



JÖNKÖPING UNIVERSITY
School of Health and Welfare

Doctoral Thesis

Co-producing healthcare quality improvement

– the prerequisites for, the value of
and the lessons from co-production
in a Swedish cardiac care setting

Anne-Marie Suutari

Jönköping University
School of Health and Welfare
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Eksjö, April 2023

Anne-Marie Suutari

Abstract

Background: The promotion of the best possible health and care is challenging to healthcare organizations worldwide. Healthcare organizations' capability to improve the quality of care is therefore crucial to the sustainability of the welfare state. Research implies that co-production of healthcare, involving persons with disease, their families and healthcare professionals, has the potential to promote healthcare quality improvement and the best possible health and care. However, the evidence base for co-production in social and healthcare contexts is rather weak. Thus, the overall aim of this thesis was to explore the prerequisites for and the value of co-production and to provide lessons for future co-produced healthcare quality improvement initiatives in cardiac care.

Methods: All studies were conducted in a cardiac care setting in the southern part of Sweden between the years 2016 and 2023. The research had a qualitative design with a practice-oriented interactive research approach, underpinned by healthcare improvement science and pragmatism. Persons with atrial fibrillation or heart failure, their family members, and healthcare professionals participated in the research. Two models for co-production were explored – the Learning Café (LC) and Experience-Based Co-Design (EBCD). Data collection included patients' ratings regarding their sense of security in everyday life, focus group interviews, project documentation, individual interviews, field notes from observations, and meeting minutes from stakeholders' individual and joint EBCD feedback events. Data analysis entailed inductive or deductive qualitative content analysis and reflexive thematic analysis. Self-determination theory, the COM-B model and the MUSIQ framework were applied during the research process to promote an in-depth understanding of the concept of co-production.

Findings: This research exemplifies a learning journey toward co-production in a Swedish cardiac care setting. Barriers to and facilitators of co-production were identified on different levels – the individual, the relational and the systemic levels. Individual barriers to co-production included poor health and limited health literacy among persons with heart disease. Relational barriers included professionals not inviting patients and their family members to be involved in healthcare co-

production. Barriers on the systemic level included time and resource constraints and varying understanding of how co-production might be applied in practice. Both self-centered motivations, such as wanting to learn more about a specific disease, and community-centered motivations, such as wanting to improve healthcare services, were identified to be facilitators to co-production. The LC and the EBCD process created value for its participants and the organization, including improved disease knowledge; relatedness; strengthened coping strategies and improved self-efficacy; awareness about the patient and family member perspective; and knowledge about what needs to change in heart failure care.

Conclusions: This thesis proposes how healthcare co-production might be practiced, particularly in cardiac care contexts which have seen only limited implementation of such initiatives. Self-centered motivations to co-produce were common among persons with heart disease and their family members, whereas community-centered motivations dominated among professionals. Future co-production initiatives should draw on these motivations. Furthermore, future co-production initiative should seek to overcome barriers to co-production by letting stakeholders participate on their own terms, by promoting a cultural change toward shared power between patients, family members and professionals and by encouraging healthcare leaders and managers to support healthcare quality improvement. Furthermore, this thesis proposes that co-production brings value to its stakeholders in terms of improved coping strategies persons with heart disease and family members and enhanced work satisfaction among professionals. Future research is warranted to understand how co-production might be implemented and play out in various healthcare contexts and with other groups of persons living with chronic disease.

Key words: Co-production of healthcare; cardiac care; atrial fibrillation; heart failure; healthcare quality improvement; healthcare improvement science; pragmatism; Learning Café, Experience-Based Co-Design; COM-B; Self-Determination Theory; MUSIQ; case study; content analysis; reflexive thematic analysis.

Svensk sammanfattning

Bakgrund: Att kunna erbjuda bästa möjliga vård är en utmaning för hälso- och sjukvårdsorganisationer världen över. Organisationernas förmåga att förbättra vårdens kvalitet är därför avgörande för framtiden. Forskning tyder på att samskapande av hälso- och sjukvård (engelskans *co-production of healthcare*), som involverar personer med sjukdom, deras familjer och vårdpersonal, främjar bästa möjliga hälsa och vård. Det övergripande syftet med denna avhandling var att utforska förutsättningar för och värdet av samskapande och att identifiera främjande lärdomar för framtida samskapade kvalitetsförbättringsinitiativ inom sjukvården.

Metod: Samtliga studier genomfördes inom hjärtsjukvården i södra Sverige mellan åren 2016-2023. Studierna hade en kvalitativ design med en interaktiv forskningsansats. Personer med förmaksflimmer eller hjärtsvikt, deras familjer och sjukvårdspersonal deltog i forskningsstudierna. Två modeller för samskapande utforskades – lärcafé och erfarenhetsbaserad verksamhetsutveckling (engelskans *Experience-Based Co-Design, EBCD*). Databaseringen inkluderade patientskattningar avseende trygghetskänsla, fokusgruppsintervjuer, projektdokumentation, individuella intervjuer, fältanteckningar från observationer och mötesprotokoll från individuella och gemensamma EBCD-sammankomster. Data analyserades med induktiv eller deduktiv kvalitativ innehållsanalys och reflexiv tematisk analys.

Resultat: Hindrande och underlättande faktorer för samskapande identifierades på olika nivåer – den individuella, den relationella och den systemiska nivån. Individuella hinder för samskapande bestod av nedsatt hälsa och begränsad hälsoliteracitet hos personer med hjärtsjukdom. Relationella hinder bestod av att inte bli inbjuden att samskapa. Hinder på systemnivån bestod av brist på tid och resurser samt varierande förståelse för hur samskapande kan tillämpas i praktiken. Deltagarnas motivation för att delta i projekten främjade samskapande och varierade från att delta för sin egen skull till att delta för att förbättra vården för andra med liknande utmaningar till

följd av kronisk sjukdom. Lärcaféet och EBCD-processen skapade ett värde för deltagarna och organisationen, framför allt förbättrad sjukdomskunskap, stöd från andra med liknande erfarenheter, stärkta strategier för att hantera sjukdom och självförmåga, ökad medvetenhet om patient- och närståendeperspektiv samt kunskap om vad som behöver förändras inom hjärtsviktsvården.

