

## Understanding social inequality in ischemic heart disease from a psychosocial perspective

*A qualitative study of the influence of psychosocial factors on socially disadvantaged patients' lived experience of life with ischemic heart disease*

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# **UNDERSTANDING SOCIAL INEQUALITY IN ISCHEMIC HEART DISEASE FROM A PSYCHOSOCIAL PERSPECTIVE**

**BY  
AMANDA NIKOLAJEW RASMUSSEN**

**DISSERTATION SUBMITTED 2021**



**AALBORG UNIVERSITY**  
DENMARK



# **UNDERSTANDING SOCIAL INEQUALITY IN ISCHEMIC HEART DISEASE FROM A PSYCHOSOCIAL PERSPECTIVE**

A QUALITATIVE STUDY OF THE INFLUENCE OF PSYCHOSOCIAL  
FACTORS ON SOCIALLY DISADVANTAGED PATIENTS' LIVED  
EXPERIENCE OF LIFE WITH ISCHEMIC HEART DISEASE

by

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**AALBORG UNIVERSITY**  
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## CV

Amanda Nikolajew Rasmussen holds a bachelor's degree from 2014 and a master's degree from 2017 in Anthropology from Aarhus University. During her training as an anthropologist, Amanda has gained experience and expertise within qualitative methods, medical anthropology, and research with vulnerable patients.

From 2017-2018, Amanda worked as a work environment consultant at Norddjurs Municipality. Through this employment, she developed an interest in the influence of structural, social, and psychosocial conditions on health and well-being.

Since 2018, Amanda has been enrolled as a PhD Fellow at the Public Health and Epidemiology Group at the Department of Health Science and Technology at Aalborg University. Her PhD project is funded by the Karen Elise Jensen Foundation and centers on the role of psychosocial factors on social inequality in ischemic heart disease. During her PhD fellowship, Amanda has supervised and held lectures for students studying for the bachelor's degree in Medicine and the master's degree in Public Health at Aalborg University. Furthermore, Amanda has disseminated the insights gained from her PhD project through participation in international academic conferences, including an oral presentation at the British Sociological Association's Annual Medical Sociological Conference 2019 and an oral presentation at the European Public Health Association's 16th World Public Health Congress 2020.

As a part of her PhD project, Amanda was a Visiting Research Scholar at the Social Science Group at the Department of Population Health Sciences at King's College London between August 2019 and November 2019. The group is specialized in research that deploys a social science perspective to public health issues. During her stay, Amanda was under supervision by Dr. Andrew Guise, who provided valuable guidance in her project and contributed to two of her articles. Furthermore, Amanda participated in the group's activities and held a lecture at the master's program in Public Health at King's College London. This affiliation continues, with ongoing discussion about future research projects after the PhD.





# ENGLISH SUMMARY

## Background

Social inequalities in the health and well-being of patients living with ischemic heart disease constitute a growing public health problem. When trying to understand and intervene on these inequalities, research and policies often emphasize individually oriented factors, such as the patient's lifestyle or health literacy. Nevertheless, studies indicate that psychosocial factors may play a more fundamental role in these inequalities. However, in-depth studies on the influence of psychosocial factors on social inequality in ischemic heart disease are lacking.

## Overall objective

The overall objective of this PhD study is to provide an in-depth understanding of social inequality in ischemic heart disease by exploring the influence of underlying psychosocial factors on socially disadvantaged patients' lived experience of life with ischemic heart disease.

## Sub-studies

The study is operationalized in three sub-studies with three individual research aims:

- Sub-study 1 aims to explore the role of social support from close social relationships in socially disadvantaged patients' lived experience of life with ischemic heart disease
- Sub-study 2 aims to explore socially disadvantaged ischemic heart patients' lived experience of healthcare interactions through the lens of the theoretical framework of cultural health capital
- Sub-study 3 aims to explore the influence of psychosocial stress on life with ischemic heart disease for socially disadvantaged patients at midlife

## Methods

The PhD study was designed as an in-depth qualitative study. The critical hermeneutic approach, as outlined by Paul Ricoeur, constitutes the philosophy of science of the study. Data were collected through in-depth qualitative interviews and supplementary observations. The data collection was conducted in Denmark between October 2018 and August 2019. Using a purposeful sampling strategy, 30 socially disadvantaged ischemic heart patients were included through an adjunct survey study. Sub-study 1 is based on data from interviews with all 30 participants, sub-study 2 also draws on data from interviews with all 30 participants as well as supplementary observations, and sub-study 3 relies on data from interviews of 18 of the 30 participants who were between 40-60 years old. The analysis and interpretation of data were performed using a critical hermeneutic approach, including three steps: naïve reading, structural analysis, and critical interpretation and discussion.

**Findings**

The findings of the study showed that the socially disadvantaged participants were confronted with straining external psychosocial stressors related to their social relationships, financial and occupational situation, healthcare interactions, and experiences of stigmatization. Furthermore, the participants seemed to lack the resources and thus the ability to cope with these stressors. They therefore experienced a burden of psychosocial stress, which affected their mental and physical health and well-being as well as their motivation to follow their medical treatment and adhere to lifestyle recommendations. However, in some cases, a few of the participants gained important support from close social relationships or healthcare professionals, which made their lives with ischemic heart disease less stressful.

**Conclusion and implications for practice**

This study highlights important psychosocial factors influencing the socially disadvantaged patients' experience of life with ischemic heart disease. Furthermore, the study showed how these meso-level psychosocial factors connected macro-level social factors to micro-level individual factors with importance for the socially disadvantaged patients' health and well-being. While existing studies on social inequality in ischemic heart disease tend to focus on individually oriented factors, such as lifestyle or health literacy, and to deploy quantitative study designs, the present study contributes with a psychosocial and in-depth understanding of the complex mechanisms that drive social inequality in ischemic heart disease. The study indicates that socially disadvantaged ischemic heart patients and their families should be accommodated occupationally and financially, supported in their efforts to cope with the stress of illness, and met by healthcare professionals in an acknowledging and non-judgmental way.

# DANSK RESUME

## Baggrund

Social ulighed i sundhed og trivsel blandt patienter, der lever med iskæmisk hjertesygdom, udgør et stigende folkesundhedsmæssigt problem. Forskning og politiske initiativer, som har forsøgt at forstå og reducere disse uligheder, har ofte fokuseret på individuelt orienterede faktorer, såsom patientens livsstil og sundhedskompetence. Studier har dog indikeret, at psykosociale faktorer kan spille en mere grundlæggende rolle i denne ulighed. Der er dog mangel på dybdegående studier, som undersøger psykosociale faktorerers indflydelse på social ulighed i iskæmisk hjertesygdom.

## Studiets overordnede formål

Det overordnede formål med dette Ph.d.-studie er at bidrage til en dybere forståelse af social ulighed i iskæmisk hjertesygdom ved at undersøge underliggende psykosociale faktorerers indflydelse på socialt belastede patienters levede oplevelse af livet med iskæmisk hjertesygdom.

## Delstudier

Studiet er operationaliseret i tre delstudier med hvert sit formål:

- Formålet med delstudie 1 er at undersøge, hvilken rolle social støtte fra tætte sociale relationer spiller i socialt belastede patienters levede oplevelse af livet med iskæmisk hjertesygdom
- Formålet med delstudie 2 er at undersøge socialt belastede iskæmiske hjertepatienters levede oplevelse af sundhedsplejende interaktioner ved brug af teori om kulturel sundhedskapital
- Formålet med delstudie 3 er at undersøge, hvilken indflydelse psykosocial stress har på livet med iskæmisk hjertesygdom for socialt belastede patienter mellem 40-60 år

## Metoder

Ph.d.-studiet er designet som et dybdegående kvalitativt studie. Den kritiske hermeneutiske tilgang, som beskrevet af Paul Ricoeur, udgør studiets videnskabsteoretiske ramme. Data blev indsamlet gennem dybdegående interviews og ved hjælp af supplerende observationer. Dataindsamlingen blev udført i Danmark mellem oktober 2018 og august 2019. Ud fra en formålsrettet tilgang til sampling blev 30 socialt belastede iskæmiske hjertepatienter rekrutteret gennem et tilknyttet survey-studie. Delstudie 1 er baseret på data fra interviews med alle 30 deltagere, delstudie 2 bygger på data fra interviews med alle 30 deltagere og supplerende observationer, og delstudie 3 tager udgangspunkt i data fra interviews med 18 af de 30 deltagere, som alle var mellem 40-60 år. Analysen og fortolkningen af data blev udført med

anvendelse af en kritisk hermeneutisk tilgang, der inkluderer tre trin: naïv læsning, strukturanalyse og kritisk fortolkning og diskussion.

### **Resultater**

Resultaterne viste, at de socialt belastede deltagere blev konfronteret med betyngende eksterne psykosociale stressorer, der var relateret til deres sociale relationer, finansielle og beskæftigelsesmæssige situation, sundhedsplejende interaktioner og stigmatisering. Deltagerne syntes desuden at mangle ressourcerne, og dermed evnerne, til at mestre disse stressorer. De oplevede derfor en overvældende byrde af psykosocialt stress, som havde indflydelse på deres mentale og fysiske helbred samt deres motivation til at følge behandling og overholde anbefalinger til livsstil. Nogle af deltagerne fik dog, i få tilfælde, vigtig støtte fra tætte sociale relationer eller sundhedsprofessionelle, hvilket gjorde deres liv med iskæmisk hjertesygdom mindre stressfuldt.

### **Konklusion og implikationer for praksis**

Dette studie fremhæver vigtige psykosociale faktorer, som havde en stor indflydelse på de socialt belastede patienters oplevelse af livet med iskæmisk hjertesygdom. Studiet viste desuden, hvordan disse psykosociale faktorer på et mesoniveau forbandt sociale faktorer på et makroniveau til individuelle faktorer på et mikroniveau, samt hvordan dette havde indflydelse på de socialt belastede iskæmiske hjertepatienters sundhed og trivsel. Tendensen i eksisterende studier om social ulighed i iskæmisk hjertesygdom er at fokusere på individuelt orienterede faktorer såsom livsstil eller sundhedskompetence og bruge kvantitative studiedesigns. I modsætning hertil giver dette Ph.d.-studie en psykosocial og dybdegående forståelse af de komplekse mekanismer, der driver social ulighed i iskæmisk hjertesygdom. Studiet indikerer, at socialt belastede iskæmiske hjertepatienter og deres familier bør imødekommes arbejdsmæssigt og finansielt, støttes i deres forsøg på at mestre den stress, der følger med sygdommen, samt mødes af sundhedsprofessionelle på en anerkendende og ikke-dømmende måde.

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During my time as a PhD student, I was fortunate enough to spend three months as a Visiting Research Scholar at the Social Science Group at the Department of Population Health Sciences, King's College London. I would like to thank the research group for welcoming me and inviting me to join your professional and social activities during my stay. A special thanks to Andy Guise who took me under his wings and contributed with valuable insights and perspectives to two of my articles and the PhD project in general.

Furthermore, I wish to thank the Karen Elise Jensen Foundation for recognizing the importance of this study, contributing to it financially, and thereby making it possible.

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# CHAPTER 1. INTRODUCTION

## 1.1. SOCIAL INEQUALITY IN ISCHEMIC HEART DISEASE

Ischemic heart disease is one of the diseases that contributes most to social inequality in health worldwide (Havranek et al., 2015). Social inequality exists both in the risk factors for, incidence and prevalence of, mortality from, and life with ischemic heart disease (Beauchamp et al., 2010; Havranek et al., 2015; Kelli et al., 2019; Korda et al., 2016).

Ischemic heart disease is a heart condition where plaque builds up in the coronary arteries, which hardens and narrows the arteries. This inhibits the flow of oxygen-rich blood and creates an imbalance between oxygen demand and oxygen supply to the heart (Severino et al., 2020). Ischemic heart disease is a chronic, progressive disease that can translate into an unstable acute and life-threatening condition at any time, typically due to plaque disruption and blood clot formation. This may cause unstable angina pectoris or a heart attack (Jensen et al., 2020).

The cause of ischemic heart disease is considered to be a combination of age, genetic predispositions, and environmental factors, such as lifestyle or stress (Severino et al., 2020). Medical treatment of ischemic heart disease and prevention of the occurrence and reoccurrence of heart attacks focus on surgical procedures, medication, and lifestyle changes (Joseph & Teo, 2011; Severino et al., 2020). Patients living with ischemic heart disease are affected by the illness mentally and physically to a variable degree. While many patients experience physical limitations, discomfort in the chest, or mental health issues such as anxiety or depression, others experience no nuisances (Morys et al., 2016).

Social differences in ischemic heart disease are referred to in various ways in the academic literature (Kawachi et al., 2002). Throughout this dissertation, when referring to social differences in ischemic heart disease, the term ‘social inequality’ will be used, drawing on Paula Braveman’s definition of the concept:

*“Health disparities/inequalities are potentially avoidable differences in health (or in health risks that policy can influence) between groups of people who are more and less advantaged socially; these differences systematically place socially disadvantaged groups at further disadvantage on health”* (Braveman, 2006, p. 180).

Braveman’s definition is less normative and political than Whitehead’s well-known definition of ‘health inequity’, referring to “*differences which are unnecessary and avoidable but, in addition, are also considered unfair and unjust*” (Whitehead, 1992, p. 5). Still, Braveman’s definition refers to social differences that are “*potentially avoidable*” and which “*policy can influence*” and thus does not include natural and unavoidable differences, such as the greater prevalence of cardiovascular disease among 80-year-olds than among 20-year-olds (Braveman, 2006).

This PhD study applies Braveman's definition of social inequalities in health, as her definition is neither purely normative nor completely objective. The scope of this study is not to provide a political report but to explore the problem in a scientific way. However, the study is not, and can never be, objective. The study therefore recognizes social inequality in ischemic heart disease as a problem and provides suggestions to actions that may reduce it.

## **1.2. SOCIAL INEQUALITY IN THE EXPERIENCE OF LIFE WITH ISCHEMIC HEART DISEASE**

Research shows that ischemic heart patients with low socioeconomic status experience worse physical functioning, poorer mental health and health-related quality, and more comorbidity than patients with high socioeconomic status (Barbareschi et al., 2009; Matetic et al., 2020; Nobel et al., 2017). This inequality in the health and well-being of patients living with ischemic heart disease constitute a growing public health problem, which may be related to the rising prevalence of people living with ischemic heart disease since the 1970s (Havranek et al., 2015). Significant improvements in prevention and treatment since the 1970s have contributed to a general decrease in mortality from ischemic heart disease (Havranek et al., 2015). During this time, an increase in the general prevalence of ischemic heart disease has been seen as the decrease in mortality means that ischemic heart disease, for some patients, has shifted from being a fatal to becoming a chronic disease; more people are therefore living with the disease without immediately dying from it (Havranek et al., 2015). Furthermore, within this growing group of people living with ischemic heart disease, significant social differences have been reported (Havranek et al., 2015).

Studies of social inequalities in life with ischemic heart disease tend to use quantitative study design and be based on patient-reported outcomes (PROMs) collected by use of standardized measurement tools (Badaricén et al., 2020; Nobel et al., 2017; Schultz et al., 2018; Shahu et al., 2020). Several generic assessment tools exist enabling exploration of the patient's perceived quality of life, symptoms and functional status, feelings and attitude about illness as well as their experience of healthcare (Forestier et al., 2019). For example, Nobel et al (2017) used the MOS 36-item short-form health survey (SF-36) (Larsson, 1997) and the Seattle Angina Questionnaire (SAQ) (Spertus et al., 1995) to show that patients with low socioeconomic status had a worse health-related quality of life after hospitalization for acute coronary syndromes than patients with a higher socioeconomic status in Massachusetts and Georgia, USA. The use of such assessment tools makes it possible to understand the magnitude of the social differences within and across geographical areas. Furthermore, quantitative study designs facilitate exploration of casual relationships by adjusting for potential confounders (Williams & Elliott, 2010). Nevertheless, the in-depth experience of living with ischemic heart disease and the complex influence of social and psychosocial factors on the individual's experience are difficult to capture through quantitative study designs (Williams & Elliott, 2010).

Social inequality in life with ischemic heart may also be studied with the use of qualitative research designs and exploration of the patient's experience. Medical anthropologist Arthur Kleinman, a pioneer within the field of patient experiences, contended that to thoroughly understand the causes of disease and to effectively heal them, the illness experience is essential (Kleinman, 1988). He distinguished between the terms 'illness', meaning the patient's personal experience of discomfort and pain, and 'disease', meaning the objective biomedical understanding of the patient's problem (Kleinman, 1980). Throughout this dissertation, these terms will be used to describe events of illness and disease, respectively. Furthermore, Kleinman used ischemic heart disease as an example to demonstrate the importance of understanding the illness experience. He argued that ischemic heart disease should not just be understood as narrowed coronary arteries but also as a dynamic dialectic between cardiovascular processes, psychosocial stress, and environmental situations. The illness experience provides insights into these dialectics (Kleinman, 1988). Decades later, Williams and Elliot (2010) argued, in line with this, that focusing on patient experiences in studies of social inequality in health provides understandings of the complex links between personal lives, history, social contexts, and wider social structures.

A few studies have explored social inequality in life with ischemic heart disease from a qualitative patient experience perspective (Clark et al., 2011; Harkins et al., 2010; McGarrol, 2020; Pedersen et al., 2017; Schröder et al., 2017, 2018; Smith & Dumas, 2019). The following sections will elaborate on the quality and relevance of these studies in relation to the present PhD study.

### **1.3. SOCIAL CONDITIONS AS FUNDAMENTAL CAUSES OF DISEASE**

The mechanisms driving social inequality in life with ischemic heart disease have been widely debated (Bartley, 2017). Lifestyle factors, such as smoking, diet, alcohol and physical activity, have often been highlighted as important mediators between socioeconomic status and ischemic heart disease (De Bacquer et al., 2021; Hald et al., 2019; Hicks et al., 2020; Hutchison & Holdsworth, 2019; Kulhánová et al., 2016; Notara et al., 2014; Virtanen & Kivimäki, 2018). However, research based on the British Whitehall studies performed in 1981 and followed-up in 2011 convincingly showed that lifestyle factors account for only a part of the social inequality in mortality from ischemic heart disease (Rose & Marmot, 1981; Stringhini et al., 2011). Additionally, a substantial body of epidemiological evidence indicates that social determinants, such as socioeconomic status, race, ethnicity, social support, culture, language, access to care, and residential environment, significantly impact the risk for and outcomes of cardiovascular disease (Havranek et al., 2015).

Several influential researchers, including Göran Dahlgren and Margaret Whitehead (1991), Bruce G. Link and Jo Phelan (1995), and Michael G. Marmot (2017), have long advocated that studies of social inequality in health should focus on social and structural conditions and not merely on lifestyle factors. Link and Phelan's landmark article "Social Conditions as Fundamental Causes of Disease" published in 1995

offered a major contribution to the work on the impact of social conditions on health and well-being (Link & Phelan, 1995). They argued that social conditions should be seen as more fundamental causes of disease than individual-oriented proximate factors, such as lifestyle factors. By social conditions, they meant anything that involves people's relationship to other people, including both intimate social relationships and broader social structures (Link & Phelan, 1995). They presented comprehensive evidence showing that the impact of social conditions on health and disease persists over time and affects a broad variety of risk factors and health outcomes, while the effect of proximal factors changes over time and affect only specific forms of diseases (Link & Phelan, 1995). Additionally, Link and Phelan argued that social conditions are often a more underlying cause of proximal causes of disease, and they called for research trying to understand the social conditions that make some people more exposed to proximal causes of disease than others (Link & Phelan, 1995). Furthermore, in their later work, Link and Phelan argued that socioeconomic status is a fundamental cause of disease because it provides access to important resources, including money, knowledge, power, prestige, and beneficial social connections. They refer to these resources as 'flexible resources' because they continue to be relevant through different time periods and in different settings (Phelan et al., 2010; Phelan & Link, 2013).

