFIRMED**
	H3b	**INAS_RI-> MARS5**		Increased level of illness rejection results in a **higher** level of non-adherent behaviour.		**REJECTED (sig but reverse)**	**REJECTED**
MODERATING EFFECTS	**H4a**	**BMQ_N**xINAS_RI -> MARS5	**BMQ_N**_Xyears -> MARS	Increased illness rejection **negatively** moderates the relationship between necessity beliefs and non-adherent behaviour.	The time since diagnosis **positively** moderates the effect of necessity beliefs on non-adherent behaviour.	**CONFIRMED**	**CONFIRMED**
	H4b	**BMQ_C**xINAS_RI -> MARS5	**BMQ_C**_Xyears -> MARS	Increased illness rejection **positively** moderates the relationship between concern beliefs and non-adherent behaviour.	The time since diagnosis **negatively** moderates the effect of concern beliefs on non-adherent behaviour.	**REJECTED**	**REJECTED**
	H4c	**INAS_TT**xINAS_RI -> MARS5	**INAS_TT**_Xyears -> MARS	Increased level of illness rejection **positively** moderates the relationship between treatment testing and non-adherent behaviour.	The time since diagnosis **negatively** moderates the relationship between treatment testing and non-adherent behaviour.	REJECTED (sig but reverse)	CONFIRMED
	H4d	-	**INAS_RI**_Xyears -> MARS	-	The time since diagnosis **negatively** moderates the effect of resisting illness on non-adherent behaviour.	-	REJECTED

7.2 Practical Implications

The findings of this dissertation offer several practical implications, especially in the critical liminal period following a diagnosis. Tailored interventions can have a strong impact on patient outcomes.

Addressing patients' beliefs about medications early in their treatment is essential to ensuring better medication adherence (Unni et al., 2015). To boost medication adherence, programs intended for this purpose should begin at the onset of therapy. At this crucial time, patients form their beliefs and views about their prescribed medications and the necessity of following their treatment protocols. Early implementation of these interventions can help improve these mindsets, increasing patients' chances to follow their recommended therapies (Petrilla et al., 2005). Healthcare providers should prioritise establishing a strong therapeutic relationship during the initial phase. Engaging patients with clear but empathetic communication about their condition and the necessary treatments contributes to non-adherence. Educating patients about the consequences of non-adherence and the benefits of staying on the prescribed regimen during this time is crucial. To do so, they must be trained (White et al., 2013).

The results underscore the importance of influencing patients' rational understanding of their treatment. Knowledge expansion programs explain how medications work. These programs might be supported by marketing communication tools that build on patient stories to make the results of medication adherence and non-adherence more lifelike (Hackley et al., 2021) and foster identification.

It is crucial to provide additional support for patients experiencing financial difficulties. This might include access to financial counselling and assistance programs to ensure that financial barriers do not hinder medication adherence. Policies that reduce the economic burden of chronic disease management are also needed.

Implementing these practical strategies requires a coordinated effort among healthcare providers, communicators, and policymakers. Medication adherence rates can be improved by focusing on the critical period following diagnosis and continuously adapting to patients' changing needs. This not only enhances patient health outcomes but also contributes to the overall effectiveness of the healthcare system in managing chronic diseases.

7.3 Limitations

In this dissertation, while providing insights into medication adherence, several limitations should be considered.

The study employed a cross-sectional design, which limits the ability to infer causality. The data was self-reported, which may lead to an overestimation of medication adherence rates (Ágh et al., 2024). Participants may have reported higher medication adherence due to recall bias or social desirability bias. Most of the interviewees were not in their liminal stage during the data collection; there is a chance for retrospective bias.

The scales used to measure the concept of liminality, particularly the INAS Resisting Illness and AADQ, raised certain methodological concerns that may affect the reliability and validity of the results.

While the multimorbid nature of the sample aids in generalising the findings, it also overlooks the specific characteristics of individual disease groups. The sample consisted exclusively of Hungarian patients. This geographical limitation restricts the generalizability of the findings to other cultural or healthcare contexts.

Data was collected online during the quantitative research phases. This method restricted participation to individuals with access to the necessary technology, internet services, and digital literacy, potentially excluding a significant portion of the target population.

7.4 Further Research Recommendations

Based on the limitations identified, future research directions emerge. By addressing these specific aspects, future research can provide deeper insights into effective strategies for improving medication adherence.

Future research should employ longitudinal designs to track changes in medication adherence over time. Incorporating measures of how patients initially perceive their illness severity and symptom strength could provide context for understanding medication adherence trajectories. Examining specific disease groups separately would help identify unique medication adherence patterns and challenges that may vary between different diseases.

There is a need to develop a stable disease acceptance and/or denial scale. This scale should be designed to measure acceptance across various chronic conditions and cultural settings accurately.

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Appendices

1. Appendix: Research Ethics Approval

BUDAPESTI CORVINUS EGYETEM

Corvinus University of Budapest
Office of the Vice-Rector for Research
Research Ethics Committee
H-1093 Budapest, Fővám tér 8.

File number: KRH/118/2024
Administrator: Krisztián Ágai
Extension: 5196
Attachment: -

Principal Researcher: Kun Zsuzsanna PhD student
Unit: Institute of Marketing and Communication Sciences
Email: zsuzsanna.kun@uni-corvinus.hu
Project title: Exploring the impact of liminality on medication adherence.

DECLARATION

On the basis of the fully completed review questionnaire and the supporting professional documents relating to the submitted request for research ethics approval the Committee grants the request and

grants the research ethics approval for the research.
The research shall be conducted in accordance with the review questionnaire.