Slutsatser: Avhandlingen visar hur samskapande kan tillämpas inom hjärtsjukvård. Personer med hjärtsjukdom och deras familjer deltog i projekten främst för sin egen skull medan medarbetare huvudsakligen deltog för att förbättra vården för andra som lever med kronisk sjukdom. Framtida samskapandeprojekt behöver utgå från dessa motiverande faktorer. Framtida projekt bör dessutom sträva efter att övervinna de faktorer som hindrar samskapande genom att låta deltagare delta på sina egna villkor, genom att främja en kulturförändring inom hälso- och sjukvården mot delad makt mellan patienter, närstående och medarbetare och genom att uppmuntra chefer till att stötta vården förändringsarbete. Vidare ger denna avhandling en ökad förståelse för det värde som samskapandet genererar i form av förbättrad sjukdomsbemästring bland personer med hjärtsjukdom och deras familjer samt förbättrad arbetstillfredsställelse bland medarbetare. Framtida forskning behövs för att förstå hur samskapande av hälso- och sjukvård kan överföras till andra vårdmiljöer för och med andra grupper av personer som lever med kroniska sjukdom.

Abbreviations

AF	Atrial fibrillation
CMS	Clinical microsystem
COM-B	Capabilities, Opportunities, Motivation, Behavior
EBCD	Experience-based co-design
FGI	Focus group interview
HRQoL	Health-related quality of life
HF	Heart failure
HL	Health literacy
LC	Learning Café
MUSIQ	Model for Understanding Success in Quality
PCC	Primary care center
PDSA	Plan, Do, Study, Act
PWAF	Persons with atrial fibrillation
PWHF	Persons with heart failure
QI	Quality improvement
RJC	Region Jönköping County
SEK	Swedish krona
SDT	Self-determination theory

Original papers

Papers 1-5 are enclosed as appendices. Papers 1-4 are published with open access and are free to reprint for noncommercial use when properly cited.

Paper 1

Suutari, A.-M., Areskoug Josefsson, K., Kjellström, S., Nordin, A., & Thor, J. (2019). Promoting a sense of security in everyday life—A case study of patients and professionals moving toward co-production in an atrial fibrillation “learning café”. *Health Expectations*, 22(6), 1240–1250. doi: [10.1111/hex.12955](https://doi.org/10.1111/hex.12955)

Paper 2

Suutari, A.-M., Thor, J., Nordin, A., Kjellström, S., & Areskoug Josefsson, K. A. (2021). Improving Health for People Living with Heart Failure: Focus Group Study of Preconditions for Co-Production of Health and Care. *Journal of Participatory Medicine*, 13(2), e27125. doi: [10.2196/27125](https://doi.org/10.2196/27125)

Paper 3

Suutari A.-M., Nordin A., Kjellström S., Thor, J. & Areskoug Josefsson, K. (2022). Using stakeholders’ experiences to redesign health services for persons living with heart failure: a case study protocol in a Swedish cardiac care setting. *BMJ Open* 2022;12:e058469. doi: [10.1136/bmjopen-2021-058469](https://doi.org/10.1136/bmjopen-2021-058469)

Paper 4

Suutari, A.-M., Thor, J., Nordin, A., & Josefsson, K. A. (2023). Improving heart failure care with an Experience-Based Co-Design approach: what matters to persons with heart failure and their family members? *BMC Health Services Research*, 23(1), 294. doi: [10.1186/s12913-023-09306-w](https://doi.org/10.1186/s12913-023-09306-w)

Paper 5

Suutari, A.M., Thor, J., Nordin, A., & Areskoug Josefsson, K. (2023). Experiences of and conditions for re-designing heart failure care – a qualitative evaluation of an Experience-Based Co-Design case in a Swedish cardiac care setting. *In manuscript*.

Contents

Original papers	8
Prologue	13
Introduction	14
Background	16
Healthcare quality improvement	16
Patient and family member involvement in quality improvement	17
Levels of patient and family member involvement	18
Co-production of healthcare	21
Defining co-production in healthcare	21
The thesis's definition of co-production	22
Co-production and power	23
Promoting evidence for co-production of healthcare	24
Cardiovascular disease and the Swedish healthcare system	25
Cardiovascular disease	25
Atrial fibrillation	27
Heart failure	27
The Swedish healthcare system	28
The clinical microsystem	29
Theoretical framework	30
Healthcare improvement science	30
The ontology and epistemology of pragmatism	32
Rationale	34
Aim	34
Research questions	35
Research methods	36

Overview of and relation between included papers	36
The research process	36
A practice-oriented interactive research approach.....	39
Empirical context at the regional and the local levels	39
Designs, settings, participants, data collection methods and analysis	41
Paper 1	41
An organizational case study	41
The Learning Café	41
Cardiac care with PWAF, family members, and professionals	41
Qualitative and quantitative data	43
Descriptive statistics and qualitative content analysis	43
Paper 2	45
A qualitative design with focus groups.....	45
Cardiac care with PWHF, family members, and professionals	45
Qualitative data	45
Qualitative content analysis	47
Paper 3	49
A protocol of the EBCD methodology	49
Paper 4	50
A case study	50
The EBCD process “in real-life”	50
Cardiac care with PWHF, family members, and professionals	51
Qualitative data	52
Reflexive thematic analysis	52
Paper 5	55
A qualitative design with focus groups.....	55
Cardiac care with PWHF, family members, and professionals	55

Qualitative data	57
Reflexive thematic analysis.....	57
Ethical considerations	59
Ethical values in co-production of healthcare	59
Main findings	64
Paper 1: Promoting a sense of security in everyday life	64
Paper 2: Improving health for people living with heart failure.....	67
Paper 3: Using stakeholders’ experiences to redesign health services	71
Paper 4: Improving heart failure care with an EBCD approach	72
Paper 5: Experiences of and conditions for redesigning HF care	77
Summary of main findings.....	80
Discussion	82
Moving toward co-production in cardiac care – a learning journey	82
The prerequisites for co-production in a cardiac care setting	88
The value of co-production in a Swedish cardiac care setting.....	99
Methodological considerations	106
Conclusions and implications	114
Conclusions	114
Implications	115
Implications for co-production theory	115
Implications for healthcare practice	116
Guiding principles for future co-production	116
Future research	119
Epilogue - My own learning	120
References	122

Prologue

Working as a cardiologist, I have had the privilege of helping many persons with heart disease and their family members. I have worked with many skilled colleagues who always strive to deliver the best possible healthcare, based on the ever-increasing amount of medical evidence. Early in my career, I found myself pondering about why this available evidence did not always translate into “real-life” improvements in patient care. I got interested in trying to improve working practices and healthcare processes locally at my hospital department in Eksjö, Sweden.