Out of the seven above-mentioned studies exploring social inequality in life with ischemic heart disease from a qualitative patient experience perspective, five emphasized the influence of the patient's individual capabilities on their adherence to lifestyle recommendations or their access to treatment (Harkins et al., 2010; Pedersen et al., 2017; Schröder et al., 2017, 2018; Smith & Dumas, 2019), while only two studies emphasized the role of social conditions in the experience of life with ischemic heart disease (Clark et al., 2011; McGarrol, 2020).

In a Canadian study, Clark et al (2011) explored patients' adherence to a healthy lifestyle. However, using a critical realism approach which views behavior as the product of both individual and contextual factors (Clark et al., 2008), they highlighted the importance of social conditions, such as lacking economic resources and transport possibilities, for adherence to a healthy lifestyle (Clark et al., 2011). In a later study, McGarrol (2020) also emphasized patients' attitude towards lifestyle and health behavior but used a comparative approach to show how living in two socioeconomically different social contexts in Scotland influenced these attitudes. The comparative approach of that study makes it possible to understand not only the influence of living in one context, but also how that contrast to the impact of living in another context. However, the findings are closely related to specific geographical areas in Scotland, which may challenge the transferability of the findings. Generally, recent studies exploring the influence of social conditions on the experience of life with ischemic heart disease from a qualitative perspective are lacking.

#### 1.4. THE PSYCHOSOCIAL PERSPECTIVE ON SOCIAL INEQUALITY IN HEALTH

The psychosocial perspective on social inequality in health emerged in the 1990s (Bartley, 2017; Elstad, 2000). This perspective builds on the heritage from Link and Phelan (2013), and others, by highlighting the importance of understanding the role of social and structural conditions on social inequality in health. However, what distinguishes the psychosocial perspective is that it emphasizes how psychosocial factors which can be categorized as meso-level factors connect macro-level social factors to micro-level individual factors (Martikainen et al., 2002).

In the following excerpt, Wilkinson and Pickett (2009) argue for the importance of understanding the link between micro-level individual factors and macro-level structural factors:

*“The powerful mechanisms which make people sensitive to inequality cannot be understood in terms of either social structure or individual psychology alone. Individual psychology and societal inequality relate to each other like lock and key. One reason why the effects of inequality have not been properly understood before is because of a failure to understand the relationship between them.”* (Wilkinson and Pickett, 2009, p. 33).

The psychosocial perspective on social inequality in health offers a possibility to explore and understand this interrelationship by focusing on the connecting level of psychosocial factors (Martikainen et al., 2002).

In studies deploying the psychosocial perspective on social inequality in health, psychosocial stress is often understood as the link between social structures, social environments, psychological well-being, and health (Elstad, 2000). One of the core arguments in the psychosocial perspective on social inequality in health is therefore that people with a low socioeconomic status generally experience higher levels of unhealthy psychosocial stress than people with a higher socioeconomic status (Elstad, 2000). Psychosocial stress is defined as psychological distress that has a social origin and thus includes stressful feelings deriving from something in the individual’s social environment (Yeung, 2016).

When trying to understand why people with low socioeconomic status tend to experience elevated levels of unhealthy psychosocial stress, it may be productive to divide psychosocial theories into the epidemiology of the social stress model and the vulnerability hypothesis (Elstad, 2000). Based on high-quality longitudinal cohort studies, the epidemiology of social stress model argues that people with low socioeconomic status are generally exposed to more external stressors, such as less job control, more economic hardship, and more marital issues, than people with a high socioeconomic status (Chandola & Marmot, 2011; Turner & Turner, 2005; Turner et al., 1995). The vulnerability hypothesis, on the other hand, argues that people with a low socioeconomic status generally lack the ability to handle, adjust to, and cope with external stressors (Elstad, 2000). An example of this kind of psychosocial theory is the theoretical framework of sense of coherence presented by Aron Antonovsky (1987), which conceptualizes the ability to find one’s existence comprehensive,



manageable, and meaningful, which makes it easier to overcome stressful stimuli. A study by Lundberg (1997) has shown that people with low socioeconomic status generally have a lower sense of coherence than people with higher socioeconomic status. However, this study is several decades old, and there is a lack of more recent studies exploring the correlation between sense of coherence and socioeconomic status.

Questionnaire-based research has also shown that among patients with ischemic heart disease, those with a low socioeconomic status experience higher levels of psychosocial stress than those with a high socioeconomic status (Dupre et al., 2017; Vancampfort et al., 2017). Psychosocial stress may influence ischemic heart patients in different ways. A comprehensive review study demonstrated that stress has a biological impact on both the occurrence and prognosis of ischemic heart disease as it influences activity in the sympathetic nervous system and the hypothalamic-pituitary-adrenal axis, which may increase atherosclerotic inflammation (Dar et al., 2019). Furthermore, a methodologically sound survey study showed that stress may worsen ischemic heart patients' quality of life (Staniute et al., 2013). Additionally, a thorough longitudinal cohort study showed that stress affected ischemic heart patients' compliance with lifestyle and medication (Lissåker et al., 2017).

As explained in the previous section, only two qualitative studies seem to have explored the influence of social conditions on social inequality in ischemic heart disease (Clark et al., 2011; McGarrol, 2020). These studies primarily emphasized how the participants' economic and geographical situation influenced their ability to afford healthy foods and use transportation to attend healthcare services (Clark et al., 2011; McGarrol, 2020). They did thus not go into depth with meso-level psychosocial factors, such as for example stress associated with economic hardship, that may link macro-level social conditions to micro-level lifestyle factors.

A systematic search in CINAHL, PubMed, Embase, and PsycINFO identified no existing studies exploring the specific situation of being socially disadvantaged and living with ischemic heart disease from an in-depth qualitative and psychosocial perspective. Nevertheless, Dubbin, McLemore, and Shim (2017), Jin et al (2020) and Potter et al (2018) explored the experience of life with ischemic heart disease among ethnic minorities or other patient groups from a qualitative psychosocial approach. These studies showed how macro-level social and structural conditions are related to micro-level individual psychological factors through meso-level psychosocial factors (Dubbin et al., 2017; Jin et al., 2020; Potter et al., 2018). For example, Dubbin et al (2017) showed how macro-level structural factors, including racism and unequal distribution of materials and information, created meso-level psychosocial experiences of anger and stress, which the participants connected to micro-level individual factors, including their lifestyle and cardiovascular health. These studies have been published recently and thoroughly and explicitly described the qualitative methods they used. Furthermore, they included participants from three different geographical contexts, including America, China, and England (Dubbin et al., 2017; Jin et al., 2020; Potter et al., 2018). The studies thus indicate that psychosocial factors

have a profound influence on the experience of life with ischemic heart disease across different settings.

The following sections will present different factors that may be relevant to explore in qualitative psychosocial studies of social inequality in ischemic heart disease.

#### **1.4.1. SOCIAL SUPPORT**

Several influential studies have shown that social relationships, both in their presence and in their absence, have a profound impact on human beings' health and well-being (Berkman et al., 2000; Thoits, 2011; Uchino et al., 1996; Umberson & Karas Montez, 2010). The mechanisms through which social relationships impact health and well-being have been explored with the use of different theories, concepts, and notions, such as social support, social influence, social control, social identity, purpose and meaning, sense of control, and belonging (Andersen et al., 2021; Berkman et al., 2000; Thoits, 2011).

The theory of social support is one of the most widely deployed and well-documented theories conceptualizing the influence of social relationships on health and well-being. This theoretical concept has been defined in different ways by different scholars (Uchino et al., 2018). One of the most influential definitions is the one offered by Sheldon Cohen and Thomas Ashby Wills (1985) who conceptualize social support as psychological, material, and practical resources provided by close social relationships that positively impact health and well-being. Cohen and Wills (1985) distinguished between two processes through which support from social relationships has a beneficial effect on well-being. First, the 'buffering model' proposes that support may buffer the effect of, protect the individual from, or make it easier to cope with, stressful events (Cohen & Wills, 1985). Second, the 'main effect model' suggests that social resources have a beneficial effect on the individual regardless of exposure to stress. Engagement in social networks provides the individual with positive experiences, stability, socially rewarded roles, self-worth and a sense of meaning (Cohen & Wills, 1985). This dissertation relies on Cohen and Will's conceptualization of social support.

Social support from close social relationships has been shown to play an important role in social inequality in health (Bower et al., 2020; Campbell-Grossman et al., 2005; Eapen et al., 2019; Klein et al., 2012; Vonneilich et al., 2012). Studies using comprehensive quantitative longitudinal cohort study designs have shown that social support attenuates the correlation between low socioeconomic status and poor quality of life (Vonneilich et al., 2012), and that social support accounts for up to 35% of the inequalities demonstrated in self-rated health (Klein et al., 2012). Furthermore, studies using in-depth qualitative study designs have shown that people of low socioeconomic status experience receiving different kinds of social support as a help that mitigated different challenges, including giving birth to an infant with low birth weight (Eapen et al., 2019), and the experience of low quality of life as an older citizen (Bower et al., 2020). However, there is generally a lack of qualitative studies exploring the role of social support on social inequality in health.

Furthermore, research has demonstrated the important role of social support for the health and well-being of ischemic heart patients (Barth et al., 2010; Buursma et al., 2020; Galick et al., 2015; Green et al., 2020; Hanna et al., 2020; Hansen et al., 2017; Karataş & Bostanoğlu, 2017; Lurie et al., 2015). High-quality quantitative studies relying on thorough systematic reviews, cross-sectional surveys designs, and longitudinal cohorts designs have demonstrated how support from social relationships negatively affects the mortality, readmission, anxiety, depression, psychosocial adjustment, hopelessness, and frailty of ischemic heart patients (Barth et al., 2010; Buursma et al., 2020; Green et al., 2020; Hansen et al., 2017; Karataş & Bostanoğlu, 2017; Lurie et al., 2015). Furthermore, thorough qualitative studies relying on meta-analysis of other studies and in-depth qualitative interviews have shown that support from social relationships affects ischemic heart patients (Galick et al., 2015; Hanna et al., 2020). Hanna et al (2020) for example showed how social support provided ischemic heart patients with a feeling of being genuinely cared for, which motivated them to adhere to lifestyle changes.

Existing research thus points to both social inequality in health and life with ischemic heart disease as fields within which social support plays an important role. However, there is generally a lack of both quantitative and qualitative studies exploring the influence of social support on social inequality in ischemic heart disease (Child & Albert, 2018; Skodova et al., 2008).

#### **1.4.2. HEALTHCARE INTERACTIONS**

The clinical encounter is an important part of chronic patients' social milieu. Healthcare interactions are therefore another angle from which the psychosocial perspective on social inequality in health may be explored (Bartley, 2017). A comprehensive survey study has shown that ischemic heart patients with low socioeconomic status are more likely to report poor patient satisfaction and problematic patient-provider communication than ischemic heart patients with a higher socioeconomic status (Shahu et al., 2020).

Studies exploring unequal cardiac care often use quantitative study designs to emphasize patients' personal assets and shortcomings, such as low levels of health literacy (Schultz et al., 2018). The European Health Literacy Consortium defines health literacy as: "people's knowledge, motivation and competences to access, understand, appraise, and apply health information in order to make judgments and take decisions in everyday life concerning healthcare, disease prevention and health promotion to maintain or improve quality of life during the life course" (Sørensen et al., 2012). The concept of health literacy may be seen as a way to explore patients' knowledge as one of the flexible resources presented by Link and Phelan (2013). However, in contrast to Link and Phelan's theory of fundamental causes of disease, most conceptualizations of health literacy are not concerned with the underlying social factors that enable patients' access to health-related knowledge.

Within the past decade, a ‘second wave’ of health literacy research has emerged, which, similarly to Link and Phelan, highlights the importance of recognizing the influence of underlying social factors (Chinn, 2011). The second wave of health literacy research has criticized the original conceptualizations of health literacy for viewing patients as cognitive agents instead of emotional, social, and embodied beings influenced by the social context they engage in (Samerski, 2019). These scholars therefore argue that health literacy should be seen as a socially contextualized phenomenon (Chinn, 2011; Papen, 2009; Samerski, 2019).

Furthermore, Janet Shim (2010) has introduced the theoretical framework of cultural health capital, which may accommodate some of the limitations of the original conceptualization of health literacy. This framework explores how unequal treatment is influenced by social, contextual, structural, and interactional factors. Cultural health capital draws on Bourdieu’s (1986) theory of cultural capital and suggests that a specific form of cultural capital is relevant in healthcare settings. Cultural health capital thus conceptualizes a set of cultural, verbal and nonverbal skills, attitudes, behaviors, and interactional styles (Shim, 2010). When cultural health capital is displayed by patients or healthcare professionals, it may be exchanged into satisfying and attentive healthcare interactions (Shim, 2010). The ability to exchange cultural health capital depends on the individual’s habitus. Habitus is social dispositions acquired through socialization processes that determines a person’s actions and perceptions (Bourdieu, 1984). Habitus is related to a person’s social status, and cultural health capital is therefore unequally distributed between different socioeconomic groups (Shim, 2010).

Shim (2010) argued that cultural health capital both resembles and differs from the concept of health literacy. Both notions, she argued, focus on the influence of patient characteristics on unequal treatment (Shim, 2010). Furthermore, as also proposed in the second wave of health literacy research (Chinn, 2011), cultural health capital emphasizes the social context within which these characteristics function (Shim, 2010). However, while the second wave of health literacy research has predominately emphasized the social context of social networks (Chinn, 2011), the cultural health capital framework highlights the social context of the healthcare setting (Shim, 2010).

Several high-quality qualitative studies have deployed the framework of cultural health capital to understand mechanisms contributing to unequal treatment and care in different setting and of different conditions (Chang et al., 2016; Gengler, 2014; Madden, 2015; Næss, 2019; Sacks, 2018). Nevertheless, the cultural health capital framework has not yet been used to explore the influence of structural, psychosocial, and interactional factors on unequal treatment of ischemic heart patients.

### **1.4.3. MIDLIFE PATIENTS**

Midlife can be defined as the period between early and later adulthood. People at midlife are typically defined as those between 40 and 60 years of age. This particular age group has been shown to be especially burdened by psychosocial stress (Infurna

et al., 2020; Lachman, 2004; Turner & Turner, 2005), which makes it a relevant object of psychosocial research.

In 2004, Margie Lachman published an influential article reviewing existing literature on midlife and presenting a conceptual framework for understanding the opportunities and challenges of midlife (Lachman, 2004). Additionally, in 2015 and 2020, in collaboration with her colleagues, Lachman published two follow-ups on her article from 2004 (Infurna et al., 2020; Lachman, 2015). Generally, the articles argued that midlife presents opportunities, such as life experience and better emotional regulation (Infurna et al., 2020; Lachman, 2004, 2015). However, midlife was also presented as a particularly demanding period of life characterized by competing demands related to roles of being a spouse, co-worker, friend, and caregiver of both elder parents, parent in-laws, children, and sometimes also grandchildren. Furthermore, at the same time, people at midlife are often exposed to many stressors, including declining health, occurrence of chronic illnesses, death of parents, divorce, job loss, and financial burdens of childcare, mortgage, nursing homes, etc. (Infurna et al., 2020; Lachman, 2004, 2015).

Recent empirical qualitative studies have indicated that living with a chronic illness at midlife may also create distinct and particularly burdening psychosocial challenges (Markle et al., 2015; Martinsen et al., 2015; McCallum & Alaggia, 2020). Markle, Attell, and Treiber (2015) showed how midlife patients living with multiple chronic illnesses experienced psychosocial challenges, such as inconsistency between the illness identity and their self-image, concerns about the future, loss of job identity, and stigmatization related to their illness, all of which created social isolation. This study, however, drew on online narratives from blogs, which comes with the risk of decontextualization of the findings (Markle et al., 2015).

Midlife ischemic heart patients may be categorized as relatively premature patients, since the risk of experiencing and dying from ischemic heart disease increases with age (Allison & Campbell, 2009; Dégano et al., 2015; Klein & Nathan, 2003). Data from a high-quality longitudinal cohort study across different European countries demonstrated that heart attack rates are three times higher in older age groups (65–74 years) than in younger age groups (35–64 years) (Dégano et al., 2015). Furthermore, another comprehensive but relatively old longitudinal study showed that premature ischemic heart patients are more likely to leave the workforce early, live longer with disabilities, and die prematurely than older patients (Cole et al., 2003).

A few qualitative studies also explored the experience of living with ischemic heart disease at midlife (Allison & Campbell, 2009; Andersson et al., 2020; Andersson, Borglin, & Willman, 2013; Andersson, Borglin, Sjöström-Strand, et al., 2013). For example, a study by Andersson, Borglin, and Willman (2013b) showed how midlife ischemic heart patients experienced an emotional battle to regain foothold in life. Physical and mental fatigue caused by the illness made it difficult for them to meet the demands from employers, healthcare professionals, and family members, which placed them in a burdening situation (Andersson, Borglin, & Willman, 2013). Another

study by some of the same authors showed that midlife ischemic heart patients' close social relatives were also burdened by their illness, because it made them solely responsible for the patient and the family's wellbeing and consequently they had to put their own life on hold (Andersson, Borglin, Sjöström-Strand, et al., 2013). The quality of both studies seems high as the methods were explicitly and thoroughly described and as the findings appeared thorough and well substantiated.

Additionally, the epidemiology of social stress model has shown that the elevated exposure to external psychosocial stressors demonstrated among people with low socioeconomic status is particularly high among those at midlife and higher than among people of other age groups (Chandola & Marmot, 2011; Turner & Turner, 2005; Turner et al., 1995).

Current research thus indicates that both being at midlife and having a low socioeconomic status while living with ischemic heart disease are situations that may create a substantial burden of psychosocial stress. However, studies exploring the experience of life with ischemic heart disease among patients who are both socially disadvantaged and at midlife are lacking.

## **1.5. POLICIES AND INTERVENTIONS TARGETING SOCIAL INEQUALITY IN ISCHEMIC HEART DISEASE**

Policies and interventions have been developed to reduce social inequality in health. In the following, a brief overview of these policies and interventions will be presented.

### **1.5.1. POLICIES**

Throughout the past decades, social inequality in health has been on the agendas of both national and global politics. In 2005, the World Health Organization established The Commission on Social Determinants of Health with the aim to address the social determinants leading to social inequalities in health. The Commission presented a report in 2008 highlighting risk factors leading to social inequality in health globally (Organization, 2008). Based on the insights from this report, in 2009, the Sixty-second World Health Assembly encouraged all member states to identify national causes for and solutions to social inequality in health (World Health Organization, 2009). In Britain, this resolution was met with the report "Fair Societies, Healthy Lives" (Marmot et al., 2010), which became an important inspiration for many other member states, including Denmark.