JUSTIFICATION

The Committee's assessment is as follows:

The attached documents such as the project plan worked out for the referred application, the declaration form designed for this purpose and fully completed by the applicant are compliant with the principles formulated in article (6) of the *Provisions of the Rector* ***No 2/2020. (V. 26.)*** *on setting up the CUB Ad Hoc Research Ethics Committee, and on issuing research ethics permissions*, which governs these provisions and the planned research is in accordance with the CUB's research strategy and institution building plan. *Please note that the declaration forms issued in the annexes 2.a, 2.b and 2.c of the referred Provisions of the Rector shall be completed and signed in all cases during the course of the research.* The decision set out in the operative part was made by the Committee on its meeting of April 11th, 2024.

Budapest, April 15th, 2024

CORVINUS UNIVERSITY OF BUDAPEST L. 8.

Dr. Zoltán Oszkár Szántó
Vice-Rector for Research
Chair of the Research Ethics Committee

2. Appendix: Qualitative Interview Guide

Introduction

Thank you for agreeing to participate in this interview. Today's discussion aims to understand better the habits and factors influencing how individuals take prescribed medication.

This interview contributes to a doctoral dissertation written by Zsuzsanna Kun from Corvinus University of Budapest (Hungary).

Please be assured that all the information you provide will be kept confidential and anonymous and that your participation is voluntary. You have the freedom to withdraw at any time without any consequences. Also, with your permission, we would like to record this conversation to ensure we accurately capture your experiences. Do I have your consent to proceed with recording this interview?

Ask for consent on the recording when the recording has started.

Warming-up

- Could you introduce yourself a little? *(age, nationality, profession, family situation, hobbies, etc.)*
- Can you tell me about your journey with your health condition? *(Do you have any chronic illness? For how long? Do you take medications?)*
- How does your health condition affect your everyday life?
- How do you feel about your current health condition?
- Is there anything concerning your health condition (illness) that bothers you? *(if yes:)* Could you explain?

  If not mentioned in the warming-up discussion:
  - *What kind of diagnoses does the interviewee have?*
  - *Since when (years)?*
  - *How many types of medication does the interviewee take?*
  - *How many times a day does the interviewee take?*

Medication taking

- Can you tell me a bit about your journey with your medication?
- How would you describe the time when you had to start to take your first regular medication?
- How do you feel about your medications?

- How would you describe your current stage in managing your medication?
- How do you feel about taking medications regularly?

Adherence

- Was there any situation when you changed your medication by your decision? (did stop it, or take less dose, other) *(if yes:)* Why? Can you explain them?
- Are there any situations when something prevents you from taking medication properly? *(if yes:)* Can you explain them?
- What factors can provide you support in taking your medication more appropriately? *(family members, devices, health providers, etc.)*
- If you had to rate yourself from 1 to 10, where 1 means you do not follow your doctor's prescriptions, and 10 means you do everything according to your doctor's prescriptions, what score would you give yourself? Why?

Medication in changing situations

- How do changes in your work or personal life influence your medication-taking habits? Can you share an example?
- During these transitional phases, how did you perceive your health and medication needs?
- How do you manage your medication during these transitional phases?
- What factors can support you in taking your medication more properly while being in life changes?
- Is there anything how healthcare providers should help you manage your medication during these difficult periods?

Closing

Is there anything else you would like to share about your experiences with medication taking during transitional periods?

Thank you for your participation, time, and contribution to the research.

Remember to be flexible with the guide, allowing follow-up questions based on participant responses.

3. Appendix: Modification List After Questionnaire Pilot Test (Hungarian)

Kedves …..!

Alább találhatóak a módosítandó részek a kérdőívben a kérdőív sorszámaira hivatkozva:

D8: keresetünkből HELYETTE: keresetünkből / nyugdíjunkból

Az 1-10-ig tartó kérdések esetén (K1, K4, K10, K11) érdemes lenne már a kérdésbe beleírni, hogy mi lesz majd az 1-10 jelentése, mert nagyon sokat kell görgetnie a végső válaszig. Illetve felmerül a kérdés, hogy itt nem tudnának-e megjelenni a lehetőségek vízszintesen inkább)

K2, K3 kérdéseknél jelezni kell, hogy a vitamin NEM tartozik ide.

K2: Hányféle gyógyszert szed naponta? (kérjük, adja meg a számot) (Kérem, a vitaminokat NE számolja bele!)

K3: Naponta hány darab tablettát/kapszulát kell szednie? (kérjük, adja meg a számot) (Kérem, a vitaminokat NE számolja bele!)

K8: Meg kell jelennie a „másodlagosan" kiválasztott betegségeknek is a listában.

K9: Szükséges egy kiegészítése, hogy még mindig a legsúlyosabb betegségére gondoljon

Hány éve diagnosztizálták Önnél ezt a betegséget? (Kérem, az ön által legsúlyosabbnak ítélt betegségére gondoljon!)

K10-nél szintén szükséges: (Kérem, az ön által legsúlyosabbnak ítélt betegségére gondoljon!)

K12-től a skálás kérdések esetében (K18-ig!) az utolsó NT/NV opciót töröljük, legyen kötelező.

K12 – betegségelfogadás blokk esetében javaslom megváltoztani a Soha-Mindig végpontokat: Egyáltalán nem igaz rám – Teljes mértékben igaz rám

A kérdést is meg kell válaszolni

K15 – INAS felvezető szöveg esetében az elmúlt 6 hónap zavart okozott annál, aki nem változtatott semmit a gyógyszerelésén.

Kérjük, a következő állításoknál jelölje be mindegyiknél azt, hogy az állítás mennyire volt érvényes Önre az elmúlt 6 hónapban. HELYETTE: Kérjük, a következő állításoknál jelölje be mindegyiknél azt, hogy az állítás mennyire érvényes Önre.

Ugyanitt: vastagítani inkább ezt kellene: Időnként szüneteltetem a gyógyszereim szedését, mert…

A felette levő rész lehet sima betűvel.