In fall 2014, I had the opportunity to join the master’s program on quality improvement and leadership in health and welfare at Jönköping University, Sweden. This program provided me with tools, methodologies and frameworks that helped me to understand how generalizable scientific evidence could be translated into measured performance improvements. To me, healthcare quality improvement represented “the missing link” between research evidence and the best possible health and care. During my master’s education, I was introduced to the concept of co-production of healthcare. It made sense to me to understand co-production as an approach to healthcare quality improvement – of course healthcare service improvements need to draw from the experiences of those who interact with the service!

In spring 2018, I was enrolled as a PhD student at the School of Health and Welfare, Jönköping University. The research in my thesis draws on my interest in healthcare quality improvement, co-produced by persons with heart disease, their family members and professionals. The five papers in my thesis report on individual and organizational perspectives on co-produced healthcare quality improvement within cardiac care.

Introduction

“I mean, if you don’t have the knowledge you can come up with any kind of claim, which there is no value in [...] To participate in designing the health care services [...] My views obviously wouldn’t be worth anything.” [Focus group interview with persons with heart failure]

“I mean, before we can say that we can have patients involved in making decisions concerning their own care, then we must have a good concept to deliver to them, and we are not there yet.” [Focus group interview with professionals in cardiac care]

Promotion of the best possible health for persons living with chronic disease is a challenging task for health systems worldwide. It puts demands on the health systems’ capacity to improve the quality of care (Dixon-Woods & Martin, 2016).

The Swedish national health strategy “Nära Vård” (“*Closer Care*”) aims at promoting the best possible health and care based on the patients’ and family members’ capabilities and needs. This strategy emphasizes engaging patients and family members as active partners in co-production of healthcare processes, thereby improving self-care and quality of life (Swedish Association of Local Authorities and Regions, 2023b). Co-production of healthcare services – involving patients, family members and professionals – has been proposed to create joint learning about how to meet the needs of persons with chronic disease, thus promoting the best possible health (Batalden et al., 2016; Elwyn et al., 2020; Turakhia & Combs, 2017). Co-production can therefore be understood as an approach to healthcare quality improvement (QI) (Batalden et al., 2016). Still, scholars agree that the evidence base for co-production in social and healthcare contexts is rather weak (Masterson et al., 2022).

The above quotes exemplify patients’ and healthcare professionals’ limited understanding of what co-production means and how this concept might be applied in practice. To address this gap in knowledge,

I set out to write this thesis on co-produced healthcare QI within cardiac care. The overall aim of this thesis was to explore the prerequisites for and the value of co-production and to provide lessons for future co-produced healthcare QI initiatives in cardiac care. Two models promoting co-produced healthcare QI were tested and evaluated – the Learning Café (LC) with persons with atrial fibrillation (PWAF) and Experience-Based Co-Design (EBCD) with persons with heart failure (PWHF). The prerequisites for, the value of and the lessons from co-production in a Swedish cardiac care setting are discussed. By adopting a practice-oriented interactive approach to the healthcare QI and research, I took the role of an insider researcher within cardiac care in the Highland health district, Region Jönköping County, Sweden.

Background

Healthcare quality improvement

Promotion of the best possible health for persons living with chronic disease is a challenging task for health systems worldwide. An aging population present with a high burden of disease, with cardiovascular disease being one of the largest contributors to the global burden of disease (Prince et al., 2015). Patients and family members expect to be involved in their own care, putting further demands on health systems and professionals (Eriksson-Liebon et al., 2021). To address these challenges, health systems' capacity to improve quality is crucial (Dixon-Woods & Martin, 2016).

Healthcare QI has a quadruple aim, i.e., to improve the health of populations, to improve patients' care experiences, to reduce healthcare costs and to improve professionals' well-being (West, 2016). Healthcare QI draws on system thinking, the understanding of process variation, different stakeholders' epistemologies and knowledge about how social interactions impact systems (Deming, 1994). QI tools and methodologies were initially developed for industrial purposes. However, the interest in healthcare QI increased in the 1990s when QI was found to be a useful approach to address healthcare inequalities (Nilsen et al., 2020). Since then, numerous QI tools and methodologies have been applied globally to various healthcare contexts. Healthcare improvement science, discussed in detail under 'Theoretical framework', evolved as a multidisciplinary research field to provide a scientific knowledge base for QI (Nilsen et al., 2020).

Batalden and Davidoff (2007) define healthcare QI as

[...] the combined and unceasing efforts of everyone – healthcare professionals, patients and their families, researchers, payers, planners and educators—to make the changes that will lead to better patient outcomes (health), better system performance (care) and better professional development (learning). (Batalden & Davidoff, 2007, p. 2)

Early healthcare QI projects drew mainly on clinicians' experiences rather than on the service users' needs (Bate, 2007). Barriers to clinicians' engagement in healthcare QI still exist, such as time constraints, lack of QI mentorship and organizational support, lack of indicators to track performance, and mixed effectiveness (Dixon-Woods & Martin, 2016; Iqbal et al., 2019; Shaikh et al., 2020). In spite of this, clinicians' appreciation of healthcare QI as an approach to improved patient care is growing. Nowadays, clinicians participate in improvement efforts on different organizational levels to improve patient care (Batalden, 2018).