The Danish contribution to the World Health Assembly's resolution was published in 2011. This report showed that 20% of social inequality in remaining life expectancy in Denmark originated from ischemic heart disease (The Danish Health Authority, 2011). The report suggested that early detection of ischemic heart disease in socially disadvantaged populations should be prioritized (The Danish Health Authority, 2011). Furthermore, in 2020, two reports were published as follow-ups to the Danish report published in 2011 (The Danish Health Authority, 2020b, 2020a). The first report mapped the development of social inequality in health in Denmark between 2010-2017 (The Danish Health Authority, 2020b). The second report presented suggestions

for action to reduce social inequality in health (The Danish Health Authority, 2020a). Like the report from 2011 (The Danish Health Authority, 2011), this report also emphasized ischemic heart disease as one of the diseases requiring most action (The Danish Health Authority, 2020a).

Since the publication of the first Danish report in 2011, funds have been allocated to a few projects aiming to reduce social inequality in health. First, in 2013, as a part of the “Mere borger, mindre patient” (“More citizen, less patient”) project, the Danish government assigned funds to the reduction of social inequality in health in the period between 2014 and 2017 (The Danish Ministry of Health, 2013). These funds were assigned to different initiatives, including “Navigatorprojekterne” (“The Navigator projects”), which will be presented in the following section (The Danish Health Authority, 2018). Second, in 2018, funds were allocated from the Danish Finance Act to improve care for vulnerable families in relation to pregnancy and early childhood (The Danish Ministry of Children and Social Affairs, 2018). The purpose of this policy was to further early detection and prevention of social inequalities in health (The Danish Ministry of Children and Social Affairs, 2018). Some of the social inequalities later seen in ischemic heart disease could thus potentially be prevented by this initiative.

Thus, even though the Danish government has underlined the importance of introducing initiatives to reduce social inequality in health, only a few policy funds have been allocated specifically to this. Furthermore, even though the reports highlighted ischemic heart disease as an important point of action, no policies have emphasized social inequality in ischemic heart disease specifically.

### **1.5.2. INTERVENTIONS**

Several interventions aiming to reduce social inequality in ischemic heart disease have been initiated internationally. Such interventions often emphasize the individual’s agency, abilities, or behavior, for example through the improvement of their lifestyle or health literacy, while there is generally a lack of more social or psychosocially oriented interventions (Greenberg et al., 2019; Schultz et al., 2018; Siren et al., 2014).

For example, in Finland, all male citizens aged 40 years old were invited to a health counselling intervention. All participants at increased risk of cardiovascular disease received lifestyle counselling based on their individual risk profile (Siren et al., 2014). An evaluation of the intervention indicated that it generally appeared to have a significant effect on the participants’ cardiovascular risk score. However, this effect was not seen for the participants in the lowest educational group (Siren et al., 2014). The reason for this ineffectiveness could be that, as has been shown in the previous parts of this Introduction, more underlying social and psychosocial factors may affect these patients’ motivation and ability to change their lifestyle.

However, as mentioned, in Denmark, funds from the “Mere borger, mindre patient” (“More citizen, less patient”) project were assigned to the “Navigatorprojekterne”

(‘The Navigator projects’). In these projects, citizens supported vulnerable patients’ involvement with the healthcare system on a voluntary basis (The Danish Health Authority, 2018). Thus, the projects did not specifically target socially disadvantaged ischemic heart patients but more generally patients with vulnerabilities, such as psychological diagnoses, lacking social network, or ethnic minorities (The Danish Health Authority, 2018). The purpose of the projects was to strengthen vulnerable patients’ health literacy, improve their access to the healthcare system, and reduce mental consequences and social isolation (The Danish Health Authority, 2018). Nevertheless, the activities in the intervention mainly consisted of helping patients understand health-related information and healthcare professionals’ instructions (The Danish Health Authority, 2018). The actual focus of the intervention seemed thus primarily to be to improve vulnerable patients’ health literacy and not so much their mental well-being or contact to other people. Furthermore, the projects highlighted the role of the patient in the healthcare interactions, and thereby not the healthcare professionals, or the interactional dynamics between them.

## **1.6. RATIONALE FOR THE STUDY**

Existing research has shown that social inequality in health and well-being of those living with ischemic heart disease is a growing international public health concern (Barbareschi et al., 2009; Matetic et al., 2020; Nobel et al., 2017). When trying to understand and reduce these inequalities, research and policy often emphasize patients’ individual actions and capabilities (De Bacquer et al., 2021; Hald et al., 2019; Hicks et al., 2020; Hutchison & Holdsworth, 2019; Kulhánová et al., 2016; Notara et al., 2014; Schultz et al., 2018). However, research indicates that psychosocial factors may be more fundamental, underlying factors shaping these inequalities (Bartley, 2017; Elstad, 2000). To intervene effectively on social inequalities in ischemic heart disease, it is thus necessary to understand the psychosocial factors that may create physically and mentally harmful burdens of stress or make the patients less motivated to and capable of adhering to medical recommendations. Even so, studies focusing on socially disadvantaged ischemic heart patients from a psychosocial perspective are generally lacking.

Furthermore, studies of social inequality in the experience of life with ischemic heart disease often deploy quantitative study designs and standardized measurement tools (Badaricén et al., 2020; Nobel et al., 2017; Schultz et al., 2018; Shahu et al., 2020). These study designs may provide an overview of the magnitude of the problem and demonstrate causal relationships. However, to understand in-depth socially disadvantaged patients’ experience of living with ischemic heart disease and the complex structural, social, psychosocial, and interactional dynamics that shape these experiences, in-depth qualitative research exploring patient experiences is relevant (Williams & Elliott, 2010). Such in-depth qualitative research may allow us to better understand socially disadvantaged ischemic heart patients’ specific needs, challenges, perspectives, and preconditions, which should all be taken into account when designing policies and interventions targeting this group, and by healthcare professionals providing therapy and guidance for this group of patients.



## 1.7. OVERALL OBJECTIVE AND RESEARCH AIMS

The overall objective of this PhD study is to provide an in-depth understanding of social inequality in ischemic heart disease by exploring the influence of underlying psychosocial factors on socially disadvantaged patients' lived experience of life with ischemic heart disease.

As shown in Table 1, the PhD study is operationalized in three sub-studies with specific research aims and varying participants and data sources. Furthermore, the findings from the three sub-studies are reported in three articles.

Additionally, the study is related to a wider research project about social inequality in ischemic heart disease also including a health survey study (Svendsen et al., 2020), which will be further described in the Methods section.

**Table 1.** Overview of sub-studies in the PhD study

	Sub-study 1	Sub-study 2	Sub-study 3
<b>Article title</b>	“The role of social support in the experience of life with ischemic heart disease for socially disadvantaged patients: A qualitative study”	“Understanding social inequalities in cardiac treatment through the lens of cultural health capital: A study of Danish socially disadvantaged ischemic heart patients' lived experiences of healthcare interactions”	“An overwhelming burden of psychosocial stress: Life with ischemic heart disease for midlife patients with low socioeconomic status and lack of flexible resources”
<b>Aim</b>	To explore the role of social support from close social relationships in socially disadvantaged patients' lived experience of life with ischemic heart disease	To explore socially disadvantaged ischemic heart patients' lived experience of healthcare interactions through the lens of the theoretical framework of cultural health capital	To explore the influence of psychosocial stress on life with ischemic heart disease for socially disadvantaged patients at midlife
<b>Included participants</b>	30 of the overall 30 participants included in the PhD study	30 of the overall 30 participants included in the PhD study	18 of the overall 30 participants included in the PhD study – under the age of 60 years old
<b>Source of data</b>	Interviews	Interviews and observations	Interviews

## CHAPTER 2. METHODS

### 2.1. CRITICAL HERMENEUTICS AS PHILOSOPHY OF SCIENCE

The critical hermeneutic approach as outlined by Paul Ricoeur constitutes the philosophy of science for this PhD study (Ricoeur, 1981). Ricoeur's critical hermeneutic approach was originally oriented towards interpretation of written texts (Ricoeur, 1976a). However, he later extended it to the field of social science where he used it to explore and interpret human action and spoken words (Ricoeur, 1973). Furthermore, in 1999, the nursing researcher Birthe D. Pedersen presented a Ricoeur-inspired method for data analysis (Pedersen, 1999). This approach has later been developed by different health researchers (Geanellos, 2000; Lindseth & Norberg, 2004; Simoný et al., 2018; Singsuriya, 2015) and used in several empirical studies (Andersson, Borglin, & Willman, 2013; Kitzmüller et al., 2019; Leichtentritt & Weinberg-Kurnik, 2016; Petersen et al., 2012; Thrysoe et al., 2012). In this PhD study, Simoný et al's (2018) description of a critical hermeneutic approach to data analysis and interpretation has been used for data analysis and interpretation.

In the following sections, the critical hermeneutic approach will be introduced. Furthermore, it will be explained why this approach was chosen as the philosophy of science in this study and how it has affected the research process.

#### 2.1.1. A HERMENEUTICS INSPIRED BY PHENOMENOLOGY AND CRITIQUE OF IDEOLOGY

Ricoeur was known for uniting otherwise contradictory epistemologies. His hermeneutic philosophy is inspired by Hans-Georg Gadamer's version of hermeneutics, Edmund Husserl and Martin Heidegger's phenomenology, and Jürgen Habermas' critique of ideology (Ricoeur, 1981). The following will describe Ricoeur's critical hermeneutics by explaining the inspiration he drew from these three epistemologies.

The inspiration from phenomenology can primarily be seen in Ricoeur's focus on lived experience (Ricoeur, 1976a). When phenomenologists explore lived experiences, they are interested in a person's first-hand experience of something and how the person makes sense of this experience (Husserl, 2012). Similarly to the phenomenologists, Ricoeur was interested in how people make sense of their living experiences (Ricoeur, 1981) and argued that the researcher must listen to these conceptions and take them seriously on their own terms (Ricoeur, 1970).

However, while the scope of a phenomenological inquiry is primarily the informant's subjective experience (Husserl, 2012), Ricoeur was also inspired by Gadamer's (2013) hermeneutics and therefore argued that in order to understand these lived experiences, interpretation is needed. He contended that when lived experience is

expressed both through spoken and written language, it is transformed into a discourse, which means that it is directed at someone (Ricoeur, 1976a). Through this transformation, a distancing becomes possible. Distancing means that the lived experience is distanced from the one who lived it. A primitive form of distancing happens when discourse is produced in oral form as it becomes detached from the speaker's inner world (Ricoeur, 1981). Moreover, a further step of distancing happens when language is fixed in writing as the text becomes detached from the author's intention and it becomes possible for the reader to interpret it and create a new meaning of it (Ricoeur, 1976a). Additionally, in their development of Ricoeur's approach, Simonj et al (2018) argued that interviews and observations can be used to explore lived experiences in Ricoeur-inspired studies. When the participants' lived experiences are listened to, or observed, by the researcher and written down in notes or transcripts, a distancing also happens (Simonj et al., 2018). The distancing makes it possible for the reader to interpret and understand the lived experience (Ricoeur, 1981). In Ricoeur's understanding of the critical hermeneutic approach, a dialectic movement between understanding and explanation is important (Ricoeur, 1976a). When the lived experience is fixed in writing, the researcher must first try to understand the text by preliminarily interpreting its meaning. This interpretation is then validated through an act of explanation, which makes it possible to make a new interpretation and gain a more sophisticated understanding of the meaning of the text, and the process is then repeated (Ricoeur, 1976a).

Furthermore, in the 1960s and 1970s, a debate played out between Gadamer and Habermas that had an important influence on Ricoeur's work (Piercey, 2004). Gadamer argued that readers must accept that their interpretations are always a product of the tradition from which they derive (Gadamer, 2013). Habermas criticized Gadamer for lacking a critical perspective and argued that readers should not just passively accept the traditions from which they originate but instead be critical of them (Habermas, 1988). Even though Ricoeur was otherwise primarily inspired by Gadamer, he agreed with Habermas that hermeneutics could, and should, be critical, but that the critical potential of hermeneutics was often overlooked because of the dominance of Gadamer's work (Ricoeur, 1981). According to Ricoeur, through the process of distancing, the text becomes detached from the author's world and decontextualized into the reader's world. Thus, it becomes possible to use the text to be critical of the reader's world and thereby understand it at a deeper level (Ricoeur, 1981).

The critical hermeneutic approach was chosen as the philosophy of science for this PhD study since, as mentioned in the Introduction, there is a need for qualitative studies focusing on patient experiences. The critical hermeneutic approach focuses on lived experiences (Ricoeur, 1976a), which makes it possible to grasp the first-hand experience of living with ischemic heart disease. Furthermore, in the Introduction, it was argued that there is a lack of studies exploring social inequality from a psychosocial perspective and thereby showing the relation between psychological and biological experiences, psychosocial processes, and broader social structures. Through distancing and interpretation, the critical hermeneutic approach makes it

possible to use lived experiences to be critical of the world within which the reader derives and gain a deeper understanding of it (Ricoeur, 1981). The critical hermeneutic approach thus enables this PhD study to be critical and gain a deeper understanding of the psychosocial processes that drive social inequality in ischemic heart disease.

### **2.1.2. MIMESIS AND THE CRITICAL HERMENEUTIC RESEARCH PROCESS**

Inspired by Aristotle, Ricoeur used the term ‘mimesis’ to describe the intersection between the world of the author and the reader in interpretation of texts (Ricoeur, 1984). In this section, Ricoeur’s thoughts on mimesis will be adapted to the context of qualitative research processes as formerly done by other health researchers (Missel & Birkelund, 2020; Pedersen & Dreyer, 2018). Mimesis will thus be used to describe the process through which the participants’ lived experiences were transformed into scientific knowledge through a critical hermeneutic research process.

To describe the process of mimesis, Ricoeur used the terms mimesis 1 (prefiguration), mimesis 2 (configuration), and mimesis 3 (refiguration) (Ricoeur, 1984). Ricoeur argued that people use narratives to imitate or represent human action and lived experiences. Mimesis 1 is the prefiguration of these narratives. It thus refers to the lived experience before it is articulated through language (Ricoeur, 1984). Mimesis 2 is the configuration between mimesis 1 and mimesis 3. It refers to the process of imitating the prefiguration through oral language or written texts, which then makes it possible to create a refiguration (Ricoeur, 1984). Mimesis 3 is the refiguration that happens when the imitation of the prefiguration is appropriated and interpreted by the receiver of the narrative (Ricoeur, 1984).

Table 2 illustrates how the process of mimesis was adapted to and performed in the research process of the present PhD study. In mimesis 1, before any data was collected, the participants lived and experienced their life (Missel & Birkelund, 2020). Through the configuration in mimesis 2, their lived experiences were articulated in narratives through interviews and observations and then transcribed into a text. This process created a distancing of the lived experiences from the participants (Missel & Birkelund, 2020). In mimesis 3, the narratives were appropriated and then analyzed and interpreted within the context of present scientific knowledge (Missel & Birkelund, 2020). Furthermore, according to Simoný et al (2018), this final step also includes a discussion.

In the following sections, the process of data collection (mimesis 2) and the data analysis, interpretation, and discussion (mimesis 3) will be further elaborated.

**Table 2.** The process of mimesis in the research process of the PhD study

The process of mimesis	The research process
Mimesis 1 (prefiguration)	<i>Before data collection</i> The participants' lived experience of life with ischemic heart disease
Mimesis 2 (configuration)	<i>Data collection and transcription</i> The participants' lived experiences are articulated in narratives through oral and written text and thereby become detached from the participants
Mimesis 3 (refiguration)	<i>Analysis, interpretation, and discussion</i> The narratives of the lived experiences are appropriated by the researcher, which makes it possible to analyze, interpret, and discuss them

## 2.2. DATA COLLECTION

The empirical data for this PhD study derives from a nationwide qualitative data collection in Denmark between October 2018 and August 2019. The data was collected using in-depth qualitative interviews and included supplementary observations.

### 2.2.1. IN-DEPTH QUALITATIVE INTERVIEWS

The primary source of data in this study was in-depth qualitative interviews. Interviews are relevant as a source of data when using a Ricoeur-inspired critical hermeneutic approach, since language, both written and oral, plays an important role in Ricoeur's critical hermeneutic philosophy (Ricoeur, 1976a; Simony et al., 2018).

Ricoeur saw language as something that expresses a discourse (Ricoeur, 1976a). He described the discourse as containing two forms of meanings. First, it contains the utterance meaning, which means the objective semiotic meaning of the combination of words. Ricoeur termed this meaning the 'sense' of the discourse. Second, it contains the utterer's meaning, which is the subjective intentional meaning the speaker lays into the discourse. Ricoeur termed this the 'reference' of the discourse (Ricoeur, 1976a). Ricoeur describes the relation between experience, reference, and language in the following extract:

*"Language is not a world of its own. It is not even a world. But because we are in the world, because we are affected by situations, and because we orient ourselves comprehensively in those situations, we have something to say, we have experience to bring to language. This notion of bringing experience to language is the ontological condition of reference."* (Ricoeur, 1976a, p. 20-21).

By transforming experience into language, it becomes possible to understand the reference, which is the preunderstanding of the speaker or writer (Ricoeur, 1976a). Interviews are therefore relevant in a critical hermeneutic study as they enable an

understanding of how the interviewee makes sense of his or her experiences and thereby their lived experiences (Simoný et al., 2018).

One to four interviews were conducted with each participant. After each interview with the participants, the PhD student assessed whether another interview was needed to gain a deeper understanding of the respective participant's lived experience. Some of the participants needed more interview sessions to feel comfortable in the interview context and to gain trust in the PhD student. Furthermore, some of the participants shared complex accounts that needed to be elaborated through more than one interviews. To enhance the participants' feelings of being safe and comfortable, they chose the setting for the interview (Herzog, 2005). Most of the interviews took place in the participants' homes. A Dictaphone was used to record the interviews. All interviews were undertaken by the PhD student.

After conducting the interviews, they were transcribed by the PhD student into a written text. As mentioned previously, when the preconfigured lived experience is transformed into oral and written language, it becomes detached from the reader's inner world (Ricoeur, 1981). In the act of recording and transcribing the interviews, the interviews thus became detached from the participants' intention and the discourse event and thus became interpretable (Simoný et al., 2018).

The interviews of this study were semi-structured and guided by an interview guide consisting of a list of themes relevant to the aim of the three sub-studies. The interview guide was used as a guideline but not followed strictly as the interviewer was open to unexpected, relevant turns in the interview (Fylan, 2005). The themes included in the interview guide were the participants' life trajectory, experience of illness, experience of treatment and healthcare encounters, and social relationships. A copy of the interview guide is available as Supplemental Table 2 in the article reporting on sub-study 3 (Rasmussen, Pedersen, et al., 2021).

### **2.2.2. SUPPLEMENTARY OBSERVATIONS**

Observations provided data supplementing the qualitative interviews. Simoný et al (2018) advocate for the use of observations in critical hermeneutic studies as they, together with interviews, can be a way of gaining access to lived experiences. Observations, they argue, allow the researcher to understand the context in which the participants engage, their bodily expressions, interactions with healthcare professionals, and how they experience their life situation (Simoný et al., 2018).

Observations were used in this PhD study in two ways. First, prior to the interviews with the participants, the PhD student observed five rehabilitation classes for surgical heart patients at a regional hospital. The participants in the rehabilitation course were not necessarily socially disadvantaged, and the data from these observations were not included as data in the study. Instead, they created background information on general life with, and treatment and healthcare of, ischemic heart disease.

Second, for sub-study 2, observations of the socially disadvantaged participants' interactions with healthcare professionals were used as data supplementing the qualitative interviews. The PhD student conducted one to two observations of five of the participants. These observations provided contextual knowledge about the participants' experience of clinical encounters and an understanding of the interactional dynamics unfolding between healthcare professionals and participants. After these observations had been made, an interview was conducted in which the participant was able to express further their experience of the situation. The observations thereby also enriched the interview data. Ideally, observations of all participants in sub-study 2 should have been conducted. However, even though all participants were in active medical treatment for their ischemic heart disease, only a few of them were in frequent contact with their general practitioner or the specialized healthcare system.