K16 – BMQ. javaslat: Ezek a gyógyszerek rejtélyesek a számomra. HELYETTE Ezek a gyógyszerek érthetetlenek a számomra.

4. Appendix: Questionnaire – Primary Quantitative Stage

Dear Sir/Madam,

……. The panel is conducting research related to chronic diseases. The results will be aggregated for statistical purposes only! Completing the questionnaire takes approximately 20 minutes.

To complete the questionnaire, you will receive 200 points. If you do not meet the research screening criteria, we will give you 10 points for starting the questionnaire.

Above/below some questions, you will find instructions to assist with filling them out. At various points, the filling program checks the answer provided during the completion process and will notify you if it is not appropriate. Suppose you see a "Your answer is incomplete" or "Invalid number" message. In that case, you cannot proceed to the next question until you have responded to the current one or provided an understandable answer. If you select the "other" option, the program expects you to type in your specific thoughts in the provided space.

You may interrupt the questionnaire at any time. To resume answering, log back into your email account and click on the link, continuing from where you left off.

We are expecting responses from a total of 500 participants, after which the survey will be closed.

Thank you for sharing your opinion with us!

Should you have any questions or issues related to the research or the completion process, please email..... We will respond to your email as soon as possible.

DEMOGRAPHY

1. **What is your gender:**
   □ Female
   □ Male

2. **How old are you?** *(filter: above 18 years)(dropdown from 1 to 99)*
   □ □

3. **Please provide your postal code:**
   □ □ □ □

4. **What is your highest level of education?**
   □ elementary school
   □ high school without graduation
   □ high school with graduation
   □ MsC/BsC/postgraduate

5. What is your family status?

□ single
□ in a relationship / married
□ divorced /separated
□ widow(er)

6. How many members live in your household, including you?

…… *(dropdown from 1-20 persons)*

7. What is your employment status *(single choice)*

□ full-time employee
□ part-time employee
□ unemployed
□ self-employed / entrepreneur
□ retired
□ student
□ Other, please specify: _____

8. Which of the following categories best describes your household? *(single choice)*

□ we live without worries, and we can regularly save money
□ we manage well with our income, and occasionally, we can save money
□ we have no living problems, but we cannot save money
□ we barely get by on our monthly income
□ we have financial issues month after month

8B. Taking everything into account, what was the net income per capita in your household last month?

□ 50.001-75.000 forint
□ 75.001-100.000 forint
□ 100.001-150.000 forint
□ 150.001-200.000 forint
□ 200.001-250.000 forint
□ 250.001-300.000 forint
□ 300.001-350.000 forint
□ above 350.000 forint
□ I don't know / I don't answer

HEALTH STATUS

9. Have you been diagnosed with any of the following *(multiple choice) (filter: if none, then end of the questionnaire)*

□ diabetes
□ hypertension
□ Musculoskeletal disorder (spinal problems, arthritis, rheumatism, etc.)
□ high-cholesterol
□ cardiovascular disease
□ none of the above

10. Are you currently taking any medication(s) for the treatment of your chronic illness? *(filter: if no, then end of questionnaire)*

- □ yes
- □ no

11. Have you been diagnosed with any other illness? *(multiple choice)*

- □ I do not have any other diseases besides those mentioned above.
- □ Osteoporosis
- □ Asthma
- □ Allergy
- □ Cancer
- □ Liver disease
- □ Other, please specify: _____

12. How would you generally describe your health status? Please rate it on a scale from 1 to 10, where 1 means "poor" and 10 means "excellent."

1 – poor …….10 – excellent

13. How many different medications do you take daily? (Please specify the number. Do not include vitamins!)

…… *(dropdown from 1 to 99)*

14. How many tablets/capsules do you need to take daily? (Please specify the number. Do not include vitamins!)

…… *(dropdown from 1 to 99)*

15. For you, taking medications on an average day is...
(Please rate on a scale from 1 to 10, where 1 means "Not at all unpleasant" and 10 means "Very unpleasant")

1 – Not at all unpleasant …….10 – Very unpleasant

16. In what form do you regularly need to take your medications? *(Multiple choice)*

- □ Oral (tablet/capsule/solution/syrup)
- □ Insulin injection
- □ Insulin pump
- □ Asthma inhaler ("puff")
- □ Drops (e.g., eye, ear, nasal drops)
- □ Patch (transdermal medication)
- □ Other, please specify: _____

17. How many times a day do you need to take medication? *(single choice)*

- □ Once a day
- □ Twice a day
- □ Three times a day
- □ Four times a day
- □ Five times a day
- □ Six times a day
- □ Seven or more times a day

18. Who ensures that you take your medications properly? *(multiple choice)*

- □ Myself
- □ A family member living with me
- □ Family member not living with me
- □ Healthcare personnel (doctor, nurse, caregiver)
- □ Other, please specify: _____

19. Which do you consider to be the most severe illness? *(List only those already selected in questions 9 or 11. Do not ask this question to those who have only one diagnose.)*

If you have been diagnosed with multiple illnesses, for the following questions, please think about the disease you consider to be the most severe.

20. How many years ago were you diagnosed with this illness? (Please think of the illness you consider the most severe!)

…… *(dropdown from 1 to 99)*

21. In your opinion, how severe is this illness? (Please think of the illness you consider the most severe!) Please rate it on a scale from 1 to 10, where 1 means "Not severe at all" and 10 means "Very severe".

1 – Not severe at all ..... 10 – Very severe

22. In your opinion, as time progresses, how do you think your health condition will change due to your illness? Please rate on a scale from 1 to 10, where 1 means "Will improve" and 10 means "Will worsen."