However, the definition of healthcare QI, provided by Batalden & Davidoff (2007), sees patients and their families as self-evident partners in healthcare QI initiatives (Batalden & Davidoff, 2007). Thus, continuous healthcare QI should not only be informed by professionals' medical expertise and improvement knowledge but also by patients' knowledge (Gustavsson et al., 2022). Family members' and carers' knowledge should similarly inform healthcare QI, given their valuable contributions to QI projects in various healthcare contexts over time (Bench et al., 2020).

Patient and family member involvement in quality improvement

Batalden argues that “providing healthcare services” differs from “producing healthcare” (Batalden, 2018). The difference between these two logics is that the service logic, i.e., “providing healthcare services”, employs patient and family member involvement in healthcare processes, also when it comes to healthcare QI and research.

There are several benefits of patient and family member involvement in healthcare QI. Their involvement is argued to improve patient outcomes and service delivery changes (Bombard et al., 2018). When patients are involved in healthcare QI, they define what healthcare quality means in practice (Elwyn et al., 2020). Involving patients and family members in healthcare QI can further promote organizational change that addresses the service users' true needs (Pizzo et al., 2014). Facilitators promoting patient and family member involvement in healthcare QI include individual motivation, techniques for enhancing

patient/carer input (Bombard et al., 2018), support from leaders (Clarke et al., 2017; Connolly et al., 2020), and learning networks including patients, non-formal care givers and professionals (Batalden et al., 2016).

However, there are barriers to patient and family member involvement in healthcare QI. Virlée (2020) suggests that patients' motivation to be involved in healthcare depends on barriers on three different levels: the individual, relational and systemic levels (Virlée et al., 2020). Individual, patient-related barriers to healthcare involvement include acute illness (Holland-Hart et al., 2019), frailty and old age (Clarke et al., 2017), limited health literacy (HL) (Palumbo & Manna, 2018) and a low self-efficacy (Virlée et al., 2020). Relational barriers include professionals' lack of communication skills (Palumbo & Manna, 2018). Barriers on the system level include resource constraints, e.g., staff shortages, lack of care continuity and short appointment times (Holland-Hart et al., 2019; Virlée et al., 2020). Other system barriers relate to organizational culture and professionals' attitudes toward patient and family member involvement in healthcare QI (Steen & Tuurnas, 2018). However, over time, professionals' attitudes toward patient and family member involvement can change from skepticism to appreciation and trust (Boström et al., 2017).

Given these barriers, there is a risk of involving small and narrow groups of individuals in healthcare QI (Ocloo & Matthews, 2016). This, in turn, might lead to a non-generalizable project and research results. Although different approaches can be employed to evaluate stakeholder engagement in research, there is a lack of a unifying definition of meaningful engagement (Martinez et al., 2019). Furthermore, it is unclear whether or not patient and family member involvement truly improves care quality and outcomes (Modigh et al., 2021).

Levels of patient and family member involvement

Arnstein has proposed a “citizen ladder of participation” (Arnstein, 1969). This ladder explains different levels of citizen involvement in society. The levels of involvement span from manipulation to citizen control (Arnstein, 1969). Modifications of Arnstein's ladder have been published to describe *patient* involvement in healthcare contexts

(Williams & Caley, 2020). Patient involvement spans from coercion to co-production. Building on previous interpretations of Arnstein's ladder of participation, an updated and adjusted version of the ladder explaining levels of patient and family member involvement is proposed in this thesis, the co-production pathway (figure 1).

Modifications of Arnstein's ladder suggest that "informing" represents a higher level of involvement than "educating" (Williams & Caley, 2020). "Informing", usually employing unidirectional communication, aims at creating awareness of or acquaintance with knowledge of a subject (Pickett, 2018). "Educating", on the other hand, aims at developing mental, moral and social capabilities by schooling or instruction (Pickett, 2018). These definitions indicate that educating, in contrast to informing, aims at empowering and transforming individuals through support and guidance. Thus, this thesis argues that "educating" is a higher level of involvement than "informing", as indicated in figure 1. Further modification from previous ladder models includes an adjusted definition of the highest levels of involvement. In previous ladder models, co-production is the highest level of involvement followed by co-design (Williams & Caley, 2020). However, when aligning with the definition by Batalden (2016), further elaborated on in the next section, the process of co-design is included within co-production (Batalden et al., 2016). Therefore, co-design does not have a separate level in the ladder proposed in figure 1. The type of healthcare QI that is undertaken on different levels of involvement is specified in the co-production pathway (Williams & Caley, 2020). Furthermore, the power distribution between patients, their families, and professionals at different levels of involvement is indicated.

The co-production pathway indicates that there are three main levels of involvement: doing *to*, doing *for*, and doing *with* patients and their families. *Doing to* represents the first, although weak, level of involvement. Here, professionals have the power over patients and their family members. If the stakeholders perceive healthcare as something that is done *to* the patients and their families, healthcare QI is characterized by service-led initiatives focusing on the organization's needs (Williams & Caley, 2020).

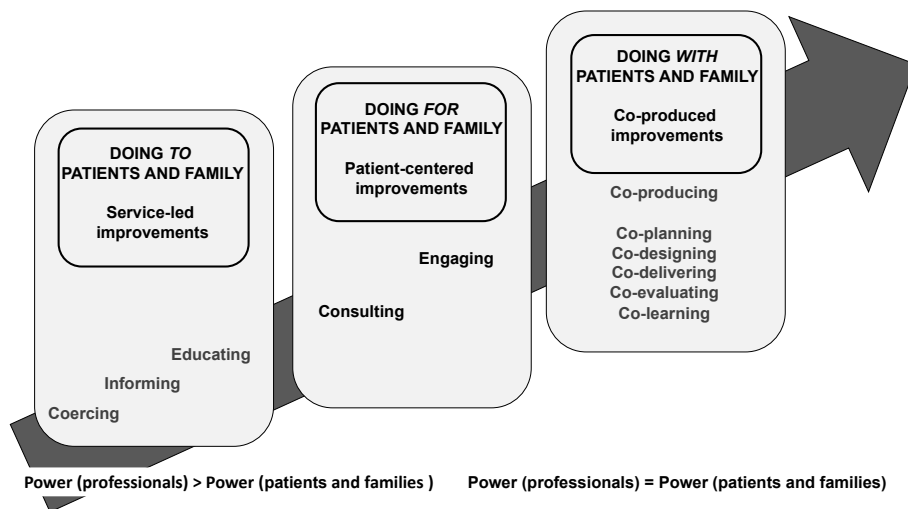


Figure 1. The co-production pathway (modified by author A-MS after Arnstein (Arnstein, 1969); Williams & Caley (Williams & Caley, 2020)) (Suutari et al., 2019).