The observations were unstructured and not determined by a list of predefined behaviors but instead guided by a list of relevant themes (Mulhall, 2003). The observation guide for the rehabilitation course was as follows: experiences of living with ischemic heart disease, willingness to participate, interactional dynamics among the patients, and interactional dynamics between the patients and the healthcare professionals. The observation guide for the supplemental observations of participants in sub-study 2 was focused on physical communication, verbal communication, interpersonal dynamics, power dynamics, and the patient's mental well-being.

### **2.3. SETTING**

The study was set in Denmark, and participants were included from all around the country. Denmark is a social welfare state with high standards of living, low income inequality, and publicly funded healthcare (Diderichsen et al., 2015). All citizens with ischemic heart disease are eligible for free preventive, surgical, medical, and rehabilitative treatment (Olejaz et al., 2012).

Nevertheless, the general income inequality in Denmark rose from 2000 to 2018 (The Danish Health Authority, 2020b). Furthermore, a rise in social inequality in life expectancy was observed from 1990 to 2016 (The Danish Health Authority, 2020b). Substantial social inequality is also seen in ischemic heart disease in Denmark, both in terms of risk factors (Nordahl et al., 2013), incidence, (Christensen et al., 2015), coronary procedures, and survival after out-of-hospital cardiac arrest (Møller et al., 2020).

The Scandinavian countries generally face substantial social inequalities in health despite the presence of structural conditions that have otherwise been shown to reduce social inequality in health, including having a generous welfare state, low income inequality, and free healthcare (Diderichsen et al., 2015). Several researchers have tried to understand this paradoxical situation, which has been termed 'The Scandinavian Welfare Paradox' (Hurrelmann et al., 2011).

## 2.4. SAMPLING

The participants of the PhD study were purposefully sampled. They were included based on their ability to provide information-rich data and in-depth knowledge of the topic of inquiry (Patton, 2002). Hence, they had to meet two criteria related to the overall aim of the study: They had to have ischemic heart disease and be socially disadvantaged.

The participants were considered ischemic heart patients if they had been hospitalized with ischemic heart disease. Furthermore, they were characterized as socially disadvantaged based on Link and Phelan's (2013) theory of fundamental causes of disease. Link and Phelan argue that socioeconomic status is a fundamental cause of disease because it is linked to health and well-being across different geographical settings and through different time periods. The reason for this fundamentality, they argue, is that socioeconomic status provides access to what they term 'flexible resources' that may be used to avoid risks and adopt protective strategies. These resources include money, knowledge, power, prestige, and beneficial social connections (Phelan et al., 2010; Phelan & Link, 2013). In this PhD study, social disadvantage is therefore not defined based on low socioeconomic status alone but also on lack of access to flexible resources.

To indicate lack of access to flexible resources among the participants of this PhD study, the concepts of health literacy and social support were used. Health literacy conceptualizes the ability to understand, appraise, and apply health-related knowledge (Sørensen et al., 2012), and was therefore used as an indicator of the flexible resource of knowledge. Furthermore, the notion of social support, meaning resources provided by social relationships that positively impact health and well-being (Cohen & Wills, 1985), was used as an indicator of the flexible resource of beneficial social relationships. Both health literacy and social support have been shown to mediate the relationship between socioeconomic status and health (Stormacq et al., 2019; Vonneilich et al., 2012).

The way in which the sample is described differs among the three articles. In the articles reporting on sub-study 1 and 2, the sample is termed "patients who are socially disadvantaged" (Rasmussen, Guise, et al., 2021b, 2021a) and in the article reporting on sub-study 3, the sample is referred to as "patients with a low socioeconomic status and lack of flexible resources" (Rasmussen, Pedersen, et al., 2021). This difference was a product of the reviewers' different requests.

Furthermore, sub-study 3 had an additional criterion. As this sub-study explored the lived experiences of socially disadvantaged ischemic heart patients within the midlife population, the participants of this study also had to be 40-60 years old. This age span was decided based on comparable studies of midlife patients using similar age spans (Allison & Campbell, 2009; Markle et al., 2015).



## 2.5. RECRUITMENT

The process of recruitment is illustrated in Figure 1. First, potential participants were identified based on their answers in an adjunct health survey study. As mentioned, this PhD study is a part of a wider research project about social inequality in ischemic heart disease also including a health survey study (Svendsen et al., 2020). The PhD student was therefore able to recruit participants through this survey study. In the survey study, 7,085 participants who had been hospitalized with ischemic heart disease were identified through The Danish National Patient Register. These participants completed a survey that contained questions from the European Health Literacy Survey Questionnaire (HLS-EU-Q) (Pelikan & Ganahl, 2017) and questions about social support based on Berkman et al's (2000) conceptualization. The survey thus made it possible to identify potential participants who could be characterized as patients with ischemic heart disease with low health literacy and limited social support.

Next, 97 potential participants identified in the survey study were informed about the PhD study in a letter sent to their private address. This letter is seen in Appendix A. In the letter, the potential participants were first thanked for their participation in the survey study and then informed about this qualitative PhD study. They were thus advised beforehand about a potential phone call in which they would be asked if they wanted to participate in the study.

Furthermore, 61 potential participants were then contacted by phone. In the telephone call, the participants were asked questions about their occupation and education. The participants' socioeconomic status was thereby identified based on their occupational and educational level. The potential participants' occupational level was indicated according to The Danish Occupational Social Class measurement (Christensen et al., 2014), and their educational level was identified according to the Danish Qualifications Framework for Lifelong Learning (The Danish Evaluation Institute, 2011).

Last, 45 out of the 61 potential participants matched the criteria and were invited to participate in the study; and out of those, 30 agreed to participate.



**Figure 1.** Recruitment process

## 2.6. SAMPLE SIZE

The number of participants included in the study was decided based on the concept of information power as described by Malterud, Siersma, and Guassora (2016). This concept takes its point of departure in the following assumption: “The larger information power the sample holds, the lower N [number of participants, red.] is needed, and vice versa.” (Malterud et al., 2016, p. 1754). When using information power to guide the sample size, it is necessary to make an approximation of the sample size during the planning of the study. Furthermore, this sample size is continuously evaluated during the process of data collection, analysis, and interpretation (Malterud et al., 2016). Malterud et al (2016) present five items that are important to consider when determining the sample size.

The first item deals with the broadness of the study aim. If the study aim is narrow, fewer participants are needed than with a broader research aim (Malterud et al., 2016). The overall aim of this PhD study is rather broad as it seeks to provide an in-depth understanding of social inequality in ischemic heart disease by exploring the influence of psychosocial factors on the socially disadvantaged patients' lived experience of life with ischemic heart disease. Both lived experience and psychosocial factors are extensive concepts that may be related to a broad variety of phenomena.

The second item considers the specificity of the sample in relation to the research aim. If the participants hold characteristics that are highly specific for the research aim, fewer participants are needed than if they have sparse specificity (Malterud et al., 2016). In this PhD study, a purposive sample strategy was used, and participants therefore held several characteristics important for the research aim, including low socioeconomic status, low health literacy, and limited social support.

The third item centers on the level of theoretical involvement in the study. The more theoretically informed the study is, the fewer participants are needed (Malterud et al., 2016). Because of the use of the critical hermeneutic approach (Simoný et al., 2018), the PhD study is theoretically well substantiated.

The fourth item is the quality of the dialogue between the researcher and the participants. The higher quality, the lower sample size (Malterud et al., 2016). Through the period of data collection, it was assessed that the in-depth qualitative methods provided a rather high quality of data.

The last item is concerned with the analysis strategy. If an in-depth understanding is sought for a single case, fewer participants are needed than if an exploratory cross-case analysis is sought (Malterud et al., 2016). In this PhD study, the scope was rather exploratory. Furthermore, as it was necessary to understand both participants from the midlife population and older participants, enough participants had to be recruited to understand both situations.

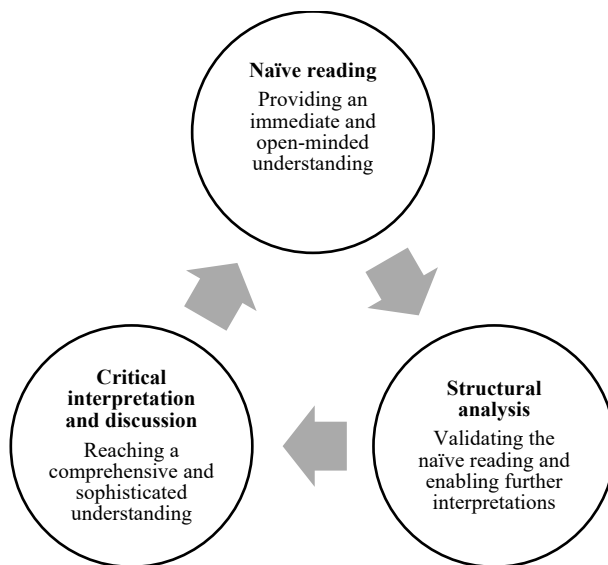
To embrace these five items, the PhD student anticipated including a relatively large number of participants, approximately 30-40, before sampling and data collection began. The number of participants was continuously reevaluated according to the five items through the research process.

## **2.7. DATA ANALYSIS AND INTERPRETATION**

Four processes of data analysis and interpretation were performed in the PhD study. First, the analysis and interpretation are presented in the three sub-studies. Furthermore, the kappa offers an overall analysis and interpretation across the dataset.

This PhD study draws on Ricoeur's (1976a) own description of data analysis and interpretation and on Simoný et al's (2018) development of the approach. Simoný et al's (2018) version was chosen as it is specifically oriented towards interpretation of both interviews and observations.

As previously explained, an important part of Ricoeur's understanding of analysis and interpretation is the dialectic movement between explanation and understanding (Ricoeur, 1976a). First, an immediate interpretation is made that enables a premature understanding, which is then validated through an act of explanation; then a new interpretation is made, which enables a further understanding, and the process is repeated (Ricoeur, 1976a). Simoný et al (2018) have specified this process. As illustrated in Figure 2, they describe the process as a dialectic movement between three steps, starting with a naïve reading, followed by a structural analysis, and then a critical interpretation and discussion. This process is repeated continuously through the research process until a rich interpretation is reached (Simoný et al., 2018). The analysis and interpretation of data in the present PhD study followed this process. In the following, the three steps and how they were performed in this PhD study will be elaborated.



**Figure 2.** Steps of the analysis and critical interpretation (inspired by Simoný et al (2018)).

The naïve reading intends to initially understand the meaning of the transcribed text. This reading is open-minded and does not actively deploy the theoretical framework. The researcher thus notes his or her immediate impression of the dataset (Simoný et al., 2018). In the present PhD study, this was done by reading all the transcripts and

then writing immediate interpretations. Both in this kappa and in the articles, the naïve reading is presented in the beginning of the Findings section.

The purpose of the structural analysis is to validate and explain the immediate interpretation performed in the naïve reading and to make further interpretations possible (Ricoeur, 1976a; Simonÿ et al., 2018). In the structural analysis, the researcher finds patterns across the data and structures them into units of meaning, units of significance, and themes (Simonÿ et al., 2018). Units of meaning refer to ‘what is said or observed’ and consist of extracts from the transcripts or field notes. These are paired with units of significance that represent ‘what is being talked about or what the observation is about’. The units of significance are thus micro interpretations of the text. Furthermore, the units of significance are structured into overall themes, thereby creating patterns across the dataset and enabling the interpretation of the dataset as a whole (Simonÿ et al., 2018). The structural analysis in the three sub-studies as well as the analysis across the whole dataset involved coding the data with the use of Nvivo 12 software. The codes thus represented units of significance and these units of significance were structured into themes. Simonÿ et al (2018) propose a table that may be used to illustrate examples of the structural analysis. This table is included in article 1 and 3 (Rasmussen, Guise, et al., 2021a; Rasmussen, Petersen, et al., 2021) Furthermore, below Table 3 shows an example of the structural analysis across the whole dataset. In this kappa and in the articles, the structural analysis is presented in the Findings section.

**Table 3.** Example of structural analysis

Units of meaning (What is said)	Units of significance (What is being talked about)	Theme
"I suffered a mental breakdown and was therefore unemployed for a longer period. And then I had to go through work capability assessment and all that crap, and, you know, all that kind of thing with the public authorities. Damn it all! I wouldn't wish it for any of my fellow human beings to go through that, because God, it was degrading and humiliating! They kept looking at me and thinking, she's just a mess. And they talked really condescending to me. It's really a way of stepping on people. They were so rude." (Interview, Lena).	Feelings of stigmatization in relation to occupational situation	Stigmatization, self-stigmatization, and feelings of inferiority
"And then, for example, when you are hospitalized, it is something they ask you about: "What about your social network?" "I don't have any." "That's not possible!" "Well, yes it is. I am a living proof of that."" (Interview, Adam).	Feelings of stigmatization in relation to social isolation	
"The first time I met that nurse, she asked me: "Do you drink a lot of beer?" And she just looked at me like I was some kind of scum. I could tell that she thought I was an alcoholic or someone who did not know how to take care of myself." (Interview, Liam).	Feelings of stigmatization in relation to lifestyle	

In the critical interpretation and discussion, a further comprehensive and more sophisticated understanding of the dataset is reached (Simoný et al., 2018). As argued by Ricoeur (1981a), and described previously, through distanciation, the lived experiences become detached from the author's world and it becomes possible to use them to be critical and gain a deeper understanding of the reader's world. In this PhD study, as it will be further explained in the next section, psychosocial theories were actively used to further interpret and understand the participants' lived experiences. By interpreting and discussing the participants' lived experiences in a dialogue with existing theory and research, it became possible to bring the experiences to a more universal level (Simoný et al., 2018). The experiences were thus seen both as reflections of broader social phenomena described in the existing literature and as a way of being critical of these phenomena and thereby gain a deeper understanding of

them (Simoný et al., 2018). Through the critical interpretation and discussion, the PhD study thus contributes to our understanding of social inequality in ischemic heart disease as a social phenomenon. In this dissertation and in articles 1 and 3, the critical interpretation and discussion are presented in the Discussion section. In article 2, the critical interpretation is presented together with the structural analysis in the Findings sections and the discussion is presented in the Discussion section. This was done to make the article fit the standards of the journal.

In critical hermeneutic studies, internal validation of interpretations is not obtained through member checks. Instead, co-authors may be included to help discuss the interpretations and thereby strengthen the internal validation (Simoný et al., 2018). During the process of data analysis and interpretation, the co-authors of the three articles were therefore invited to discuss the codes, themes, and interpretations of the sub-studies and the overall analysis and interpretation of the PhD study.

## **2.8. THEORETICAL FRAMEWORK**

### **2.8.1. THE PSYCHOSOCIAL PERSPECTIVE ON SOCIAL INEQUALITY IN HEALTH**

The psychosocial perspective on social inequality in health constitutes the overall theoretical framework of this PhD study. In the above-described steps of critical interpretation and discussion (Simoný et al., 2018), psychosocial theories were actively used to interpret, understand, and discuss the data.

The psychosocial perspective is termed a ‘perspective’ rather than a unified theory because it entails a set of related theoretical approaches, all providing a possible explanation for why people with a low socioeconomic status experience higher levels of health-harming stress than people with a higher socioeconomic status (Bartley, 2017; Elstad, 1998).

### **2.8.3. THE USE OF THEORY IN THE THREE SUB-STUDIES**

In the analysis and interpretation of this kappa and the three sub-studies, different psychosocial theories were used to interpret, understand, and discuss the data.

The first sub-study mainly draws on the theory of social support as outlined by Cohen and Wills. Their theory describes resources provided by social relationships that positively impact health and well-being (Cohen & Wills, 1985). As explained in the Introduction, research indicates that social support may play an important role in social inequality in ischemic heart disease, but there is a lack of knowledge on the mechanisms that drive this inequality (Child & Albert, 2018). Cohen and Will’s theory of social support was therefore used to understand the meaning of having or not having social relationships that provide support and the different kinds of support that affected participants’ experience of their life with ischemic heart disease.

The second sub-study draws on the theory of cultural health capital presented by Shim, which conceptualizes a set of unequally distributed cultural skills, competencies, attitudes, behaviors, and interactional styles that may be displayed by patients and healthcare professionals and thereby be exchanged into attentive and satisfying healthcare encounters (Shim, 2010). As explained in the Introduction section, problematic healthcare interactions are often explained by the participants' low level of health literacy (Schultz et al., 2018). However, original conceptualizations of health literacy have been criticized by a second wave of health literacy researchers for being too rationalistic and individually oriented instead of emphasizing the important influence of social contexts (Chinn, 2011). Nevertheless, this second wave of health literacy research has done little to highlight the social context of healthcare interactions. The cultural health capital framework was therefore used in this PhD study to gain new insights into unequal cardiac treatment and healthcare because it may help us understand the structural and interactional factors shaping interactions between patients and healthcare professionals.

The third sub-study is primarily inspired by the epidemiology of social stress theory, which argues that people with a low socioeconomic status are more exposed to external stressors than people with a higher socioeconomic status (Turner & Turner, 2005). As illustrated in the Introduction, research indicates that both midlife and low socioeconomic status are associated with high levels of psychosocial stress (Chandola & Marmot, 2011; Turner & Turner, 2005; Turner et al., 1995). Nevertheless, there is a lack of studies exploring the experience of psychosocial stress while living with ischemic heart and being at midlife and socially disadvantaged. The epidemiology of social stress theory was therefore used to understand the specific stressors that make socially disadvantaged midlife ischemic heart patients experience elevated levels of unhealthy stress.

The critical interpretation and discussion across the dataset in this kappa draws more generally on the psychosocial perspective as a whole theoretical framework (Elstad, 2000). The overall objective of the PhD study is to provide an in-depth understanding of social inequality in ischemic heart disease by exploring the influence of underlying psychosocial factors on socially disadvantaged patients' lived experience of life with ischemic heart disease. This aim calls for the use of different psychosocial theories.

## **2.9. ETHICS**

Danish legislation dictates that ethical approval of qualitative studies is based on informed consent from participants and therefore not approval from a national or public agency (National Committee on Health Research Ethics, 2019; Danish Ministry of Health, 2011). Before the first interview with each of the participants, an informed consent contract was signed by both the PhD student and the participant. A copy of the informed consent contract is seen in Appendix B. The informed consent contract was based on the principles of the Helsinki Declaration developed by the World Health Organization as a guideline for ethical principles in medical research



involving human subjects (World Medical Association, 2013). In accordance with the Helsinki Declaration (World Medical Association, 2013), the PhD student informed the participants that their consent was voluntary and that they had the right to withdraw from the study at any time before the dissemination of the data. Furthermore, the PhD student provided information about the study's aim and methods to ensure that the consent was sufficiently informed. This information was first provided in the initial phone call in the recruitment process and then repeated when the PhD student met the participants before the first interview. The participants were also encouraged to ask questions about the study at all times.

When conducting health research, it is important to consider potential risks regarding the health of the participants in the study and to inform them about these considerations (World Medical Association, 2013). The PhD student therefore ensured the participants that despite of the observations of their involvement with the healthcare system, the PhD study would not affect their medical treatment and no information would be shared with the health system or other healthcare professionals.