1 – Will improve ..... 10 – Will worsen

SCALES

23. Please indicate how often the following statements occur with you. *(one answer per line)*

	AADQ	1 (not true at all)	2	3	4	5 (absolutely true)
AADQ1	I try to avoid reminders of my disease.					
AADQ2	I have thoughts and feelings about being diabetic that are distressing.					
AADQ3	I do not take care of my disease because it reminds me that I have the disease.					
AADQ4	I eat things I shouldn't eat when the urge to eat them is overwhelming.					

AADQ5	When I have an upsetting feeling or thought about my disease, I try to get rid of that feeling or thought.					
AADQ6	I avoid taking or forgetting to take my medication because it reminds me that I have the disease.					
AADQ7	I avoid stress or try to get rid of it by eating what I know I shouldn't eat.					
AADQ8	I often deny to myself what disease can do to my body.					
AADQ9	I don't exercise regularly because it reminds me that I have the disease.					
AADQ10	I avoid thinking about what disease can do to me.					
AADQ11	I avoid thinking about the disease because someone I knew died from the disease.					

24. People take their medications in various ways, which may differ from the doctor's instructions or what is written on the label. We want to ask you a few questions about how you take your medication. Below, we have described some examples that people have mentioned in relation to taking medication.
For each statement, please mark the point that best fits you. Your method of taking medication: *(one answer per line)*

	MARS5	1 (never)	2 (rarely)	3 (sometimes)	4 (often)	5 (always)
MARS1	I forgot to take the medicine.					
MARS2	I alter the dose of medicine.					
MARS3	I stopped taking the medicine for a while					
MARS4	I decided to miss out on a dose.					
MARS5	I take less than instructed.					

25. Please indicate to what extent the following statements are true for you! *(one answer per line)*

	AFF	1 (never)	2 (rarely)	3 (sometimes)	4 (often)	5 (always)
AFF_1	If I am worried about money, I take less of my medicine to make it last longer.					
AFF_2	I have to leave getting my prescription dispensed until I get paid.					

AFF_3	If I have a number of different items on my prescription, I do not get them all dispensed because I cannot afford them all at once					
AFF_4	In the past, I borrowed money to pay for my prescription medicines.					
AFF_5	Knowing that I will not be able to afford the prescription stops me from going to see my doctor.					
AFF_6	I ask my general practitioner to prescribe a larger quantity of medication, enough for several months, so that I don't have to buy medication when I no longer have enough money.					
AFF_7	If I cannot afford my prescription, I do not get my medicine dispensed at all.					

26. People have different experiences when taking medication and use their medications in ways which suit them. Sometimes, people forget or decide not to take their medication for various reasons. We are interested in your personal views and experiences of your prescribed medication regime and the way you use your medications.
All of the information you provide is confidential. There are no right or wrong answers to these questions – an answer is correct if it is true for you. We are most interested in your own opinion. Please choose the response that best fits your circumstances.

Listed below are some of the reasons why people sometimes stop taking their medications. We would like to know how often each of the following statements is true for you. For each statement please tick (□) one box which best represents you. *(one answer per line)*

	INAS	1 (strongly disagree)	2	3	4	5 (strongly agree)
TT_1	To see if my illness is still there					
TT_2	To see if I can do without it					
TT_3	To see if I really need it					
TT_4	Because I am not convinced that the medicine is really right for me					
	Because I am not sure that the doctor chose the right medicine for me					
TT_5	To give my body a rest from the medicine					
	Because the medicine is harsh on my body					

	Because I don't like the medicine to accumulate in my body					
RI_1	Because my body is sensitive to the effects of medicine					
	Because I don't like the side effects					
	Because I don't like chemicals in my body					
	Because it may affect the body's natural healing processes					
	Because I think I am on too high a dose					
	Because I think the drug might become less effective over time					
RI_2	Because I worry about becoming dependent on my medicine					
RI_3	Because I want to think of myself as a healthy person again					
RI_4	Because it reminds me that I have an illness					
RI_5	Because I want to lead a normal life again					
RI_6	Because it is good not to have to remember					
RI_7	Because it is inconvenient to take all the time					
RI_8	Because the drug schedule doesn't fit with my lifestyle					
	Because I don't think the treatment is worth it					

27. Now, we would like you to share your personal opinion about the medications prescribed to you. These are statements that other people have made about their medications. Please indicate how much you agree or disagree with the statements by clicking on the appropriate point. There are no right or wrong answers. We are interested in your personal opinion. *(one answer per line)*

Your opinion about THE MEDICATIONS PRESCRIBED TO YOU:

	BMQ	1 (strongly not agree)	2 (not agree)	3 (uncertain)	4 (agree)	5 (strongly agree)
N_1	My health, at present, depends on my medicines.					
C_1	Having to take medicines worries me.					
N_2	My life would be impossible without my medicines.					
C_2	I sometimes worry about the long-term effects of my medicines.					
N_3	Without my medicines, I would be very ill.					
C_3	My medicines are a mystery to me.					

N_4	My health in the future will depend on my medicines.					
C_4	My medicines disrupt my life.					
C_5	I sometimes worry about becoming too dependent on my medicines.					
N_5	My medicines protect me from becoming worse.					
C_6	These medicines give me unpleasant side effects.					