The next level of involvement, *doing for* patients and their families, represents a progression toward greater patient and family member involvement. Although the power balance between the stakeholders is more balanced compared to the previous level of involvement, the power balance is still in favor of the professionals. By consulting and engaging, the patients and family members are invited to be heard. However, their opinions and ideas do not shape service redesign (Williams & Caley, 2020). If healthcare is perceived as something that is done *for* the patients and their families, QI initiatives are characterized by patient-centered initiatives. These initiatives focus on what is best for the patients and their families but they are still carried out on the premises of healthcare professionals (Williams & Caley, 2020). This kind of healthcare QI has for example been reported by Kuipers (2021), who describes the implementation of an improvement initiative aiming at patient-centered care in a primary care setting. Here, patients were consulted during the evaluation of the project (Kuipers et al., 2021).

At the last stage of the co-production pathway, *doing with*, patients, their families and professionals work with shared power. The stakeholders are co-producing healthcare, i.e., co-planning, co-designing, co-delivering, and co-evaluating healthcare processes, co-learning from the improvement efforts to be able to achieve the best possible health and care (Williams & Caley, 2020). The next section offers a deeper understanding of the concept of co-production of healthcare.

Co-production of healthcare

The term “co-production” was first used within the field of economics (Ostrom et al., 1978). The interest in co-production of healthcare has grown in recent decades. Co-production, involving patients, their families, and professionals in care processes, provides co-learning about how to meet the patients’ and families’ needs, thus promoting the best possible health and care (Batalden et al., 2016). On a societal level

“[...] the purpose of co-production is to encourage [people] to use the human skills and experience they have to help deliver public or voluntary services. It is [...] about ‘broadening and deepening’ public services so that they are no longer the preserve of professionals or commissioners, but a shared responsibility, both building and using a multi-faceted network of mutual support.” (New Economist Foundation, 2008)

Defining co-production in healthcare

Coldham (2018) has proposed five key features of co-production: sharing power; including all perspectives and skills; respecting and valuing the knowledge of all those being involved; reciprocity and building and maintaining relationships (Coldham, 2018).

However, it is difficult to find a consistent definition of co-production in healthcare contexts (Masterson et al., 2022). Various definitions of co-production in healthcare contexts have been proposed, all of them emphasizing important aspects that are useful when trying to transfer the concept to healthcare settings. Loeffler (2013) defines co-

production of health and care as a collaboration between patients, their families and the healthcare professionals at four levels: (1) co-planning including co-prioritization and co-financing of health and care; (2) co-design of health and care; (3) co-delivery including co-managing and co-performing health and care, and (4) co-assessment including co-monitoring and co-evaluation of health and (Loeffler et al., 2013). Rather similarly, Batalden (2016) has described the co-production of healthcare services as “The interdependent work of users and professionals to design, create, develop, deliver, assess and improve the relationships and actions that contribute to the health of individuals and populations” (Batalden et al., 2016). Drawing on this definition, co-production can be understood as an approach to healthcare QI. Furthermore, Osborne (2016) states that more attention should be paid to the role of learning from co-production, i.e., learning about how to co-produce effectively together and how the lessons from co-production can be used for service improvement (Osborne et al., 2016).

The definitions of co-production in healthcare contexts highlight the importance of patient and family member involvement in every step of healthcare processes. These definitions further highlight that the concept of co-design can be understood as a process within co-production, as described in the previous section. However, Vargas (2022) argue that there are differences between co-design and co-production (Vargas et al., 2022). According to Vargas (2022), co-design refers to an active stakeholder collaboration when designing solutions to a pre-specified problem, whereas co-production refers to the joint implementation of the co-designed solution. Still, rather than focusing on universal definitions of co-production and co-design, applied research on these concepts should focus on explaining and operationalizing important underlying principles and values that these terms translate to in practice (Masterson et al., 2022).

The thesis's definition of co-production

Co-production of healthcare is understood in this thesis as when persons living with heart disease, their family members and healthcare professionals interact with shared power when co-planning, co-designing, co-delivering and/or co-evaluating healthcare services, co-learning from the processes and outcomes to further improve healthcare

services. The aim of this interaction should be to achieve the best possible health and care from the patients', families', and professionals' points of view. This definition of co-production draws attention to co-production being an approach for healthcare QI rather than an end goal of healthcare processes. This thesis also acknowledges that there are two levels on which co-production can be employed: co-production focusing on the individual patient's engagement in their own health and care, and a system approach focusing on relations between the stakeholders (patients, family member and professionals) and healthcare providers when improving healthcare processes (Gilardi et al., 2016).

Co-production and power

Historically, patients and their families have had less power than healthcare professionals (Kirkegaard & Andersen, 2018). The power balance still remains unequal in many healthcare contexts (Kirkegaard & Andersen, 2018). For example, Nimmon & Stenfors-Hayes (2016) found that physicians perceive themselves to hold power when interacting with their patients (Nimmon & Stenfors-Hayes, 2016). A key premise to the co-production of healthcare, as indicated earlier in this chapter, is shared power between the patients, their carers/ families and healthcare professionals.

In co-production, power needs to be shared through equal and reciprocal relationships between the involved stakeholders (Coldham, 2018). However, the concept of power is rarely explicitly discussed when employing participatory research approaches within healthcare contexts (Egid et al., 2021). There may even be a risk of co-production initiatives ending up reinforcing existing unequal power relations (Turnhout et al., 2020). This may be the case if co-production is initiated only by researchers, if looking for consensus solutions rather than taking all stakeholders' views into consideration when choosing a solution to a real-life problem, and if not engaging with the wider political context based on which the initiatives are co-produced (Turnhout et al., 2020).