Following the principles of the European General Data Protection Regulation (The European Parliament and the Council of the European Union, 2016), the PhD student made sure that the participant's confidentiality was protected. This was ensured by storing personal data about the participants in an encrypted file drive to which only the PhD student had access. Furthermore, pseudonyms are used instead of the actual names of the participants in this kappa, and in the articles reporting on sub-study 1 and 2. In the article reporting on sub-study 3, because of journal requirements, neither the participants' actual names nor pseudonyms were used.

The European General Data Protection Regulation requires each controller of the data and the controller's representative to keep a record of the processing activities under its responsibility (The European Parliament and the Council of the European Union, 2016). The PhD study is therefore a part of Aalborg University's list of processing activities under the journal number: 2018-899/10-0288.

The Karen Elise Jensen Foundation generously contributed financially to the PhD study. However, the foundation had no influence on the findings of the study. There are therefore no conflicts of interest to report in the study.

## CHAPTER 3. FINDINGS

The following chapter presents the findings of the PhD study in three different ways. First, an overview of all the participants included in the study is presented. Second, the findings of the three sub-studies are summarized. Last, the findings across the whole dataset are described through a naïve reading and a structural analysis.

### 3.1. PARTICIPANT CHARACTERISTICS

In this PhD study, 30 participants with the predefined characteristics were included. Through the research process, based on the items presented by Malterud et al (2016), 30 participants were estimated to be enough to reach a sufficient level of information power.

In line with the predefined inclusion criteria, all participants were ischemic heart patients who were socially disadvantaged based on a low health literacy and limited access to social support. Furthermore, the participants were between 53-77 years of age. They varied in terms of employment status, civil status, and according to whether they had children. Of the 30 participants, seven were female and 23 were male. None of the participants belonged to an ethnic minority. The unequal distribution of gender and the lack of inclusion of ethnic minorities may reflect that gender and ethnicity were not a consideration in the sampling strategy. Furthermore, only a few of the participants from the survey study who matched the predefined criteria were ethnic minorities, and none of the ethnic minorities who were called to be recruited for this PhD study responded. A detailed overview of the participants' characteristics is provided in Table 4.

**Table 4.** Characteristics of participants

Pseudonym	Years of age	Occupation	Civil status	Children	Included in sub-study
Adam	53	Employed	No partner	No children	1,2,3
Michael	53	Disability pension	Partner	Children living at home	1,2,3
Noah	55	Employed	No partner	Children living at home	1,2,3
Oliver	55	Unemployed	Partner	Children grown up	1,2,3
Kirsten	55	Employed	Partner	Children grown up	1,2,3

<b>Sally</b>	56	Employed	Partner	Children grown up	1,2,3
<b>Bo</b>	56	Self-employed	Partner	Children grown up	1,2,3
<b>William</b>	56	Unemployed	No partner	No children	1,2,3
<b>Sebastian</b>	58	Employed	Partner	Children grown up	1,2,3
<b>Nathalie</b>	58	Disability pension	No partner	Children grown up	1,2,3
<b>Viggo</b>	59	Employed	Partner	Children living at home	1,2,3
<b>Benjamin</b>	59	Employed	Partner	Children grown up	1,2,3
<b>George</b>	60	Unemployed	No partner	Children living at home	1,2,3
<b>Lily</b>	60	Employed	No partner	Children grown up	1,2,3
<b>Christopher</b>	60	Early retirement	Partner	Children grown up	1,2,3
<b>Carl</b>	60	Employed	Partner	Children grown up	1,2,3
<b>Daniel</b>	60	Unemployed	Partner	Children living at home	1,2,3
<b>Brian</b>	60	Self-employed	No partner	No children	1,2,3
<b>Jack</b>	64	Disability pension	No partner	Children grown up	1,2
<b>Lena</b>	65	Early retirement	Partner	Children grown up	1,2
<b>John</b>	65	Retired	Partner	Children grown up	1,2
<b>David</b>	66	Retired	Partner	Children grown up	1,2
<b>Jonathan</b>	66	Retired	Partner	Children grown up	1,2
<b>Liam</b>	68	Retired	No partner	Children grown up	1,2
<b>Susan</b>	74	Retired	Partner	Children grown up	1,2
<b>Julian</b>	74	Self-employed	No partner	No children	1,2
<b>Stephanie</b>	74	Retired	No partner	Children grown up	1,2

<b>Bob</b>	75	Retired	Partner	Children grown up	1,2
<b>Jacob</b>	76	Retired	Partner	Children grown up	1,2
<b>Alexander</b>	77	Retired	No partner	Children grown up	1,2

### 3.2. SUMMARY OF THE FINDINGS OF THE SUB-STUDIES

The following presents a brief summary of the findings from each of the three sub-studies to provide an overview of the specific themes and key messages they represent.

#### 3.2.1. SUMMARY OF THE FINDINGS FROM SUB-STUDY 1

Sub-study 1 explored the role of social support from close social relationships in socially disadvantaged patients' lived experience of life with ischemic heart disease (Rasmussen, Guise, et al., 2021a). Even though the participants were sampled to have a limited access to social support, the findings of the study showed that some of the participants did receive important support from a few close and caring relationships (Rasmussen, Guise, et al., 2021a). The findings showed a notable difference in how the participants lived with their illness depending on whether they had supportive social relationships or not (Rasmussen, Guise, et al., 2021a).

The participants received social support in three different ways. Firstly, supportive social relationships helped them navigate in and reconcile with their illness. Contrarily, those who lacked this kind of support generally struggled to find order, structure, and consistency in their life with ischemic heart disease (Rasmussen, Guise, et al., 2021a). Secondly, some of the participants gained support that helped them feel empowered and in control of their situation. Those who did not receive this kind of support generally felt powerless and unable to manage their condition (Rasmussen, Guise, et al., 2021a). Lastly, those who were engaged in close and caring social relationships gained a sense of meaning in their life. On the other hand, those who lived socially isolated lives felt that their life was meaningless, and these participants lacked the motivation to fight to stay alive (Rasmussen, Guise, et al., 2021a).

Partners seemed to be an especially important source of social support, particularly for the male participants (Rasmussen, Guise, et al., 2021a). Furthermore, the findings showed that not all close social relationships were supportive and that unsupportive relationships might even have a negative effect on the participants' life with ischemic heart disease (Rasmussen, Guise, et al., 2021a).

The findings from this sub-study thus indicate that social support is crucial for how socially disadvantaged patients experience their life with ischemic heart disease (Rasmussen, Guise, et al., 2021a).

### **3.2.2. SUMMARY OF THE FINDINGS FROM SUB-STUDY 2**

Sub-study 2 explored socially disadvantaged ischemic heart patients' lived experience of healthcare interactions through the lens of the theoretical framework of cultural health capital (Rasmussen, Guise, et al., 2021b). The findings showed that the participants generally struggled to live up to the healthcare professionals' expectations. Consequently, they failed to exchange cultural health capital and receive attentive treatment and care (Rasmussen, Guise, et al., 2021b).

The study identified two situations in which the participants struggled to exchange cultural health capital. Firstly, the participants and the healthcare professionals had conflicting ways of understanding and communicating about the participants' health condition. Within this mismatch, the participants experienced an unequal power balance as the healthcare professionals dominated the norms of the clinical encounter (Rasmussen, Guise, et al., 2021b). Secondly, the participants felt that they struggled to meet the healthcare professionals' expectations of their behavior and appearance. They compared themselves to patients with a higher social status, whom they thought were better at meeting these expectations and therefore received more attentive treatment and care (Rasmussen, Guise, et al., 2021b).

Nevertheless, the study also showed that a few of the participants had experiences of healthcare interactions in which they felt heard, acknowledged, and prioritized. In these encounters, the healthcare professionals adjusted their treatment and care to the specific patients' habitus and life circumstances and met them in a non-judgemental and respectful way, which made the participants feel accepted and empowered (Rasmussen, Guise, et al., 2021b).

The findings of this study show that unequal cardiac treatment and healthcare are not just products of the patient's individual cognitive abilities, but also a product of more interactional, structural, and social factors (Rasmussen, Guise, et al., 2021b).

### **3.2.3. SUMMARY OF THE FINDINGS FROM SUB-STUDY 3**

Sub-study 3 explored the influence of psychosocial stress on life with ischemic heart disease for socially disadvantaged patients at midlife (Rasmussen, Petersen, et al., 2021). The findings showed that the participants were exposed to several external stressors that appeared to reinforce each other and create an overwhelming burden of stressful feelings (Rasmussen, Petersen, et al., 2021).

Overall, the participants were exposed to three kinds of stressors. Firstly, the participants' relationship with their family members constituted an important stressor. These relationships were often characterized by conflicts and communication problems. Furthermore, the family members struggled to help each other cope with the participants' illness, which made the participants feel socially isolated and alone with their concerns (Rasmussen, Petersen, et al., 2021). Secondly, the participants experienced stressors related to their occupational and financial situation. Because of their illness, some of the participants were unable to work for longer periods, which

created financial problems, social isolation, and a lack of purpose in their lives. Furthermore, because of their low position in the hierarchy of the workplace, the participants felt that their managers did not acknowledge their illness or listen to their needs (Rasmussen, Petersen, et al., 2021). Lastly, the participants experienced stressors related to stigmatization in clinical encounters. Because of their social status, young age, lifestyle, and appearance, the participants felt judged poorly by the healthcare professionals. Many participants internalized these perceptions and blamed themselves for their premature illness (Rasmussen, Petersen, et al., 2021).

The findings from this sub-study thus indicate that the combination of being at midlife and socially disadvantaged while living with ischemic heart disease created a situation marked by straining external stressors and a burden of psychosocial stress (Rasmussen, Petersen, et al., 2021).

### **3.2. NAÏVE READING ACROSS THE WHOLE DATASET**

In this section, a naïve reading across the whole dataset of the PhD study is presented. This section provides an immediate interpretation of the findings, which will be further elaborated in the structural analysis, critical interpretation, and discussion (Simony et al., 2018).

The naïve reading revealed that the participants generally were burdened by external psychosocial stressors that made their lives with ischemic heart disease stressful. This stress appeared to affect the participants mentally, as they generally felt depressed, frustrated, resentful, and in lack of energy. Furthermore, the stressful feelings also seemed to affect the participants' willingness and motivation to adhere to their treatment and follow a beneficial lifestyle. Lastly, the participants also had the experience that the overload of stressful feelings affected their physical health by worsening their ischemic heart disease. However, in a few cases, some of the participants gained support from close social relationships or healthcare professionals, which seemed to make their lives with ischemic heart disease less stressful.

### **3.3. STRUCTURAL ANALYSIS ACROSS THE WHOLE DATASET**

This section presents the structural analysis across the whole dataset of the PhD. The purpose of the structural analysis is to validate the immediate interpretation of the naïve reading by going more into depth with the patterns that emerged across the dataset (Ricoeur, 1976a; Simony et al., 2018).

Through this overall structural analysis, five key themes were found. Four of these themes take their point of departure in external psychosocial stressors experienced by the participants: "Conflicting social relationship, social isolation, and lack of social support", "Occupational and financial strain", "Problematic interactions with healthcare professionals", and "Experiences of stigmatization". The fifth theme "Being supported in life with illness" focuses on situations in which the participants felt supported, which helped them buffer the effect of the straining stressors.

These themes cover the central themes from the sub-studies and understand the themes in relation to each other. Figure 3 shows how the five overall themes are represented in the different sub-studies. Furthermore, in the structural analysis across the dataset, the themes from the sub-studies are elaborated and new examples and quotes are included.

	Conflicting social relationships, social isolation, and lack of social support	Occupational and financial strain	Problematic interactions with healthcare professionals	Experiences of stigmatization	Being supported in life with illness
Sub-study 1	•		•		•
Sub-study 2		•	•	•	•
Sub-study 3	•	•	•	•	

**Figure 3.** Representation of the overall themes in the sub-studies

### 3.3.1. CONFLICTS, SOCIAL ISOLATION, AND LACK OF SOCIAL SUPPORT

Through the participants' lives, their social relationships generally appeared to be marked by conflicts and disruptions. Already in their childhood, the participants had experiences of abandonment and loss of close attachment figures. Either one of their parents, often the father, had left the family, or the parents had died when the participants were young. Furthermore, some had painful experiences of violent behavior in their childhood, most often shown by the father, and directed at them, their siblings, and/or their mother. Jack's relationship with his father, which he describes in the following sequence, is an example of this:

*Researcher: "How would you describe your relationship with your parents?"*

*Jack: "My mom is okay, but my dad was a tyrant."*

*Researcher: "How?"*

*Jack: "Well, it was like... how can I express it? He protected my brother, but sometimes when I couldn't keep my mouth shut, I would get beaten up. And then one day when I had moved away, I came home, and I could tell by the look on my mum that something was wrong. Then I went over to the old chap and said: "What is wrong?" He said I shouldn't interfere. Then I said: "Do you know what, let's go outside and I will give you a thorough beating. I am not afraid of you anymore." And then finally, it was my turn to beat the hell out of him. My mom had to separate us; otherwise, I would have killed him. And I would have enjoyed killing him" (Interview, Jack).*

Jack, and other participants, explained that their parents lacked financial, social, and mental resources, which, they argued, could have been the reason for their abandoning and violent behavior.

This pattern of conflicting and disrupted social relationships generally seemed to follow the participants through their lives. Most of the participants had experienced severe conflicts with, or had lost contact to, either their partner, parents, children, siblings, or close friends (Rasmussen, Guise, et al., 2021a). Like their own parents, the participants and their family members often seemed to lack the resources to

support each other because they were strained by stressors such as economic hardship and lack of job control (Rasmussen, Petersen, et al., 2021). Furthermore, most of the participants struggled to communicate with their closest relatives about sensitive topics, including their illness. The participants explained that both they and their family members feared that their illness would end in premature death. However, as they failed to communicate with each other about this, both they and the family members felt rather alone with these concerns and anxieties (Rasmussen, Petersen, et al., 2021).

The midlife participants appeared especially burdened by conflicts and lack of support in the family (Rasmussen, Petersen, et al., 2021). They had younger children who depended more on them than the older participants' children did. The midlife participants' relationship with their family members was thus a significant part of their life; and a poorly functioning family relationship was experienced as particularly stressful (Rasmussen, Petersen, et al., 2021).

The participants' illness also sometimes worsened or challenged their possibility of maintaining social contact. For some of the participants, the physical limitations they experienced due to their ischemic heart disease made it difficult for them to engage in social relationships. Liam, for example, lived remotely and struggled to drive his car because of the physical limitations he experienced. Consequently, he found it difficult to visit friends and relatives, which made him feel socially isolated. Furthermore, for some of the participants, their co-workers were their only social contacts; and when their illness prevented them from working, this added further to their feelings of social isolation and loneliness (Rasmussen, Petersen, et al., 2021).

As most of the participants lacked close and caring social relationships, the majority also lacked social support in their life with ischemic heart disease, which meant that they felt alone in their efforts to navigate in as well as reconcile and cope with their disease (Rasmussen, Guise, et al., 2021a).

Furthermore, being socially isolated was often associated with a sense of meaninglessness among the participants. As reflected in the following quotation by Julian, the participants who lived socially isolated often expressed an indifference towards their own death. They were therefore not as motivated to fight to stay alive and follow medical instructions as those who were engaged in close and caring relationships and therefore experienced a sense of meaning in their life (Rasmussen, Guise, et al., 2021a).

*"After the heart attack, my sister asked me: 'What did you think?' And then I said: 'I didn't really think much.' If I were to die from it, it wouldn't matter anyway. I don't have any family other than my siblings. No children or anything. It wouldn't really matter, you know... Then they could sell the house." (Interview, Julian).*

As illustrated in Julian's statement, the participants' experience of their existence as valuable seemed to be closely related to their social relationships.



The experience of being socially isolated and feeling a sense of meaninglessness was present among the older participants in particular. These participants were often especially burdened by physical immobility and were more often widowed than were the midlife participants.

### 3.3.2. OCCUPATIONAL AND FINANCIAL STRAIN

The participants' employment situation and occupational conditions played an important role in their lives with ischemic heart disease. This was especially the case for the midlife participants who were still at a working age (Rasmussen, Petersen, et al., 2021).

The participants often experienced hierarchical working conditions. Because their job function was not considered as critical as those of others were, they felt that they were placed in the lower echelons of these hierarchies. The participants therefore often felt that their needs were not heard or prioritized by their managers. The workplaces were therefore often not able to accommodate the limitations that the participants' illness created, which made it difficult for them to stay in their job. These experiences created a sense of inferiority among the participants (Rasmussen, Petersen, et al., 2021).

Generally, many of the participants were unable to work for longer periods of time, either because their ischemic heart disease made it difficult to meet the requirements of their jobs or due to other mental or physical health issues. Some of the participants explained that their inability to work led to social isolation. This was especially the case for participants who were already depleted of social contacts (Rasmussen, Petersen, et al., 2021). Furthermore, not being able to work seemed to deprive some of the participants of a sense of purpose in their life. These participants felt that they did not have something to wake up to in the morning or that there was no clear goal with their existence. Like the participants who lacked a sense of meaning in their life because of social isolation, participants who lacked a sense of purpose because of unemployment seemed to lack motivation to adhere to their medical treatment and implement lifestyle changes.

Furthermore, some of the participants were self-employed owners of small businesses. As these participants' presence in the company had a significant influence on its existence, the business was rather sensitive to their physical well-being and ability to work. This situation is well described in the following quotation by Bo:

*"I had just started my business in January, and this was in November [his heart attack, red.], so I had to go back to work immediately. There was no one to cover for me, so I just had to go back. Obviously, that was very hard. [...] You just must clench your teeth and then... some days it really hurts, like in your back and something, but that's just the way it is."* (Interview, Bo).

As illustrated in this excerpt, the self-employed participants sometimes had to choose between either working despite of physical strain or miss their income. For the self-employed participants, not being able to work because of their illness was therefore often accompanied by a significant mental pressure.

The participants' lives were generally marked by economic hardship and financial insecurity. Their low educational and occupational status meant that their income was often low. Furthermore, being unable to work for longer periods because of their illness, and taking care of several children, sometimes as a single parent, added additional pressure on their economic situation. The participants explained that experiences of economic hardship often created profound feelings of distress (Rasmussen, Petersen, et al., 2021).

Economic hardship also made it difficult for the participants to afford their medication and comply with a healthy lifestyle recommended by the healthcare professionals (Rasmussen, Guise, et al., 2021b). For example, at the time of his first heart attack, William had been unemployed for several years and therefore received the lowest unemployment benefit. When he had to start paying for medicine regularly, his financial situation became fragile and caused daily feelings of stress, which meant that he sometimes chose not to take his medication:

*"I was under so much pressure, financially. Bills I couldn't pay, and you know... And then, on top of all that, you also have to pay for your medicine. I will never forget the first time I had to pay for my medicine, I was shocked; it was so God damn expensive. And I couldn't get any help or anything. I applied and all that, but I couldn't get a single thing. It was just like everything started falling apart. And then sometimes, I chose to pay for dinner instead of medicine." (Interview, William).*

William's economic condition thus appeared to affect his compliance with the healthcare professionals' instructions. However, the participants often experienced that the healthcare professionals did not acknowledge or take their material conditions into account in the treatment and healthcare of their ischemic heart disease (Rasmussen, Guise, et al., 2021b).

### **3.3.4. PROBLEMATIC INTERACTIONS WITH HEALTHCARE PROFESSIONALS**

Most of the participants had negative experiences of healthcare interactions. They often felt that they had trouble communicating with the healthcare professionals, and did not feel acknowledged, heard, or prioritized in clinical encounters (Rasmussen, Guise, et al., 2021b). Severe anger towards and distrust in the healthcare system were thus widespread among the participants.