5. Appendix: ADDQ Moderated Model Results

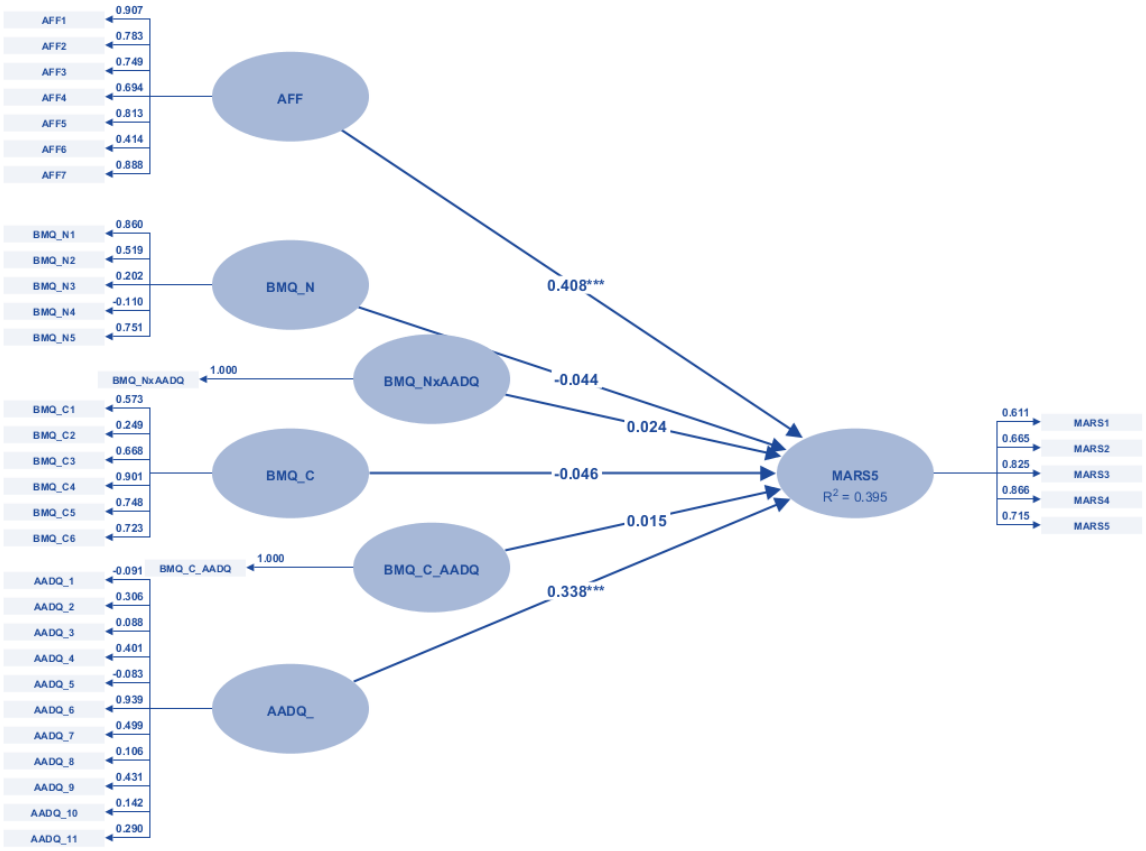
Construct Reliability			
Construct	**Dijkstra-Henseler's rho (ρA)**	**Jöreskog's rho (ρc)**	**Cronbach's alpha (α)**
TRESHOLD	**ρA>0,707**	**ρc>0,7**	**α>0,6 (Malhotra)**
MARS5	0.8701	0.8581	0.8551
AFF	0.9225	0.9048	0.8995
BMQ_C	0.8640	0.8203	0.8334
BMQ_N	0.7940	*0.5942*	0.8625
INAS_TT	0.7863	*0.4965*	*0.6918*

Convergent Validity	
Construct	Average variance extracted (AVE)
MARS5	0.5515
AFF	0.5857
BMQ_C	*0.4552*
BMQ_N	*0.3252*
AADQ	***0.1554***

Discriminant Validity: Heterotrait-Monotrait Ratio of Correlations (HTMT)							
Construct	**MARS5**	**AFF**	**BMQ_N**	**BMQ_C**	**BMQ_NxAADQ**	**BMQ_C_AADQ**	**AADQ**
MARS5							
AFF	0.5583						
BMQ_N	0.1102	0.0959					
BMQ_C	0.3638	0.5074	0.1581				
BMQ_NxAADQ	0.0055	0.0237	0.1513	0.0705			
BMQ_C_AADQ	0.1867	0.1788	0.0560	0.1052	0.2259		
AADQ	0.3460	0.2904	0.1435	0.4693	0.0998	0.2039	

LOADINGS					
Construct	**Indicator**	**loading**	**Construct**	**indicator**	**loading**
AADQ	AADQ_1	-0.0915	AFF	AFF1	0.9070
	AADQ_2	0.3063		AFF2	0.7834
	AADQ_3	0.0878		AFF3	0.7492
	AADQ_4	0.4013		AFF4	0.6940
	AADQ_5	-0.0830		AFF5	0.8132
	AADQ_6	0.9385		AFF6	0.4140
	AADQ_7	0.4991		AFF7	0.8878
	AADQ_8	0.1057	BMQ_C	BMQ_C1	0.5729
	AADQ_9	0.4314		BMQ_C2	0.2490
	AADQ_10	0.1417		BMQ_C3	0.6675
	AADQ_11	0.2895		BMQ_C4	0.9015
MARS5	MARS1	0.6113		BMQ_C5	0.7481
	MARS2	0.6648		BMQ_C6	0.7232
	MARS3	0.8249	BMQ_N	BMQ_N1	0.8600
	MARS4	0.8663		BMQ_N2	0.5192
	MARS5	0.7147		BMQ_N3	0.2018
MOD	BMQ_NxAADQ	1.0000		BMQ_N4	-0.1097
MOD	BMQ_C_AADQ	1.0000		BMQ_N5	0.7512