Promoting evidence for co-production of healthcare

Despite the belief that co-production has the potential to promote the best possible health, researchers agree that the evidence base for co-production in social and healthcare contexts is rather weak (Masterson et al., 2022). There are several challenges to building an evidence base for co-production of healthcare.

First, as discussed earlier in this chapter, it is difficult to find a consistent definition of co-production in healthcare contexts (Masterson et al., 2022). Co-production can take place in many stages of healthcare processes i.e., planning, designing, delivery, evaluation and implementation (Loeffler et al., 2013; Voorberg et al., 2015). Co-design is an established concept, whereas the other concepts, i.e., co-planning, co-delivery and co-evaluation, are not yet widespread (Durose et al., 2017). This broad and indistinct definition of co-production makes it hard to compare studies and to get an overview of existing evidence.

The second challenge to building evidence for co-production relates to research methodology. Insufficient study context and participant descriptions, scarce descriptions of engagement and participation strategies and poorly chosen methodologies for data analysis challenge evidence-building (Durose et al., 2017). A large proportion of co-production studies are done in UK healthcare contexts, limiting the evidence to this specific context and its conditions (Szescilo, 2016). Insufficient context descriptions and lack of descriptions of engagement and participation strategies used in the studies further limit the generalizability of the study results (Williams & Caley, 2020). Evaluations of co-production, with initiatives often carried out in microsystem settings, typically involve qualitative case study approaches rather than quantitative evaluation (Durose et al., 2017; Williams & Caley, 2020). Furthermore, rather than evaluation of service end outcomes in terms of improved health and care, the evaluation is often limited to process evaluations (Clarke et al., 2017). In some cases, there are many confounders, making it impossible to assess whether service user engagement was the key mechanism to reported service outcomes (Farr, 2018). There is also a lack of longitudinal evaluations of the impact of co-production (Durose et al.,

2017). To be able to build an evidence base for co-production, clinical and service-related outcomes of co-production and its cost-effectiveness need to be established (Pennington et al., 2017).

The third challenge to evidencing co-production of healthcare relates to different opinions on the nature of “good evidence” There is a risk of evidence-based government policies downgrading the value of the qualitative case study approaches frequently used to evaluate co-production initiatives (Durose et al., 2017).

Durose (2017) proposes two ways to overcome the challenges for evidencing co-production of healthcare: recognition of the knowledge-based practice and the utilization of theory-based approaches in evaluation of co-production initiatives (Durose et al., 2017). Combining these strategies might capture the relational dimension of co-production, which does not always fit traditional evaluation methods (Durose et al., 2017). Knowledge-based practice includes assessment of treatment approaches that are tailored to patients’ specific needs, the clinicians’ clinical experience and the understanding of patients’ care preferences (Ammerman et al., 2014). Recognition of the knowledge-based practice, when evidencing co-production, means that the insights of the people that co-produce healthcare processes are used to build evidence. Here the knowledge and wisdom of those working close to the core business of healthcare are recognized (Durose et al., 2017). Applying a theory-based approach for evaluation of co-production of healthcare means choosing a theory that can be used to explain *why* co-production is expected to produce its promoted benefits (Durose et al., 2017).

Cardiovascular disease and the Swedish healthcare system

Cardiovascular disease

Cardiovascular disease causes approximately 18 million deaths yearly and is thereby the number one cause of death globally (World Health Organization, 2021). In Sweden, two million persons live with cardiovascular disease (Hjärt-Lungfonden, 2022). In 2019, the yearly

Swedish healthcare costs due to cardiovascular disease reached 60 billion SEK (Andersson et al., 2019).

Cardiovascular disease refers to disorders of the heart and blood vessels caused by hypertension, use of tobacco and/or alcohol, low physical activity, and high cholesterol levels (Roth et al., 2020). Ischemic heart disease and stroke, atrial fibrillation (AF) and heart failure (HF) are common cardiovascular diseases worldwide and also in Sweden (Hjärt-Lungfonden, 2022). Ischemic heart disease, with decreased blood flow and oxygen to the heart muscle due to narrowed coronary arteries, is the most common type of chronic cardiovascular disease. This is reflected in the ever-increasing amount of research, health promotion initiatives and disease prevention programs aiming at reducing morbidity and mortality caused by ischemic heart disease.

Ultimately, ischemic heart disease can lead to chronic arrhythmia, such as AF, or chronic HF. AF affects approximately 430 000 individuals in Sweden, with yearly healthcare costs exceeding seven billion SEK due to stroke, hospital admissions and medication (Riksförbundet HjärtLung, 2021). HF affects approximately 250 000 individuals in Sweden (Swedish Association of Local Authorities and Regions, 2021). In developed countries, one to two percent of the adult population suffers from HF, with the prevalence being as high as 10% among people over 70 years of age (McDonagh et al., 2021). Thus, the absolute number of hospital admissions due to HF is expected to increase considerably in the future (McDonagh et al., 2021).

Given the above, it is important to further improve AF and HF care. Clinical AF and HF management guidelines recommend persons living with AF or HF as equal and active partners to healthcare professionals within healthcare (Hindricks et al., 2020; McDonagh et al., 2021).

In this thesis PWAF and PWHF are involved in co-produced healthcare QI initiatives aimed at the best possible health and care. These two populations are chosen to represent different groups of individuals with various challenges in life with heart disease and thus different challenges to co-production. The next sections offer an overview of AF and HF.

Atrial fibrillation

AF is the most common heart arrhythmia, associated with palpitations, weakness, fatigue, dizziness, an increased risk of stroke due to formation of thrombi inside the heart, and even premature death (Hindricks et al., 2020). AF is caused by for example ischemic or valvular heart disease, hypertension, thyroid diseases, or HF. AF is often intermittent in its nature. Thus, AF can be difficult to predict, causing stress and anxiety among those suffering from the disease. AF treatment includes medication, cardioversion (quick, low-energy shocks to restore a regular heart rhythm) and catheter ablation (a surgical procedure that uses heat or cold energy to block irregular electrical signals and to restore a normal heart rhythm) (Hindricks et al., 2020).