These interactional problems often revolved around differences in the participants' and the healthcare professionals' way of understanding and communicating about the participants' illness (Rasmussen, Guise, et al., 2021b). The following description of Michael's experience of his hospitalization illustrates how the contradictions between the participants and healthcare professionals created a tension between them. Michael was acutely hospitalized because of a heart attack. He suffered from anxiety disorder and was mentally very affected by his ischemic heart disease. However, he did not feel that the healthcare professionals responded to the mental part of his problems:

*“That hospital is just like a meat factory. One day I woke up and I was in such a state mentally that I couldn’t really take it anymore. Then I said to the nurse: ‘I know that I have the right to see someone from the psychiatric department when I feel his way.’ It is something my sister once told me, she works for the healthcare system; I have the right to talk to a psychologist when I feel like this. And I just wanted that, and it had to be right now. I was ready to jump out of the window, I told her. It felt completely awful. And then she called the psychiatric department, but they did not have time. And then my siblings and wife came, and they were shocked to see me feeling so bad. And then the surgeon who had done the surgery came and she was so proud of the work she had done, and she just said: ‘I have given you a triple bypass.’ And you could tell that she was a bit proud about it; that she had saved my life and so on. And I was just like: ‘Well okay, do you mind helping me open that window so I can jump out of it.’ I felt that bad that day. And then she was just like... because she had expected to be praised and appreciated, and I was just this stupid idiot who would rather commit suicide.” (Interview, Michael).*

In this situation, the surgeon appeared primarily focused on medical and technical aspects of Michael’s surgery, while Michael was desperate for someone to respond to and help him manage his mental reaction to the situation. As illustrated in his expression, “a meat factory,” this encounter made Michael feel like a body and not a human being with feelings. Michael’s experience reflects a general tendency in the participants’ experiences of healthcare interactions. The healthcare professionals often seemed primarily oriented towards the biomedical, objective understanding of the participants’ health problems, while the participants were oriented towards their personal experience of suffering (Rasmussen, Guise, et al., 2021b).

Within these incompatibilities and contradictions, there appeared to be an unequal power balance. This was especially the case in interactions with doctors (Rasmussen, Guise, et al., 2021b). The participants felt that the healthcare professionals defined the norms of the clinical encounter and therefore also the ways in which the participants’ problems should be understood, communicated, and treated (Rasmussen, Guise, et al., 2021b). In general, the participants felt that the healthcare professionals originated from a completely different and superior social world. To describe the social world from which the healthcare professionals originated, the participants often used phrases that referred to the healthcare professionals’ clinical, white uniforms (Rasmussen, Guise, et al., 2021b). This is for example seen in the following quote from an interview with Noah, who used the phrase ‘lonely white’ to illustrate how he found it difficult to access the healthcare professionals’ world and perspectives:

*Noah: “And that is probably my biggest problem with doctors, that they are ‘lonely white’.”*

*Researcher: “And what do you mean with that?”*

*Noah: “What I mean is that someone like me shouldn’t try and tell them something. They are the smart ones. That is what I mean, they won’t... they won’t accept that we have an opinion that could be used for something, too.” (Interview, Noah).*

The participants generally felt that they did not meet the healthcare professionals’ expectations of them as patients in terms of their behavior, their way of communicating, and their appearance. Consequently, they felt that their treatment and care received lower priority than the treatment and care other patients got who succeeded in meeting these expectations (Rasmussen, Guise, et al., 2021b). Overall,

these unequal power balances contributed to feelings of inferiority and of being unfairly treated among the participants.

Furthermore, structural and organization conditions in the healthcare system also seemed to make it harder for healthcare professionals to engage attentively with the patients and acknowledge their perspectives and experiences. The participants explained that the consultations were often restricted by limited time spans, which made it difficult for the healthcare professionals to spend enough time to thoroughly understand the patients' problem (Rasmussen, Guise, et al., 2021b).

Because the participants often felt supported neither by their social relationships nor by healthcare professionals, they generally felt rather alone with the management of their illness. They expressed that no one listened or responded to their concerns, questions, and perspectives. This added further to their general experience of their life with ischemic heart disease as chaotic, unstructured, and difficult to manage.

### 3.3.3. STIGMATIZATION AND SELF-STIGMATIZATION

Most of the participants had experiences throughout their lives of being met with stigmatizing prejudices that were often related to their social position, social network, appearance, lifestyle, or health status (Rasmussen, Guise, et al., 2021b; Rasmussen, Petersen, et al., 2021).

The participants often felt judged by markers of their low social position, such as their job status, educational level, use of words, or clothes, which were interpreted as signs of lacking motivation, engagement, and capability (Rasmussen, Guise, et al., 2021b; Rasmussen, Petersen, et al., 2021). This was especially the case in their involvement with public authorities. In the following example, Lena shared an experience of stigmatization in her engagement with the public employment office during a period of unemployment due to mental health problems:

*"I suffered a mental breakdown and was therefore unemployed for a longer period. And then I had to go through work capability assessment and all that crap, and, you know, all that kind of thing with the public authorities. Damn it all! I wouldn't wish it for any of my fellow human beings to go through that, because God, it was degrading and humiliating! They kept looking at me and thinking, she's just a mess. And they talked really condescending to me. It's really a way of stepping on people. They were so rude."*  
(Interview, Lena).

Lena explained that she felt judged as less self-disciplined because she had no education, suffered from mental health issues, and was unable to work; an experience she felt was degrading and humiliating.

Earlier experiences of stigma were often reinforced when the participants were diagnosed with ischemic heart disease as they felt stigmatized and judged poorly by healthcare professionals (Rasmussen, Petersen, et al., 2021). The participants' physical appearance was one of the main triggers of stigma in clinical encounters. They felt that their appearance was either interpreted as a sign of their low social status

or of a poor lifestyle, both of which were seen as markers of lack of self-discipline (Rasmussen, Guise, et al., 2021b; Rasmussen, Petersen, et al., 2021). Additionally, their lifestyle was often highlighted as the reason for their ischemic heart disease, both by healthcare professionals and by people in their private life. They thus felt that they were judged as responsible for their illness because they were not able to control themselves and live sufficiently healthy lives. This was especially the case for the midlife participants who felt that in order to experience premature ischemic heart disease, they must have led a very unhealthy life (Rasmussen, Petersen, et al., 2021).

Additionally, some of the participants felt degraded by healthcare professionals when no one came to visit them at the hospital. In the following example, Adam explained how his lack of social network was met with astonishment and disbelief when he was hospitalized:

*“And then, for example, when you are hospitalized, it is something they ask you about: “What about your social network?” “I don’t have any.” “That’s not possible!” “Well, yes it is. I am a living proof of that.”” (Interview, Adam).*

Adam experienced the healthcare professional’s reaction to his situation as judgmental, condescending, and disrespectful.

These stigmatizing experiences were widely associated with self-stigmatization and self-blame among the participants who appeared to internalize the healthcare professionals’ emphasis on their lifestyle, and blamed themselves for experiencing ischemic heart disease (Rasmussen, Guise, et al., 2021b; Rasmussen, Petersen, et al., 2021). Additionally, some of the participants thought that they did not deserve to be prioritized in the healthcare system because they were responsible themselves for their illness (Rasmussen, Guise, et al., 2021b).

### **3.3.5. BEING SUPPORTED IN LIFE WITH ILLNESS**

As described in the previous themes, the participants generally did not feel supported either by their closest social relationships or by healthcare professionals in their life with ischemic heart disease. However, a few participants had important experiences of being supported that positively impacted their life and care encounters.

Generally, a notable difference was seen in the data between those who were engaged in close, caring, and supportive social relationships and those who were not (Rasmussen, Guise, et al., 2021a). Most importantly, being engaged in close and caring social relationships provided the participants with a sense of meaning and thus a motivation to avoid premature mortality by following their medical treatment and adhering to lifestyle changes (Rasmussen, Guise, et al., 2021a). Furthermore, supportive social relationships helped the participants navigate their different medical appointments; and when the participants’ communication with healthcare professionals was challenged, the social relationships sometimes acted as a sort of translator between them. Moreover, talking to others who attentively listened to them about their illness helped the participants in reconciling with what had happened to

them (Rasmussen, Guise, et al., 2021a). An example of this is seen in the following quotation by Susan:

*Susan: "I still struggle to comprehend what happened to me. And it really helps to talk with my husband about it. We still sometimes do that."*

*Researcher: "And what is it that you talk about then?"*

*Susan: "We talk about the whole process, how it started with my general practitioner giving me the wrong medicine and then when the ambulance came and took me to the hospital. And then, when we are done going through that, I feel a little better."*

Susan's experience of her heart attack, which she talks about in this excerpt, took place a few years prior to the time of the interview. Nevertheless, she still needed sometimes to go through the experience with her husband to feel reconciled with what had happened.

In contrast, those who lacked social support often found their life with ischemic heart disease chaotic, uncontrollable, and meaningless. Close and supportive social relationships thus appeared to have the potential to mitigate these stressful feelings (Rasmussen, Guise, et al., 2021a).

Being in a well-functioning relationship with a caring partner appeared to be an especially important source of support. This specific type of social relationship tended to persist over time, while many other of the participants' relationships were disrupted. Furthermore, this sort of relationship often appeared to be the most deep-felt relationship and therefore also was the most important source of meaning (Rasmussen, Guise, et al., 2021a). The relationship with a partner seemed to be especially important for the male participants, while the female participants to a higher extent had close relationship with their children and female friends whom they relied on for social support (Rasmussen, Guise, et al., 2021a). Some of the female participants even found it easier to cope with their illness without a partner. For example, Lily was in a marriage marked by psychological and physical violence when she got her first heart attack. She was afraid to tell her husband about her illness because she could never anticipate his reaction and therefore received no support in relation to her ischemic heart disease. Shortly after the heart attack, she was divorced from her husband and found it much easier to cope with her illness when she was living alone. She had a close relationship with her daughter, which created meaningfulness in her life.

Receiving social support from close and caring social relationships appeared to be particularly important for the midlife participants, who, as previously explained, were often strained by conflicts and communication problems in the family. When, on rare occasions, a family member or a friend reached out to the midlife participants and asked them how they felt or offered to accompany them in medical consultations, it was therefore experienced as a crucial comfort and relief.

Furthermore, a few participants gave positive accounts of receiving significant support from health professionals. In contrast to the previously described poor experiences of clinical encounters, these participants felt that the healthcare

professionals met them with an acknowledging and respectful attitude. Moreover, they felt that the healthcare professionals paid attention to their perspectives, life circumstances, and individual needs. Additionally, the healthcare professionals provided specific suggestions on how to overcome specific challenges, which made the participants feel empowered to act on their situation (Rasmussen, Guise, et al., 2021b).

An example of this approach to care is John's experience of participating in a rehabilitation program after receiving surgical treatment for his heart attack. John enjoyed participating in this program and when it ended, he fell into a depression. His wife then made contact to one of the rehabilitation nurses whom he started talking to once a week. These conversations significantly improved his mental health (Rasmussen, Guise, et al., 2021a). In the following, John explains why he appreciated the attitude of the healthcare professionals at the rehabilitation program:

*John: "Those three persons who run that rehabilitation program, they are amazing people. Completely amazing!"*

*Researcher: "And what is it about them that is amazing?"*

*John: "They are just so straightforward. It's like they have insights into every single person. That's what I have felt. I guess you can say that they are a really good judge of character, right? They can really tell how people are. And they have the time for it. Metaphorically, they "love" all of the people who attend the course, right? You are welcome and you are there to learn something, right, in a good way."*

*Researcher: "And what do you think it was about that nurse you talked to that was good?"*

*John: "I think she really tried to put herself in my position, right? Contrary to that doctor who just gave me those pills. She knows how to ask about the person." (Interview, John).*

What characterized John's experience with these healthcare professionals was that he felt seen and acknowledged as an individual person with specific perspectives, preconditions, experiences, and needs. This made him feel welcomed and appreciated, which motivated to learn from them. As seen in the excerpt, John contrasts this to an earlier experience with a general practitioner whom he thought failed to listen to his perspectives and acknowledge his needs.

Experiencing this kind of support from healthcare professionals was important for the participants' ability to cope with their illness. As previously explained, the participants generally struggled to find structure and consistency in their life with illness and to navigate their different medical appointments and prescriptions. Furthermore, they often lacked support from social relationships to help them cope with these challenges (Rasmussen, Guise, et al., 2021a). Meeting an emphatic healthcare professional who attentively listened to their concerns and provided simple and manageable solutions thus made the participants feel accepted and understood, and reduced many of their stressful feelings.

## CHAPTER 4. DISCUSSION

### 4.1. CRITICAL INTERPRETATION AND DISCUSSION OF THE FINDINGS

In this section, drawing on the critical hermeneutic approach, the central themes from the structural analysis are interpreted and discussed in a dialogue with psychosocial theories and existing research to gain a more comprehensive understanding of the findings (Simoný et al., 2018).

The overall objective of the study was to explore the influence of psychosocial factors on socially disadvantaged patients' lived experience of their life with ischemic heart disease. As explained in the Introduction, psychosocial factors operate at a meso-level that connects macro-level social factors to micro-level individual factors (Martikainen et al., 2002). Through the next sections, the influence of psychosocial factors on the socially disadvantaged patients' life with ischemic heart disease will thus be explained by discussing the relation between macro-level social factors, meso-level psychosocial factors, and micro-level individual factors.

#### 4.1.1. MACRO-LEVEL SOCIAL FACTORS

On a macro level, broader social factors, including structural conditions and societal discourses, were found to have a profound impact on the participants' experiences of life with ischemic heart disease.

##### 4.1.1.1. Income inequality and poor working conditions

Most of the participants explained that they were burdened by low income and economic hardship and thus exposed to the consequences of income inequality. Even though Denmark generally has a comparatively low level of income inequality, income inequalities still exist in Denmark and have generally been increasing since the 1990s (Aaberge et al., 2018).

Furthermore, the participants were faced with straining working conditions, including physically demanding jobs, low job security, and a low level of support from management. Similarly, Marmot and Theorell (2020) argue that people from lower socioeconomic groups generally have poorer psychosocial working environment as they have lower skill discretion, less authority over decisions, and less social support at their workplace. The present study illustrated how falling ill in a Danish context may exacerbate economic hardship and stress for socially disadvantaged ischemic heart patients if they are no longer able to meet labor market demands (Rasmussen, Petersen, et al., 2021).



#### **4.1.1.2. Social discourses related to health behavior and social status**

Two different broad social discourses seemed to affect the participants' life with ischemic heart disease. First, the participants' individual characteristics and health-related behaviors, such as smoking or inability to comply with medical advice, were often highlighted by healthcare professionals and others as one of the primary reasons for the occurrence or worsening of their ischemic heart disease (Rasmussen, Petersen, et al., 2021). This may reflect a general tendency in policies, interventions, and epidemiological research to emphasize individually oriented factors in the prevention and treatment of ischemic heart disease (Baum & Fisher, 2014; Hutchison & Holdsworth, 2019). Furthermore, this tendency may be related to neoliberal discourses emphasizing the individual's responsibility for its own fate (Peacock et al., 2014). In a qualitative study, Peacock, Bissel, and Owen (2014) showed how neoliberal discourses in Salford, UK, created what they termed a 'no legitimate dependency' discourse, where dependency on other people was denied and the responsibility for one's health was attributed to the individual. Even though Denmark can be categorized as a social democratic welfare state emphasizing the responsibility of the community (Diderichsen et al., 2015), Danish policies and interventions still deploy a narrow focus on lifestyle (Diderichsen et al., 2015; Ravn et al., 2016; Vallgård, 2011). The dominance of discourses emphasizing individual responsibility may help explain why the participants in the present study often felt that the responsibility for their ischemic heart disease was attested to themselves.

Second, the participants felt that the healthcare professionals and others looked down on them because they did not show markers of a high social status (Rasmussen, Guise, et al., 2021b; Rasmussen, Petersen, et al., 2021). These experiences may reflect broader social discourses related to social status. Wilkinson and Pickett have argued that high social status almost always is associated with success, superiority, and capability, while low social status carries connotations of being less motivated and competent (Wilkinson & Pickett, 2009). Furthermore, a survey study across 27 nations showed that across the different countries, poor people were more often associated with low competence than were rich people (Durante et al., 2017). Additionally, qualitative studies have shown how low socioeconomic status has led to social exclusion in professional work contexts (Kallschmidt & Eaton, 2019; Lee, 2017). Research has not previously explored these discourses and stereotypes in a healthcare setting or in a Danish context. However, the present study indicates that they also appear to be present in a Danish healthcare context.

#### **4.1.2. MESO-LEVEL PSYCHOSOCIAL FACTORS**

On a meso level, psychosocial factors related to interpersonal relationships between the participants and their closest relatives and with healthcare professionals affected their experience of their life with ischemic heart disease. Furthermore, these psychosocial factors appeared to be modified by macro-level social factors.

##### **4.1.2.1. Depleted mental resources and lack of social support**

According to the epidemiology of social stress theory, people with low socioeconomic status are generally exposed to more external stressors, such as less job control and

economic hardship, than people with a higher socioeconomic status (Chandola & Marmot, 2011; Turner & Turner, 2005). In the present study, macro-level social conditions appeared to start a motion of meso-level psychosocial processes that ultimately exacerbated the participants' psychosocial stress. Economic hardship made it difficult for the participants to pay for their medicine and to defray other essential expenses. Furthermore, the participants explained that unfavorable working conditions made them feel inferior and inadequate. Their low educational and occupational level thus appeared to create a situation marked by extensive exposure to external stressors (Rasmussen, Petersen, et al., 2021).

These external psychosocial stressors generally seemed to deplete the participants' mental resources, thus reducing their and their families' support of each other. The Family Stress Model proposed by Conger, Conger, and Martin (2010) argues that people who experience economic hardship also often experience emotional distress and negative arousal, which depletes their emotional resources and causes conflicts and withdrawal of supportive behaviors. An early version of this model has been tested in a mixed-method study, which similarly to the findings of the present PhD study showed that not being able to afford basic expenses made the participants feel inadequate as parents (Mistry et al., 2008). This PhD study adds to the existing literature by showing what it means to be living with economic hardship while also suffering from a chronic condition, and how this affects family life. The study showed that the participants' emotional resources were generally depleted, which seemed to make it difficult for them to communicate with each other about the participants' illness and thereby support each other while living with this stressful condition (Rasmussen, Guise, et al., 2021a; Rasmussen, Petersen, et al., 2021).

The findings generally showed a notable difference between the participants who were engaged in close and supportive relationships and those who were not (Rasmussen, Guise, et al., 2021a). Similarly to Cohen and Will's (1985) conceptualization of social support, the findings showed two processes through which support from social relationships influenced the participants' health and well-being. First, as described in the 'buffering model' (Cohen & Wills, 1985), those who were engaged in close social relationships gained important help in managing, reconciling with, and finding structure in their life with illness. Second, similar to the 'main effect model' (Cohen & Wills, 1985), the participants who were engaged in close and caring social relationships gained a sense of meaning in their lives from these relationships. Furthermore, the present PhD study fills a gap in the literature, as studies exploring the influence of social support on life with ischemic heart disease for socially disadvantaged ischemic heart patients are generally lacking (Child & Albert, 2018). The study showed that for socially disadvantaged ischemic heart patients, the main effect model in general and gaining a sense of meaning in life in particular seemed to be the most important kind of support (Rasmussen, Guise, et al., 2021a).