Direct Effects Inference						
Effect	**Original coefficient**	**Standard bootstrap results**				
		Mean value	**Standard error**	**t-value**	**p-value (2-sided)**	**p-value (1-sided)**
AFF -> MARS5	0.4077	0.4015	0.0647	6.3069	0.0000	0.0000
BMQ_N -> MARS5	-0.0437	-0.0544	0.0503	-0.8675	0.3859	0.1929
BMQ_C -> MARS5	-0.0461	-0.0514	0.0780	-0.5914	0.5544	0.2772
BMQ_NxAADQ -> MARS5	0.0245	0.0305	0.0556	0.4404	0.6597	0.3299
BMQ_C_AADQ -> MARS5	0.0151	0.0099	0.0569	0.2661	0.7902	0.3951
AADQ_ -> MARS5	0.3381	0.3595	0.0846	3.9951	0.0001	0.0000


AFF1
AFF2
AFF3
AFF4
AFF5
AFF6
AFF7
0.907
0.783
0.749
0.694
0.813
0.414
0.888
AFF
BMQ_N1
BMQ_N2
BMQ_N3
BMQ_N4
BMQ_N5
0.860
0.519
0.202
-0.110
0.751
BMQ_N
BMQ_NxAADQ
1.000
BMQ_C1
BMQ_C2
BMQ_C3
BMQ_C4
BMQ_C5
BMQ_C6
0.573
0.249
0.668
0.901
0.748
0.723
BMQ_C
BMQ_C_AADQ
1.000
AADQ_1
AADQ_2
AADQ_3
AADQ_4
AADQ_5
AADQ_6
AADQ_7
AADQ_8
AADQ_9
AADQ_10
AADQ_11
-0.091
0.306
0.088
0.401
-0.083
0.939
0.499
0.106
0.431
0.142
0.290
AADQ_
0.408***
-0.044
0.024
-0.046
0.015
0.338***
MARS5
R2 = 0.395
0.611
0.665
0.825
0.866
0.715
MARS1
MARS2
MARS3
MARS4
MARS5

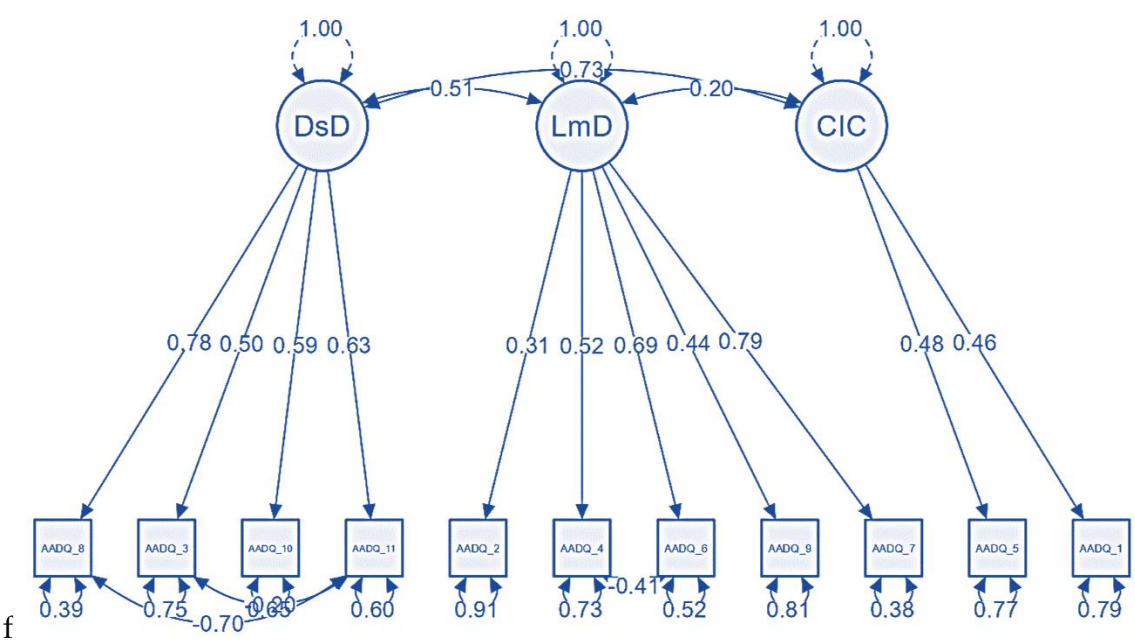
6. Appendix: CFA Results for AADQ

Factor loadings							
Factor	Indicator	Estimate	Std. Error	z-value	p	95% Confidence Interval	
						Lower	Upper
Disease Denial	**AADQ_8**	0.997	0.089	11.257	< .001	0.824	1.171
	AADQ_3	0.646	0.090	7.137	< .001	0.468	0.823
	AADQ_10	0.740	0.083	8.971	< .001	0.579	0.902
	AADQ_11	0.876	0.120	7.316	< .001	0.642	1.111
Liminal Disengagement	**AADQ_2**	0.418	0.093	4.496	< .001	0.236	0.600
	AADQ_4	0.728	0.099	7.339	< .001	0.534	0.923
	AADQ_6	0.794	0.077	10.274	< .001	0.643	0.946
	AADQ_9	0.595	0.092	6.477	< .001	0.415	0.775
	AADQ_7	1.023	0.082	12.516	< .001	0.863	1.183
Controlled Illness Consciousness	**AADQ_5**	0.579	0.111	5.207	< .001	0.361	0.797
	AADQ_1	0.625	0.123	5.089	< .001	0.384	0.865

Residual covariances							
		Estimate	Std. Error	z-value	p	95% Confidence Interval	
						Lower	Upper
AADQ_4	↔ AADQ_6	-0.407	0.086	-4.734	< .001	-0.575	-0.238
AADQ_3	↔ AADQ_11	-0.233	0.118	-1.980	0.048	-0.464	-0.002
AADQ_8	↔ AADQ_11	-0.591	0.125	-4.727	< .001	-0.836	-0.346