Research proposes that PWAF have limited health-related quality of life (HRQoL) due AF-related anxiety, symptom frequency, and symptom severity (Son et al., 2019). PWAF experience a limited ability to perform activities of daily living due to AF, causing further worry and anxiety (Stridsman et al., 2019). Research further proposes that persons living with arrhythmias have low confidence in decision-making concerning treatment options and self-care (Hedberg et al., 2018; Zhang et al., 2015). The need for decision aids to promote further shared decision-making among PWAF has been highlighted in research (Pokorney et al., 2018). Inadequate support for PWAF and family members to cope with AF further increases anxiety due to emotional distress and a lack of strategies to cope with AF (Brunner-La Rocca et al., 2021; Withers et al., 2015). Applicable clinical guidelines for AF management recommend integrated AF care, with multidisciplinary teams providing easy access to appropriate care and patient and family member support. According to these guidelines, the support should strengthen coping by giving empowerment for self-management and counseling on lifestyle changes to manage risk factors (Hindricks et al., 2020).

Heart failure

HF is a clinical syndrome with cardinal symptoms and signs (e.g., breathlessness, ankle swelling, and fatigue). HF is “due to a structural and/or functional abnormality of the heart that results in elevated

intracardiac pressures and/or inadequate cardiac output at rest and/or during exercise.” (McDonagh et al., 2021). HF management includes a multidisciplinary team approach promoting medication, physical activity, a healthy diet, and smoking cessation (McDonagh et al., 2021).

Clinical HF management guidelines promote uncovering and treating the underlying cause to HF, such as ischemic heart disease, hypertension, arrhythmias or valvular disease (McDonagh et al., 2021). Since there always is an underlying cause of HF, PWHF usually present with several comorbidities, adding to the severity of symptoms and poor quality of life. Furthermore, previous research indicates that HF is associated with cognitive impairments and dementia (Cannon et al., 2017; Li et al., 2020; Yang et al., 2020). These impairments predict a limited self-care ability among some PWHF (Lovell et al., 2019).

Management guidelines further recommend acknowledging PWHF as equal and active partners in their healthcare by supporting their engagement in the monitoring and self-management of HF (McDonagh et al., 2021). However, there are challenges to PWHF being equal partners to healthcare professionals. PWHF often experience poor physical capabilities, making it difficult to cope with life, which may be a barrier to being engaged in healthcare (Walthall et al., 2019). Furthermore, cognitive decline and limited HL among PWHF may make it difficult for them to understand and engage in healthcare service activities (Hickey et al., 2018; Jo et al., 2020; McDonagh et al., 2021). Limited HL predicts a frequent use of emergency care, high morbidity and mortality rates and recurrent hospital admissions compared to individuals with higher HL levels (Palumbo et al., 2019). These consequences, related to limited HL, also seem to apply to PWHF (Fabbri et al., 2020).

The Swedish healthcare system

Swedish healthcare is governed by laws and strategies. On a national level, the Health and Medical Services Act states that Swedish healthcare should be provided close to its citizens, building on respect for the patients’ and family members’ self-determination and integrity (Health and Medical Services act, 2017; Patient act, 2014). “Nära Vård”

(“*Closer Care*”), a Swedish national health strategy, aims at promoting healthcare based on the patients’ and family members’ capabilities and needs. This strategy emphasizes engaging patients and family members as active partners in healthcare processes, thereby improving self-care and quality of life (Swedish Association of Local Authorities and Regions, 2023a).

On a regional level, 21 Swedish healthcare counties are responsible for the implementation of national laws. Each county, divided into municipalities, provides healthcare for its inhabitants on three different levels. The primary care level consists of primary care centers (PCCs). The clinicians at the PCCs provide easily accessible care focusing on the large majority of healthcare needs and disease prevention in the area close to the PCC (Health and Medical Services act, 2017). The secondary care level consists of county hospitals that provide specialized healthcare delivered as a follow-up or referral from a primary care provider. Tertiary care centers, i.e., university hospitals, are medical facilities which provide a high degree of subspecialty expertise for patients referred from secondary care centers.

Persons with heart disease can receive care on all these principally different levels in the Swedish healthcare system – in a PCC, in a county hospital or in a university hospital. Most persons with heart disease are primarily advised to contact their closest PCC to receive care (Swedish Association of Local Authorities and Regions, 2023b). Emergency cases are referred to the nearest hospital as are those with a referral from a PCC to a specialty cardiac unit. For those persons who need highly specialized care, such as valve replacement surgery, a catheter ablation or a coronary angiography, care at a university hospital cardiac department is appropriate (Health and Medical Services act, 2017).

The clinical microsystem

The patients, their family members and/or carers and healthcare professionals are at the core of each PCC, hospital department and outpatient clinic, also when it comes to cardiac care. This core is called the clinical microsystem (CMS) (Mohr, 2002). A CMS consists of

“(a) a core team of healthcare professionals; (b) the defined population they care for; (c) an information environment to support the work of caregivers and patients; and (d) support staff, equipment, and a work environment” (Mohr et al., 2002, p. 46)

The common goal for the CMS is to achieve desired outcomes for the patients, family members and professionals included in the system (Nelson et al., 2007). The CMS guides and supports peak performance and innovation in healthcare contexts (Nelson et al., 2008). Microsystem interactions produce quality, safety and cost outcomes at the frontlines of healthcare (Bergerum et al., 2019). Thus, being the front-line place where care is produced in collaboration between patients, their family members and healthcare professionals, the CMS is the ideal site for healthcare QI.

Theoretical framework

Healthcare improvement science

Three perspectives were essential to the research in this thesis: healthcare QI; co-production of healthcare and living with heart disease and its care. These perspectives, elaborated on in detail previously in this chapter, were framed by healthcare improvement science theory.