Partners appeared to be an especially important source of social support for socially disadvantaged participants, possibly because this type of relationship often seemed to

remain well functioning for longer periods than other relationships (Rasmussen, Guise, et al., 2021a). Additionally, similar to other studies in the general population (Raparelli et al., 2018), the male participants seemed more dependent on support from their partner than the female participants (Rasmussen, Guise, et al., 2021a). This may be because the female participants relied more on support from other kinds of relationships, for example their friends, children, or siblings, than the male participants (Rasmussen, Guise, et al., 2021a).

The stressors related to family conflicts, economic hardship, and poor working conditions seemed to be more burdening for the midlife participants than for the older participants (Rasmussen, Petersen, et al., 2021). Infurna et al (2020) argue that people at midlife have to balance being a caregiver of both their own children and their parents, their parent-in-laws, and sometimes also their grandchildren, while at the same time taking care of a job. Furthermore, their financial situation is often more vulnerable than in other life periods as they may need to provide financially for their children and sometimes also for their parents. It may also be difficult to find a new job if they lose their job because of ageism and age discrimination (Infurna et al., 2020). Empirical studies have also shown that living with ischemic heart disease at midlife could pose a strain of the patients and their families (Andersson, Borglin, & Willman, 2013; Andersson, Borglin, Sjöström-Strand, et al., 2013) and that the inability to work because of illness may be especially straining for midlife people because working often used to be an important and essential part of their life (Andersson, Borglin, & Willman, 2013; Markle et al., 2015; McCallum & Alaggia, 2020).

On the other hand, the study findings showed that the older participants were more burdened by loneliness and social isolation than were the midlife participants. Research generally points to older age as a life stage associated with loneliness (Hawkley et al., 2020; Luhmann & Hawkley, 2016; von Soest et al., 2018). Furthermore, similarly to the findings of this study, Wethington and Pillemer (2013) have argued that the main reason for the association between older age and high levels of loneliness is widowhood and impaired mobility. Additionally, studies indicate that loneliness among elder populations is higher for people with low socioeconomic status than among people with higher socioeconomic status (Luhmann & Hawkley, 2016; von Soest et al., 2018), possibly because people with higher socioeconomic status have the financial resources to enable transportation and participation in social activities (von Soest et al., 2018). This PhD study thus contributes with new insights into the difference between being at midlife and socially disadvantaged while living with ischemic heart disease, which has not previously been explored in the literature.

#### **4.1.2.2. Problematic healthcare interactions and stigmatization**

The macro-level social discourses described above appeared to work by shaping the healthcare professionals' values and norms and thus also their expectations of their patients. The participants experienced that the healthcare professional favored and prioritized patients who showed markers of a high social status and a healthy lifestyle

(Rasmussen, Guise, et al., 2021b). According to the cultural health capital framework, even the best-intended healthcare professionals are dispositioned by their habitus to think of patients in a certain way. These preconceptions will more or less unconsciously affect the healthcare professionals' attitude towards patients (Shim, 2010). Bourdieu defines habitus as internalized social structures acquired through life trajectories in different social contexts (Bourdieu, 1984). In this PhD study, the healthcare professionals' attitude towards patients showing markers of an unhealthy lifestyle and low social status may thus be an internalization of the social discourses described above (Rasmussen, Guise, et al., 2021b). Chang, Dubbin, and Shim (2016) have similarly shown how healthcare professionals have internalized social discourses about drug users into their habitus, which affects their attitude towards this group of patients.

Seen from the perspective of the cultural health capital, it could be argued that by not meeting the norms of the healthcare setting, the participants failed to display and exchange cultural health capital and thereby receive attentive and satisfying treatment and care (Shim, 2010). The cultural health capital has previously not been used to understand interactional dynamics between socially disadvantaged patients and healthcare professionals in a Danish setting. The present study thus contributes with insights into the cultural health capital of the Danish healthcare setting and shows how complying with a healthy lifestyle and showing markers of a high social status appear to be important components of the cultural health capital in Denmark.

Furthermore, the participants experienced an unequal power balance between them and the healthcare professionals because the latter seemed to have the power to decide what constituted cultural health capital (Rasmussen, Guise, et al., 2021b). In his classic work on medical nemesis, Ivan Illich (1975) argued that the social organization of medical systems means that healthcare professionals have the power to define which symptoms that can be categorized as signs of disease and who are entitled to medical care. Furthermore, Chang et al (2016) argue that because the healthcare professionals are gatekeepers of crucial health resources, they also have the power to decide which ideals the patient should live up to in order to receive these resources. This may help explain the participants' experience of the healthcare professionals' dominance in this PhD study.

Feeling less prioritized and judged by the healthcare professionals because of their social status and lifestyle can be seen as signs of a fundamental stigmatization of socially disadvantaged patients (Rasmussen, Guise, et al., 2021b; Rasmussen, Petersen, et al., 2021). Link and Phelan (2001) have argued that stigmatization can happen only when unequal power balances exist. In their definition of stigma, they criticized former conceptualizations of stigma for having a too individualistic focus. Instead of focusing on the attributes of the stigmatized person, they argued that emphasis should be on the social and cultural conditions enabling stigmatization. Power, they argued, is an essential part of this. A person without power does not have the authority to discriminate the person they label with a negative stereotype (Link & Phelan, 2001). As explained above, in the present study, the healthcare professionals

did have the power to down-prioritize the participants' treatment and thereby enforce stigmatization. Furthermore, many of the participants even internalized the stigmatization and felt responsible themselves for their ischemic heart disease (Rasmussen, Petersen, et al., 2021).

While experiences of stigmatization and feelings of self-stigmatization due to low social position and failure to comply with a healthy lifestyle were widespread among the participants, they were most profound among the midlife participants (Rasmussen, Petersen, et al., 2021). A qualitative study by McCallum and Alaggia (2020) similarly showed that patients who suffered from an eating disorder felt that they carried a double stigma: stigma associated with their illness and stigma of being at midlife while suffering from their illness. The findings of this PhD study illustrate a triple stigma among midlife socially disadvantaged ischemic heart patients: stigma associated with an illness that is considered caused by the patients' lifestyle, stigma associated with developing the illness early, and stigma associated with being socially disadvantaged.

However, in a few cases, some healthcare professionals adjusted their care and treatment towards the specific patient's habitus and life circumstances, which made the participants feel acknowledged and empowered to act on their situation (Rasmussen, Guise, et al., 2021b). This approach to care and treatment is in line with the patient-centered approach which confronts medical dominance in care encounters by deploying a biopsychosocial perspective, seeing the patient as a person, and sharing the power and responsibility between patients and healthcare professionals (Mead & Bower, 2000). However, Dubbin et al (2013) argue that the accomplishment of patient-centered care depends on the exchange of cultural health capital. In their empirical study, they show how patient-centered behavior was performed by the healthcare professional only if the patient succeeded in displaying cultural health capital (Dubbin et al., 2013). Nevertheless, the findings of this PhD study showed that in some cases, even if the participants did not display cultural health capital, healthcare professionals seemed to adopt an approach to care that resembled patient-centered care. Furthermore, social relationships also sometimes acted as a sort of translator between the participants and the healthcare professionals, thus improving the healthcare interaction.

#### **4.1.3. MICRO-LEVEL INDIVIDUAL FACTORS**

On a micro level, the above-described macro-level social factors and meso-level psychosocial factors seemed to affect individual psychological, behavioral, and biological factors.

##### **4.1.3.1. Struggling to cope with illness**

The participants generally struggled to cope with their illness, but also with other stressful stimuli, such as economic hardship and poor working conditions. Furthermore, they also tended to find their life with ischemic heart disease marked by chaos, powerlessness, and meaninglessness, which could be markers of a low sense of coherence (Rasmussen, Guise, et al., 2021a). The theory of sense of coherence by

Antonovsky (1987) conceptualizes abilities that enable a person to overcome, cope with, and adjust to stressful stimuli.

The findings from the present study showed that social support processes seemed to help the participants in coping processes (Rasmussen, Guise, et al., 2021a). Antonovsky (1987) similarly argued that social support, among other social factors, can be seen as ‘generalized resistance resources’ that contribute to the development and maintenance of an individual’s sense of coherence. Additionally, difficult experiences of loss, abandonment, violence, and aggression during childhood may have negatively influenced the participants’ coping resources. Antonovsky (1987) argued that to develop a strong sense of coherence, children’s relationship with their primary caregivers should be characterized by stability, continuity, and care. This seemed rarely to be the case for the socially disadvantaged patients in the present study, which may explain their poor coping abilities. In general, the participants’ parents themselves had been faced with structural conditions that depleted their mental resources and thus their ability to show affection and support towards their children. This relation between social relationships and sense of coherence has been confirmed by epidemiological studies showing that close and stable social relations, especially in childhood but also later in life, affect the development of an individual’s sense of coherence (Volanen et al., 2004; Wolff & Ratner, 1999). Furthermore, based on qualitative interviews with patients living with chronic conditions, Potter et al (2018) argued that coping processes are socially-negotiated.

Research has also shown that people with low socioeconomic status generally have a lower sense of coherence than people with higher socioeconomic status (Lundberg, 1997). This may help explain why in terms of their well-being people with low socioeconomic status generally seem to be more dependent on social support than people with a higher socioeconomic status (Uphoff et al., 2013). As they generally seem to have a low sense of coherence, they may need more social support to help them cope with the stressors of life (Rasmussen, Guise, et al., 2021a). However, Lundberg’s study on the association between sense of coherence and low socioeconomic status is several decades old and there is generally a lack of more recent studies exploring this correlation. Furthermore, the scope of this PhD study has not been to explore sense of coherence specifically. However, this theory offers an understanding of the pathways through which socioeconomic status may influence social support processes that affect patients’ ability to cope with their ischemic heart disease. As there is generally a lack of studies exploring the mechanisms connecting socioeconomic status, social support, and ischemic heart disease (Child & Albert, 2018), the present study contributes with new important knowledge about this relationship (Rasmussen, Guise, et al., 2021a).

#### **4.1.3.2. Lack of compliance with treatment and lifestyle advice**

The participants’ struggle to cope with, and find meaning in, their life with ischemic heart disease seemed to negatively impact their ability and motivation to comply with their treatment and with lifestyle advice (Rasmussen, Guise, et al., 2021a). Furthermore, experiences of being underprioritized and stigmatized in the healthcare

system meant that many of the participants developed mistrust in the healthcare system and other public systems and therefore discontinued their treatment. Additionally, economic hardship also made it difficult for the participants to pay for their medicine and thus comply with their medication.

In the literature, lack of compliance with medical instructions and lifestyle advice among patients with a low socioeconomic status has been widely ascribed to micro-level individual factors, such as patient attributes or characteristics such as lacking knowledge and low levels of health literacy (Greenberg et al., 2019; Schultz et al., 2018). However, the present study shows that not only the participants' cognitive attributes, but also macro-level social factors and meso-level psychosocial factors profoundly affected their compliance with medical instructions. Similarly, Clark et al (2011) and McGarrol (2020) showed how compliance with lifestyle changes and medical treatment among ischemic heart patients with low socioeconomic status was affected by macro-level social factors, such as income inequality and economic hardship. However, unlike the present PhD study, these studies did not show how meso-level psychosocial factors, such as social support, interactions with healthcare professionals, and experiences of stigmatization, connected macro-level social factors to micro-level individual health behavior.

Furthermore, original interpretations of health literacy have been challenged by authors during the 'second wave' of health literacy as these authors have argued that health literacy should not just be seen as a set of individual, context-independent cognitive abilities. Instead, they argue that health literacy should be understood as a context-bound set of social practices embedded in broader social goals and cultural imperatives (Chinn, 2011; Papen, 2009; Samerski, 2019). For example, Samerski (2019) has shown how health literacy could be seen as a social practice co-produced in social relations. However, the 'second wave' of health literacy research has not yet emphasized or explored the influence of the social context of the clinical encounter. By deploying the cultural health capital framework, the present study highlights the interactional dynamics between healthcare professionals and patients as another important social context that shapes the patients' behavior and abilities.

#### **4.1.3.3. The harmful influence of psychosocial stress**

Overall, the participants' exposure to straining macro-level social factors and meso-level psychosocial factors meant that they generally experienced an overwhelming burden of stress, which was especially noteworthy among midlife patients (Rasmussen, Petersen, et al., 2021). Furthermore, because they often lacked the abilities and resources to cope with these stressors, both their mental well-being and physical health were generally threatened.

The findings showed that the psychosocial stress experienced by the participants seemed to affect their mental well-being by creating feelings of frustration, depression, anger, and anxiety. In line with these findings, earlier studies have similarly shown that ischemic heart patients with low socioeconomic status who

experience stress during their acute coronary syndrome are particularly vulnerable to subsequent depression (Dar et al., 2019; Steptoe et al., 2011).

Additionally, the participants explained that they felt that their physical health worsened with the increase of psychosocial stress. Similarly, in a qualitative study, Dubbin et al (2017) showed how African Americans connected their physical cardiovascular health to experiences of racism and feelings of stress. Furthermore, quantitative studies have demonstrated how psychosocial stress has a biological influence on the occurrence and prognosis of ischemic heart disease (Dar et al., 2019; Fioranelli et al., 2018; Havranek et al., 2015; Wei et al., 2014). Elevated levels of psychosocial stress may therefore be one of the explanations why people with low socioeconomic status are more likely to develop ischemic heart disease and to die from it (Cho et al., 2019).

## **4.2. DISCUSSION OF METHODOLOGY**

The following section will discuss important strengths and limitations of the methodology deployed in the PhD study.

### **4.2.1. BENEFITS AND SHORTAGES OF THE CRITICAL HERMENEUTIC APPROACH**

An important strength of the critical hermeneutic approach to data analysis and interpretation is its continuous interchange between interpretation and explanation (Simonyĭ et al., 2018). In the critical hermeneutic approach, preliminary interpretations are explained by testing and validating them through structural analyses and engagement with new data. This enables new and further interpretations and the process is then repeated, continuously creating deeper interpretations of the data (Simonyĭ et al., 2018). The interpretations of the socially disadvantaged patients' lived experiences in this PhD study can therefore be categorized as deep, and the study provides a thorough, in-depth understanding of social inequality in ischemic heart disease.

However, Ricoeur argued that there are always several possible interpretations of a text, and the reader's task is to find a plausible interpretation through validation (Ricoeur, 1976a). Internal validation in qualitative studies refers to the degree to which the findings are well founded. Member-checks and participant validation are often used to ensure this kind of validation in qualitative studies (Birt et al., 2016; Morse, 2015). However, the critical hermeneutic approach does not include member checks because distancation of the lived experiences from the participants is crucial (Simonyĭ et al., 2018). The interpretations are instead validated through continuous explanations based on structural analyses (Simonyĭ et al., 2018). Furthermore, Simonyĭ et al (2018) argue that co-authors may also be included to enhance the internal validation of interpretations. In the present PhD study, the co-authors of the three articles were included in the process of analyzing and interpreting the findings of the overall analysis and the specific analysis of data in accordance with the aims of the three sub-studies. Through ongoing and in-depth discussion, the co-authors contributed to internal validation of the interpretations.



#### 4.2.2. FACTORS INFLUENCING THE DATA COLLECTION

The PhD student's position as a representative from a public research institution may have influenced the interviews with and observations of the participants. Many of the participants had had negative experiences of their engagement with public systems and had therefore lost confidence in public authorities. Some of the participants even explained that they had poor experiences of participating in health research projects as they had felt abused and exploited by the research personnel. The participants may therefore have been cautious and skeptical in the interactions with the PhD student and perhaps less willing to speak freely about their experiences in the healthcare system. Distrust in the researcher is common among socially disadvantaged participants who have developed a sense of mistrust in the public system (Ellard-Gray et al., 2015). To make the participants feel more comfortable, the PhD student stressed how their anonymity would be maintained through the entire research project, that they could withdraw at any time before the dissemination of the results, and that their participation was voluntary and would not affect their treatment. Furthermore, the participants chose the setting of the interview to make them feel safe and somewhat in control of the situation (Herzog, 2005).

When conducting a critical hermeneutic study, it is important for the reader (in this case the researcher) to find a balance between understanding the author's (in this case the participants') lived experiences while at the same time creating a distancing to them in order to perform a structural analysis and critical interpretation (Ricoeur, 1981). The PhD student therefore sought to find a balance between emphatically understanding the participants' accounts while also creating a distance to them that enabled her to see their experiences as reflections of broader social phenomena.

During the data collection, it was also possible only to conduct one to two observations of five out of the 30 participants. The original intention was to include observations of clinical encounters for as many of the participants as possible, especially to cover the research aim of sub-study 2. As it turned out that only a few of the participants had frequent encounters with healthcare professional regarding their ischemic heart disease, observations of many of the participants were not possible. This may be considered a limitation of the study. Observations make it possible to record behavior as it happens instead of secondhand through accounts in interviews. Furthermore, the observers' outsider role enables him or her to notice things that the participants might take for granted (Merriam & Tisdell, 2016). Observations of more of the participants' interactions with healthcare professionals could thus likely have enabled further insights into the interactional dynamics between the participants and the healthcare professionals that were not captured by the interviews.

However, the interviews constitute the main source of data for this study, and the PhD student was able to conduct one to four high-quality interviews with 30 participants. Furthermore, through continuous evaluation during the research process, it was assessed that sufficient information power (Malterud et al., 2016) was reached after

having conducted one to four interviews of 30 participants and one to two observations of five participants.

#### **4.2.3. TRANSFERABILITY OF THE STUDY FINDINGS TO OTHER GEOGRAPHICAL SETTINGS**

The experiences of the participants in this PhD study may reflect that they live in a Danish context. Ricoeur argued that the prefiguration of the lived experiences, meaning the participants' preconceptions, is influenced by the context they live in (Ricoeur, 1984), which means that the findings are influenced by the social context within which the study is explored. Patients from settings without the same social welfare system as Denmark may face other, and perhaps more severe, psychosocial problems than the Danish participants in this PhD study (Levecque et al., 2011). For example, a study by Levecque et al (2011) has explored the relationship between economic hardship and depression in different European welfare regimes. The study showed that compared to Nordic countries, including Denmark, Norway and Finland, Anglo-Saxon countries, including Ireland and the United Kingdom, demonstrated a stronger association between economic hardship and depression. Furthermore, in the Anglo-Saxon countries, economic hardship and depression had a stronger effect on the individual's health than in the Nordic countries (Levecque et al., 2011). This may be because the Nordic social democratic welfare states generally have a higher public social protection than the more liberal Anglo-Saxon countries (Levecque et al., 2011). This difference in the effect of economic hardship between the different regimes may challenge the transferability of the findings of this PhD study to other settings.

However, as explained, the critical interpretation and discussion also makes it possible to use the lived experiences to gain a deeper understanding of broader social phenomena that may transcend geographical areas (Simoný et al., 2018). Some of the psychosocial factors found to influence the socially disadvantaged participants' experiences of their life with ischemic heart disease in this study might thus reflect broader and more universal social dynamics that are also relevant in other settings. Existing studies conducted in United Kingdom, America, and Australia, focusing on other patient groups, have for example shown some of the same psychosocial dynamics as this PhD study (Dubbin et al., 2017; Jin et al., 2020; Potter et al., 2018). This could indicate that the psychosocial factors described in the present PhD study are also relevant in other settings.