Model plot

f



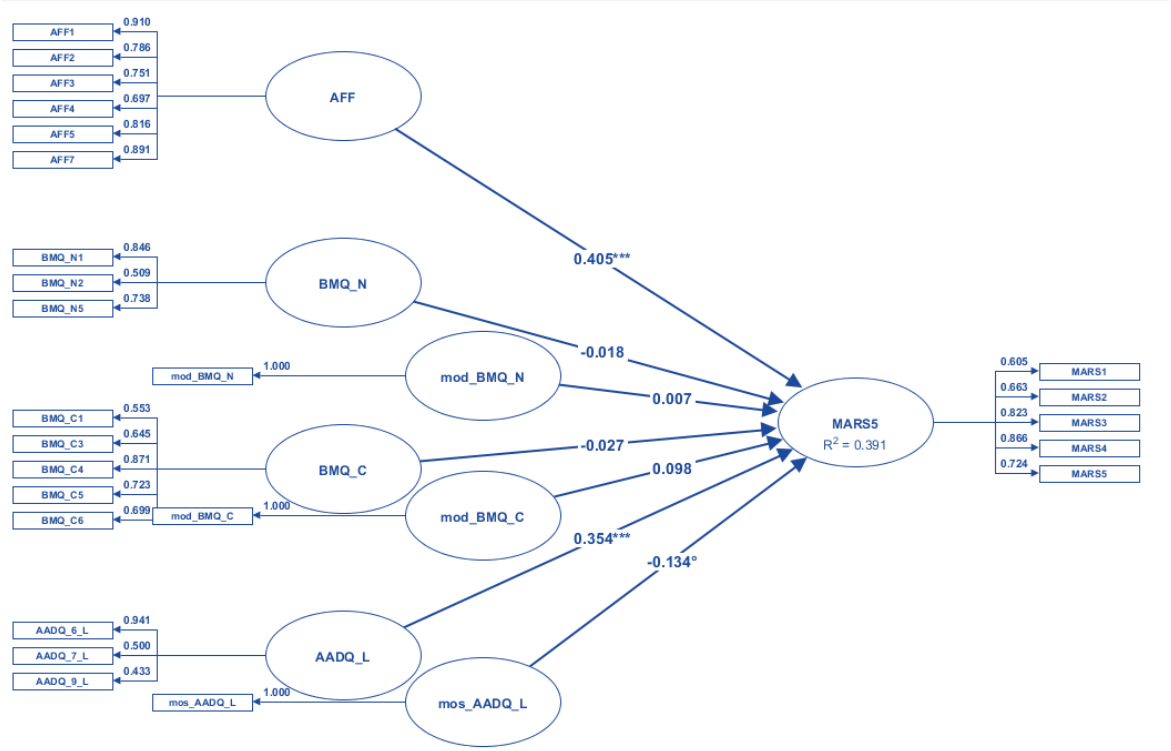
7. Appendix: AADQ – Disease Denial Moderated Model Results

Construct Reliability			
Construct	**Dijkstra-Henseler's rho (ρA)**	**Jöreskog's rho (ρc)**	**Cronbach's alpha (α)**
TRESHOLD	**ρA>0,707**	**ρc>0,7**	**α>0,6 (Malhotra)**
MARS5	0.8703	0.8582	0.8551
AFF	0.9254	0.9200	0.9209
BMQ_N	0.7820	0.7476	0.7506
BMQ_C	0.8453	*0.8295*	0.8256
AADQ_L	0.7989	*0.6771*	*0.6476*

Convergent Validity	
Construct	Average variance extracted (AVE)
MARS5	0.5518
AFF	0.6591
BMQ_N	0.5067
BMQ_C	*0.4987*
AADQ_L	*0.4413*

Discriminant Validity: Heterotrait-Monotrait Ratio of Correlations (HTMT)					
Construct	**MARS5**	**AFF**	**BMQ_N**	**BMQ_C**	**AADQ_L**
MARS5					
AFF	0.5536				
BMQ_N	0.1838	0.2095			
BMQ_C	0.3956	0.5498	0.0114		
AADQ_L	0.5230	0.5557	0.2346	0.6932	

LOADINGS		
Construct	**Indicator**	**MARS5**
AADQ	AADQ_LD_6	0.9412
	AADQ_LD_7	0.5005
	AADQ_LD_9	0.4329
AFF	AFF1	0.9098
	AFF2	0.7860
	AFF3	0.7515
	AFF4	0.6967
	AFF5	0.8157
	AFF7	0.8909
BMQ_C	BMQ_C1	0.5535
	BMQ_C3	0.6453
	BMQ_C4	0.8713
	BMQ_C5	0.7230
	BMQ_C6	0.6992
BMQ_N	BMQ_N1	0.8453
	BMQ_N2	0.5097
	BMQ_N5	0.7386
MARS5	MARS1	0.6051
	MARS2	0.6676
	MARS3	0.8304
	MARS4	0.8619
	MARS5	0.7174



8. Appendix: Further CFA Results for INAS

Residual covariances								
			Estimate	Std. Error	z-value	p	95% Confidence Interval	
							Lower	Upper
INAS_RI3	↔	INAS_RI5	0.298	0.032	9.251	< .001	0.235	0.361
INAS_TT2	↔	INAS_TT3	0.176	0.024	7.408	< .001	0.129	0.222
INAS_RI5	↔	INAS_RI6	0.108	0.021	5.093	< .001	0.067	0.150
INAS_RI7	↔	INAS_RI8	0.102	0.023	4.463	< .001	0.057	0.147

9. Appendix: Related Publications

Kemény, Ildikó; Kun, Zsuzsanna; Simon, Judit; Kulhavi, Nikoletta; Henseler, Jörg: Új lendület a PLS-SEM alkalmazásában az üzleti kutatások terén : Avagy hazai helyzetkép, szószedet és a módszertani korlátok feloldása VEZETÉSTUDOMÁNY 54 : 1 pp. 2-13. , 12 p. (2023)

Kemény, Ildikó; Kulhavi, Nikoletta Márta; Kun, Zsuzsanna: A távorvoslás igénybevételét befolyásoló tényezők a COVID-19 járvány miatti félelem tükrében STATISZTIKAI SZEMLE 100 : 1 pp. 7-43. , 37 p. (2022)

Kun, Zsuzsanna; Simon, Judit; Kemény, Ildikó; Rojkovich, Ádám Konstantin; Pusztai, Tamás: The difference in the level of adherence along medication preferences In ESPACOMP 2023: Medication Adherence from Drug Development to Patient Care Budapest, Magyarország: International Society for Medication Adherence (ESPACOMP) (2023) 95 p. pp. 90-90. , 1 p.

Simon, J.; Kemény, I.; Kun, Zs. ; Weinman, J.: Intentional non-adherence in chronic illness before and during the COVID-19 pandemic INTERNATIONAL JOURNAL OF CLINICAL PHARMACY 45: 1 pp. 278-279. , 2 p. (2023)

Kemény, Ildikó; Székely, Alíz; Rojkovich, Ádám Konstantin; Kun, Zsuzsanna; Simon, Judit Factors influencing the adaption implementation of telehealth during the COVID-19 pandemic In EMCB 2022 Conference Proceedings (2022) pp. 61-62. , 2 p.

Kemény, Ildikó; Kun, Zsuzsanna; Kulhavi, Nikoletta Márta; Rojkovich, Ádám Konstantin; Simon, Judit: The role of COVID anxiety in case of intention to use e-health services In: EMAC 2022 Annual: Proceedings of the European Marketing Academy (2022) Paper: A2022-107635

Kun, Zsuzsanna; Pusztai, Tamás; Kemény, Ildikó; Kovács, Bence; Simon, Judit: Clustering Patients According to their Medication Preference based on Conjoint Analysis In: EMAC 2022 Annual: Proceedings of the European Marketing Academy (2022) Paper: A2022-107659

Simon, Judit; Kemény, Ildikó; Kun, Zsuzsanna; Weinman, John: Intentional non-adherence in chronic illness before and during the COVID-19 pandemic In: Espacomp 2022 Abstract book (2022) p. 91, 1 p.

Kemény, Ildikó ; Simon, Judit ; Berezvai, Zombor ; Kun, Zsuzsanna: Marketingkutatás kvantitatív módszerei: Segédanyag SPSS program használatához Budapest, Magyarország : Budapesti Corvinus Egyetem (2021) , 80 p.

Kun, Zsuzsanna: Az egészségügyi szolgáltatás elfeledett tényezője: a pénzügyi lehetőségek: avagy a páciens anyagi lehetőségeinek hatása a gyógyszeres adherenciára - a szolgáltatásmarketing nézőpontja In: Molnár, Dániel; Molnár, Dóra (szerk.) Tavaszi Szél 2021 / Spring Wind 2021. Tanulmánykötet I.

Kun, Zsuzsanna ; Kulhavi, Nikoletta ; Kemény, Ildikó Helyzetkép a SEM módszertan alkalmazásáról a hazai tudományos üzleti folyóiratokban In: Mitev, Ariel; Csordás, Tamás; Horváth, Dóra; Boros, Kitti (szerk.) “Post-traumatic marketing: virtuality and reality” – Proceedings of the EMOK 2021 International Conference Budapest, Magyarország : Corvinus University of Budapest (2021) 558 p. p. 87 , 1 p.

Kun, Zsuzsanna; Kemény, Ildikó; Simon, Judit: The relationship between financial affordability and patient behaviour in medication adherence In: Proceedings of the 50th

Annual Conference of the European Marketing Academy (2021) pp. 1-11. Paper: A2021-94739 , 11 p.

Simon, Judit; Kemény, Ildikó; Kun, Zsuzsanna; Weinman, John: Investigating the Intentional Non-adherence Scale - modelling and scale validation INTERNATIONAL JOURNAL OF CLINICAL PHARMACY 43: 1 p. 302 (2021)

Zsuzsanna, Kun; Kulhavi, Nikoletta Márta; Ildikó, Kemény Status report on application of SEM methodology in Hungarian management journals In: 12th EMAC Regional Conference (2021) Paper: online

Kun, Zsuzsanna ; Simon, Judit: BMQ - az egészségügyi szolgáltatás sikerének egyik indikátora In: Ercsey, Ida (szerk.) Marketing a digitalizáció korában : Az Egyesület a Marketing Oktatásért és Kutatásért XXVI. Országos konferenciájának előadásai Győr, Magyarország : Széchenyi István Egyetem (2020) pp. 545-555. , 11 p.

Simon, Judit; Kun, Zsuzsanna: How marketing can handle chronic diseases as an effect on the household as a consumption community In Malhotra, Naresh K; Čater, Barbara; Marinov, Marin Alexander; Bodlaj, Mateja; Zečević, Mila (szerk.) Growing Business in Emerging Markets: Challenges and Drivers for Success: EMCB 2020 Conference Proceedings Ljubljana, Szlovénia: University of Ljubljana, School of Economics and Business (2020) 107 p. pp. 56-58. , 3 p.

Kun, Zsuzsanna: Szakterületi nézőpontok háromszöge a krónikus betegségek háztartási fogyasztásra gyakorolt hatása kapcsán In: Veres, Zoltán; Sasné, Grósz Annamária; Liska, Fanny (szerk.) Ismerjük a vevőt? : A vásárlás pszichológiája : Az Egyesület a Marketingoktatásért és Kutatásért XXV. Országos konferenciájának előadásai Veszprém, Magyarország : Pannon Egyetem (2019) 795 p. pp. 767-779. , 13 p.