#### **4.2.4. RECRUITING THROUGH A SURVEY STUDY**

As this PhD study is related to a wider research project about social inequality in ischemic heart disease, it was designed to recruit participants through the adjunct survey study (Svendsen et al., 2020). The recruitment through the survey study allowed for successful inclusion of 30 participants in socially disadvantaged positions, individuals who are generally considered a difficult group for researchers to reach (Bonevski et al., 2014). One of the possible reasons for this may be the direct and personalized recruitment strategy used in the second phase of the recruitment process, leading two out of three potential participants to accept the invitation.

This recruitment strategy is, however, also likely to have excluded many highly disadvantaged and vulnerable patients, as people who belong to minority groups or are in marginalized position are less likely to participate in survey studies because they are preoccupied with other more urgent priorities or stressors of daily life (Ellard-Gray et al., 2015). While this study did include highly marginalized and socially isolated participants, it was especially unsuccessful in including participants from ethnic minority groups. A limited number of the participants from the survey study who matched the predefined criteria were ethnic minorities and none of them responded when the PhD student called them by phone, which may explain why no ethnic minorities were included. This is an essential limitation as the voices of ischemic heart patients from ethnic minority groups may not have been covered in this study. Several other studies have indicated that ischemic heart patients with ethnic minority backgrounds may experience specific and particularly burdening stressors, such as language barriers in treatment, racial discrimination, or stigmatization (Dubbin et al., 2017; Jin et al., 2020; Mody et al., 2012). Ethnic minorities that are also socially disadvantaged and ischemic heart patients would therefore most likely have experienced the same burden of stressors as the participants of this PhD study. Furthermore, perhaps their situation would have been even more burdensome.

#### **4.2.5. THE INFLUENCE OF THE SAMPLING STRATEGY ON THE STUDY FINDINGS**

The participants were sampled to have a limited access to social support and low levels of health literacy. Their experiences of social isolation, lack of social support, and struggle to navigate the healthcare system were thus expected. However, a key finding was that some of the participants did receive important support from a few of their close social relations. This difference between the findings in this PhD study and those of the survey study may reflect that qualitative studies enable ‘thicker descriptions’ of ‘thin descriptions’ provided by studies using a quantitative approach (Williams & Elliott, 2010). This PhD study thus seemed to be able to present variations and complexities of the issues of limited access to social support and low levels of health literacy indicated by the participants’ answers in the survey study.

A limitation of the study sampling is that only seven out of the 30 participants were female. The study findings related to gender are therefore less substantiated and should be interpreted with caution. Furthermore, this skewed gender representation may affect the transferability of the findings as they may primarily reflect the experiences of male socially disadvantaged ischemic heart patients. Existing studies of patients living with ischemic heart disease (Dale et al., 2015; Galick et al., 2015) and social inequality in health (Smith & Dumas, 2019; Springer & Mouzon, 2011) indicate gender differences in the ways in which psychosocial factors influence ischemic heart patients. Furthermore, the findings of this PhD study also showed gender-related variations in the participants’ experiences of social support. Gender differences could have been further explored by including more female participants. However, this unequal gender division may reflect that gender was not a consideration in the sampling of the participants, and that men’s risk of experiencing ischemic heart disease is twice as high as that of women (Albrektsen et al., 2016).

Furthermore, in the present study, only patients, and not healthcare professionals, were included as the main participants. This means that the study provides detailed information on socially disadvantaged patients' perspectives and experiences, a group of patients otherwise not often heard, which makes it possible to improve policy, practice, and interventions in ways that meet these patients' needs (Newton, 2017). However, by not including healthcare professionals in the study, it provides a one-sided account of the clinical encounters. If healthcare professionals had also been included, the study would have been able to explore healthcare professionals' own experiences of being influenced by social discourses about patient ideals.

#### **4.2.6. ETHICAL CONSIDERATIONS IN RESEARCH OF SOCIALLY DISADVANTAGED PATIENTS**

During the interviews, the participants often shared straining and stressful experiences, which provided valuable insights into the psychosocial factors affecting their lives with ischemic heart disease. However, this also created ethical considerations. In studies of vulnerable or disadvantaged populations, the researcher must generally balance the importance of giving voice to these often overheard participants and also protecting their personal well-being (Alexander et al., 2018). The PhD student thus had to make sure that sharing these burdensome, and sometimes traumatic, experiences did not harm the participants or cause further distress to their lives. When asked about their experiences of participating in the project, a lot of the participants expressed that they enjoyed being able to talk about the strains of their lives and to be attentively listened to. Furthermore, they explained that it was important for them to possibly help others in similar situations by sharing their accounts. These advantages of participating in research have also previously been expressed by disadvantaged participants (Newton, 2017).

Additionally, labelling the participants as socially disadvantaged could also create ethical issues. The participants may not identify with this categorization and it could therefore be experienced as stigmatizing (Ellard-Gray et al., 2015). When recruiting the participants for this PhD study, the PhD student did therefore not use the term 'socially disadvantaged'. Instead, she explained that the participants were chosen for the study based on their education, occupation, and their own answers in the adjunct health survey.

### **4.3. IMPLICATIONS OF THE STUDY**

The following sections consider the implications of the findings in relation to policy, practice, and research.

#### **4.3.1. IMPLICATIONS FOR POLICY**

In Denmark, policies aiming to reduce social inequality in health in general, or ischemic heart disease in particular, are generally lacking. The findings of the current PhD study indicate an urgent need for initiatives to increase financial support for socially disadvantaged ischemic heart patients (and other socially disadvantaged patients) when they are unable to work. In Denmark, certain employees, such as hourly-paid workers who work in a professions and places not covered by a collective

settlement are not entitled to a full salary during a sickness absence. Instead, they are entitled to a publicly paid sickness benefit, which may be lower than their usual salary (The Danish Ministry of Employment, 2018). Workplaces should therefore be encouraged to join collective agreements and accommodate patients who are on medical leave. Furthermore, publicly paid sickness benefits should be aligned with socially disadvantaged patients' normal income.

Moreover, in Denmark it is possible to gain subsidies for medication. There are both general subsidies, which are automatically received, and individualized subsidies for which the patient or the patient's general practitioner need to apply (The Danish Ministry of Health, 2019). Nevertheless, the participants of this study were often not aware of their right to apply for additional financial support because their general practitioner did not suggest this. Others were so highly burdened by psychosocial stress that they did not have the mental resources to apply for such subsidies. General practitioners or social workers should therefore be encouraged to pay attention to socially disadvantaged ischemic heart patients' needs for compensation, inform them about their possibilities, and support them in their efforts to seek them.

Additionally, the findings of this PhD study demonstrate the relevance of securing socially disadvantaged ischemic heart patients' connection to the labor market. The patients' ability to be able to work through their illness appears to be important for their psychosocial well-being and their financial situation. Workplaces should therefore be encouraged to be flexible and attentive to socially disadvantaged ischemic heart patients' needs and limitations.

#### **4.3.2. IMPLICATIONS FOR PRACTICE**

Interventions aiming to reduce social inequality in ischemic heart disease tend to emphasize individually oriented factors, such as lifestyle or health literacy. However, the findings of this PhD study encourage implementations of interventions that support socially disadvantaged ischemic heart patients in their efforts to cope with, or buffer the effect of, stressful feelings. In Norway, a complex dialogue-based psychosocial intervention has been designed to promote psychosocial well-being and prevent depression and anxiety after survival from a stroke (Kirkevold et al., 2018). A qualitative study exploring participants' experiences of the intervention found that the dialogues helped the stroke patients become aware of their needs, face the impact of stroke on family life, reflect on basic values, take control, and look forward (Kitzmüller et al., 2019). Similar interventions may be relevant for socially disadvantaged ischemic heart patients as they appear to be particularly exposed to external stressors and vulnerable in their efforts to cope with these stressors (Rasmussen, Petersen, et al., 2021). In Denmark, "The navigator projects" were similarly implemented to target psychosocial challenges among vulnerable patients (The Danish Health Authority, 2018). However, the activities included in this intervention seemed primarily oriented towards improving the patients' health literacy (The Danish Health Authority, 2018), while the complex dialogue-based psychosocial

intervention in Norway appeared to go into depth with the patients' psychosocial experiences and well-being (Kitzmüller et al., 2019).

Moreover, the findings of the present dissertation indicate that close relatives or relations should be helped in their efforts to support socially disadvantaged patients. Interventions that train social relatives to become involved in clinical care processes have been designed but primarily focus on compliance with medication and lifestyle advice (Rosland & Piette, 2010). The findings of the present study indicate that future interventions should be designed to encourage, help, and guide socially disadvantaged ischemic heart patients and their close social relations in supporting each other in coping processes (Rasmussen, Guise, et al., 2021a). Additionally, in line with a patient-centered approach, healthcare professionals should include close social relations in the care of their ill relatives (Luxford et al., 2011). Furthermore, initiatives should be implemented to help socially isolated ischemic heart patients form new supporting social relations. Peer-support interventions have, for example, been used to help patients feel less alone in their life with illness (Embuldeniya et al., 2013).

To prevent experiences of unequal treatment and care, an approach to socially disadvantaged ischemic heart patients that adjusts the care to the individual patient should be deployed (Rasmussen, Guise, et al., 2021b). Efforts have already been made to accommodate individual ischemic heart patients' needs. An organizational health literacy intervention has, for example, recently been developed and tested in a Danish cardiac rehabilitation unit (Aaby et al., 2020). The concept of organizational health literacy responsiveness, which is defined as "the way in which services, organizations, and systems make health information and resources available and accessible to people according to health literacy strengths and limitations" (International Union for Health Promotion and Education, 2018). Nevertheless, the findings of this PhD study challenge the tendency to understand the patient from an individually oriented health literacy perspective (Rasmussen, Guise, et al., 2021b). The perspective of cultural health capital offers healthcare professionals a framework for understanding how patient interactions are affected by structural, social, and interactional dynamics (Shim, 2010).

Furthermore, the study calls for attention to the widespread stigma and self-stigma experienced by socially disadvantaged ischemic heart patients (Rasmussen, Guise, et al., 2021b; Rasmussen, Petersen, et al., 2021). Applying the cultural health capital framework to training of health professionals, including doctors, (Shim, 2010) holds potential to raise their awareness of public discourses and structural conditions and how these discourses and conditions may influence their own preconceptions of socially disadvantaged patients, allowing professionals to meet their patients in a more acknowledging, respectful, and non-judgmental way. Additionally, the findings call for healthcare professionals to acknowledge and explain to the patient the importance of not only lifestyle factors and medication compliance, but also social conditions and psychosocial factors, as demonstrated in the present study and in several other studies (Dar et al., 2019; Havranek et al., 2015; Kreatsoulas & Anand, 2010; Skodova et al., 2008).

#### 4.3.3. IMPLICATIONS FOR RESEARCH

This study has demonstrated the important influence of psychosocial factors on social inequality in ischemic heart disease. However, as patients in other settings with a more liberal regime, such as Great Britain or the USA, may face more harmful structural conditions because they have lower social protection (Levecque et al., 2011), it is relevant to conduct similar psychosocially oriented studies in these or other contexts.

The findings of this study indicate a gender disparity in the way in which socially disadvantaged ischemic heart patients depend on social support (Rasmussen, Guise, et al., 2021a). Future studies should further explore variations in how socially disadvantaged ischemic heart patients of different genders are affected by psychosocial factors.

The present study included no ethnic minorities; and thus lack the perspective from this group of patients. It is therefore relevant for future studies to explore the experience of being an ethnic minority and socially disadvantaged when living with ischemic heart disease. However, ethnic minorities seem to be difficult to recruit (Ellard-Gray et al., 2015). Future studies should therefore prioritize recruiting techniques relevant to this specific patient group, for example by becoming immersed in ethnic communities and familiar with some of the potential participants or using community partners as gatekeepers (Ellard-Gray et al., 2015).

The findings of this PhD study provide in-depth understandings of the experiences of socially disadvantaged ischemic heart patients, which made it possible to fill a gap in the existing literature on social inequality in ischemic heart disease by showing the interrelationship between structural conditions, social contexts, psychosocial mechanisms, personal lives, and bodily experiences. However, in this study no comparison was made between the socially disadvantaged participants and participants without these disadvantages. Future studies may use a comparative approach to validate further the casual pathways between socioeconomic status and psychosocial factors. Qualitative comparative analysis (QCA) may, for example, be a relevant approach to explore complex casual pathways (Hanckel et al., 2021).

## CHAPTER 5. CONCLUSION

The overall objective of this PhD study was to provide an in-depth understanding of social inequality in ischemic heart disease by exploring the influence of underlying psychosocial factors on socially disadvantaged patients' lived experience of life with ischemic heart disease. To meet this objective, qualitative interviews and observations were conducted with 30 socially disadvantaged ischemic heart patients in Denmark between August 2018 and October 2019.

The objective was operationalized into three different research aims, explored in three sub-studies. Sub-study 1 showed that social support from close social relations was important for how the socially disadvantaged participants experienced their life with ischemic heart disease. Sub-study 2 illuminated how unequal healthcare is influenced by structural, psychosocial, and interactional factors. Sub-study 3 concluded that being at midlife and socially disadvantaged while living with ischemic heart disease seemed to create a situation marked by an overwhelming burden of stressful feelings.

Overall, the PhD study showed that the socially disadvantaged ischemic heart patients were exposed to several external psychosocial stressors related to their social relationships, financial and occupational situation, healthcare interactions, and experiences of stigmatization. Furthermore, as the participants generally lacked the resources and thus abilities to cope with these stressors, they experienced a burden of stressful feelings that affected their mental and physical health and well-being. However, in a few cases, the participants received important support from their close social relations or healthcare professionals, which reduced this stress load.

The study shows the important influence of meso-level psychosocial factors by illustrating how they appear to connect macro-level social factors to micro-level individual factors important for the participants' health and well-being. While existing research on social inequality in ischemic heart disease has generally tended to emphasize individual factors within the patient, such as their lifestyle or level of health literacy, often through quantitative study designs, this PhD study contributes with an in-depth psychosocial understanding of the roots of this inequality.

To thoroughly intervene on and effectively reduce social inequality in ischemic heart disease, this study indicates that it is necessary to improve socially disadvantaged ischemic heart patients' connection to the labor market and to accommodate their financial loss. Furthermore, socially disadvantaged ischemic heart patients and their families should be supported in coping with stressful feelings. Lastly, the study calls for an approach to the healthcare for socially disadvantaged ischemic heart patients that adjusts treatment and care to the patients' habitus and life circumstances.



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## APPENDICES

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# Appendix A. Recruitment letter

## Forskningsprojekt om hjertesygdom

### Tak for din hjælp!

Vi skriver til dig, fordi du deltog i en spørgeskemaundersøgelse i 2017 der omhandlede din viden om sundhed samt brug af sundhedssystemet. Vi takker dig mange gange for din deltagelse.

Dine svar har bidraget til vigtig ny viden om danske hjertepatienter. Men for at kunne forbedre den behandling, hjælp og støtte, danske hjertepatienter tilbydes, har vi brug for at dykke endnu dybere ned i forskellige grupper af hjertepatienters erfaringer, oplevelser og behov. Derfor laver vi nu et opfølgende forskningsprojekt i form af en interviewundersøgelse, der har fokus på betydningen af uddannelse og erhverv for livet med hjertesygdom.

### Opbringning om eventuel deltagelse i interviewundersøgelse

Vi sender dig dette brev for at orientere dig om at vi i starten af 2019 muligvis vil ringe dig op for at fortælle dig mere om denne interviewundersøgelse, stille dig nogle opklarende spørgsmål, da vi leder efter borgere med forskellige profiler, og eventuelt invitere dig til at deltage i undersøgelsen. Hvis ikke du er blevet ringet op inden for et halvt år, er det fordi, vi allerede har fundet nok deltagere, og du skal derfor ikke forvente at høre fra os.

Ved at deltage i interviewundersøgelsen vil du kunne bidrage med meget betydningsfuld viden, som vil kunne forbedre den behandling, hjælp og støtte der tilbydes til danske hjertepatienter.

### Fortrolighed – vi passer på dine oplysninger

Den information, du giver os ved et eventuelt interview, samt de personoplysninger, vi bruger til at kontakte dig, vil blive behandlet strengt fortroligt og i overensstemmelse med databeskyttelsesforordningen. Aalborg Universitet er ansvarlig for at passe på dine oplysninger, og de opbevares, så det kun er projektets medarbejdere, der har adgang til dem. Så snart der ikke er behov for oplysningerne mere, fordi undersøgelsen er afsluttet eller du ikke har ønsket at deltage, slettes disse. Du kan desuden selv på ethvert tidspunkt bede om at få dine oplysninger slettet. Når resultaterne fra forskningsprojektet offentliggøres, vil information/oplysninger, som direkte afslører din identitet, ikke fremgå. Har du spørgsmål til databehandling, kan du kontakte Aalborg

Universitets databaseskyttelsesrådgiver, Teia Melvej Stennevad på mailadressen [dpo@aaau.dk](mailto:dpo@aaau.dk).

**Kontakt os gerne, hvis du har spørgsmål**

Hvis du har spørgsmål vedrørende denne henvendelse, er du meget velkommen til at kontakte projektleder, Amanda Nikolajew Rasmussen på telefonnummer 60 22 67 22.

Med venlig hilsen



Amanda Rasmussen  
Projektleder



## Appendix B. Informed consent contract

### Samtykke til deltagelse i sundhedsvidenskabeligt forskningsprojekt

Jeg bekræfter herved, at jeg indvilliger i at deltage i et interview om sociale og psykiske faktorerets betydning i forhold til at få og leve med hjertesygdom og kontakten med sundhedsvæsenet i den forbindelse.

Projektet, som interviewet kommer til at indgå i, har til formål at bidrage med viden som kan forbedre indsatser for hjertepatienter, så de har fokus på patientens sociale situation. Derfor vil der i dette interview blive spurgt til deltagerens sociale situation samt oplevelser i forbindelse med behandling af hjertesygdom.

#### Jeg er hermed informeret om og indforstået med at:

- Deltagelse er frivillig
- Jeg kan til enhver tid trække mit samtykke tilbage
- Jeg kan til enhver tid stille spørgsmål vedrørende projektet og de metoder, der tages i anvendelse
- Interviewet vil blive optaget, men lydfilen destrueres i forbindelse med projektperiodens afslutning
- Lydfilen med optagelsen fra interviewet vil blive opbevaret i forhold til gældende lovgivning om beskyttelse af personlige oplysninger og kun være tilgængelig for projektgruppens medlemmer
- Interviewet er anonymt, dvs. at informationer, som direkte afslører min identitet, ikke vil fremgå i projektet
- Interviewet vil blive anvendt til analyse og fortolkning i samspil med andre interviews og litteratur
- Resultater fra projektet vil blive formidlet mundtligt samt i en videnskabelig afhandling og artikler
- Jeg må blive kontaktet igen efter interviewet, hvis der er noget som ønskes uddybet. Jeg er dog ikke forpligtet til at deltage i yderligere interviews eller observationer og kan frit takke nej til dette
- Deltagelse i dette projekt vil ikke påvirke min nuværende eller fremtidige behandling eller kontakt til sundhedsvæsenet

Dato:

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Deltagers underskrift:

---

**Erklæring fra den, der afgiver information:**

Jeg erklærer, at deltageren har modtaget mundtlig og skriftlig information om projektet.

Navnet på den der har afgivet information:

---

Dato:

---

Underskrift:

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Har du spørgsmål eller kommentarer efterfølgende angående interviewet, kan du kontakte den ansvarlige forsker, Amanda Nikolajew Rasmussen, på mail: [anr@hst.aau.dk](mailto:anr@hst.aau.dk) eller telefon 60 22 67 22.





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