The concept “the science of improvement” was first used in 1996 (Langley et al., 1996). Healthcare improvement science draws on W. Edward Deming's System of Profound Knowledge, with four knowledge domains promoting organizational improvement: appreciation for a system, understanding variation, theory of knowledge and psychology (Deming, 1994).

Still, there is no unified definition of healthcare improvement science. This thesis aligns with the following consensus definition (Skela-Savič et al., 2017):

“Healthcare improvement science is the generation of knowledge to cultivate change and deliver person-centered care that is safe, effective, efficient, equitable and timely. It improves patient outcomes, health

system performance and population health.” (Skela-Savič et al., 2017, p. 88)

This definition highlights that healthcare services research, underpinned by healthcare improvement science, should aim at producing useful knowledge through practical learning in the CMS. The practical learning should further translate into transferable knowledge in other contexts through the collaboration between academics and front line practitioners (Nilsen et al., 2020).

Healthcare improvement science provides both theoretical perspectives and practical methodologies and tools for healthcare QI (Lewis, 2015). To add to the understanding of healthcare improvement science and Deming’s knowledge domains, Perla (2013) have identified seven propositions that provide a theoretical foundation for the science of improvement (Perla et al., 2013):

1. The science of improvement is grounded in testing and learning cycles
2. The science of improvement embraces a combination of psychology and logic
3. The science of improvement considers the contexts of justification and discovery
4. The science of improvement requires the use of operational definitions
5. The science of improvement employs Shewhart’s theory of cause systems
6. Systems theory directly informs the science of improvement
7. The philosophical foundation of science of improvement is conceptualistic pragmatism

Healthcare improvement science is grounded in for instance Plan, Do, Study, Act (PDSA) cycles that facilitate small-scale tests, evaluation, and adjustment before large scale tests (Perla et al., 2013). Multidisciplinary collaboration is advocated in healthcare QI to be able to balance the contexts of justification and discovery. This means that QI innovation and creativity must be balanced with data that demonstrates if and how the tested changes work (Perla et al., 2013). The use of operational definitions and Shewhart’s theory of cause systems promote healthcare QI and understanding of variation in the

process. Systems thinking should always inform healthcare QI and research (Perla et al., 2013). Contextual differences that may influence improvement outcomes include differences in leadership and management, differences in organizational culture and team capacity (Dixon-Woods et al., 2012).

To manage the contextual challenges, improvers are advised to clarify roles and expectations to those involved in improvement, to support participants and to adapt the project to local conditions, goals and values (Dixon-Woods et al., 2012). Finally, Perla (2013) suggests that healthcare improvement science is underpinned by conceptualistic pragmatism (Perla et al., 2013). This indicates that healthcare improvement science is underpinned by everyone's past experiences to create useful knowledge (Perla et al., 2013). Next, the ontological and epistemological underpinnings of pragmatism are reviewed.

The ontology and epistemology of pragmatism

In terms of ontology, pragmatism is not committed to any single system of philosophy. Pragmatism is positioned in the middle of the objectivity-subjectivity continuum (Maarouf, 2019). Thus, rather than taking a strong stance in one existing paradigm, pragmatic researchers need to switch between different ontological positions to fulfill their research purposes and to solve real-life problems. The switch between different positions, i.e., the switch between different worldviews and realities, can be conceptualized through a reality cycle (Maarouf, 2019).

The reality cycle (figure 2) suggests that reality depends on the context and the perceptions and behaviors of its actors. Humans and social actors perceive reality differently and these perceptions influence their behaviors. The behaviors then construct a new reality, which in turn builds a new context over time (Maarouf, 2019). Pragmatic researchers acknowledge that reality is oriented toward solving practical problems and is constantly changing as a result of individuals acting in the world (Allemang et al., 2022; Maarouf, 2019). Thus, pragmatic researchers acknowledge both the views of one true external reality, i.e., a reality that is the same for each person, and a reality that is constructed from human experience (Maarouf, 2019).

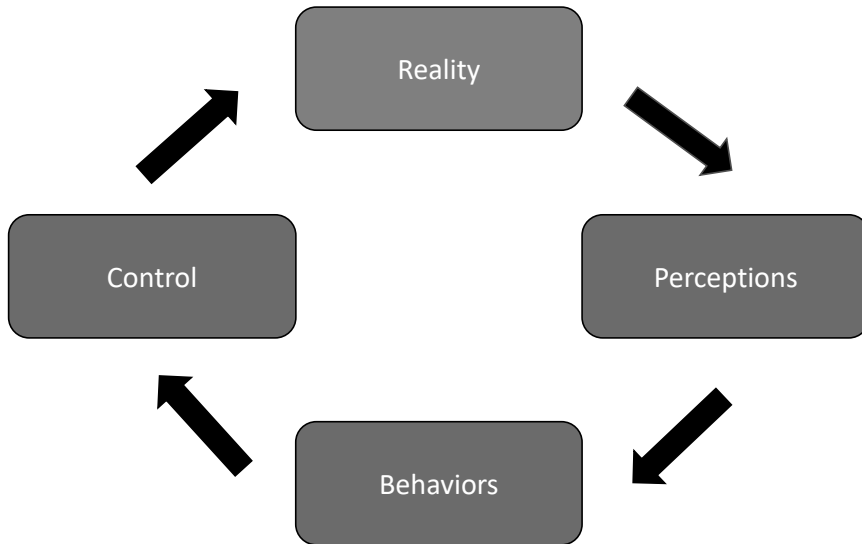


Figure 2. The reality cycle (modified by author A-MS after Maarouf (Maarouf, 2019)).

Epistemologically, pragmatism focuses on practical understandings and knowledge of concrete, real-world issues as a result of human experience (Kelly & Cordeiro, 2020). Thus, pragmatism focuses on “what is useful” instead of focusing on “what is true” (Perla et al., 2013). The practical understandings are underpinned by humans’ social experiences and are shared within the society to facilitate humans’ active participation in their own lives and in the world (Kaushik & Walsh, 2019). Pragmatism emphasizes appreciating everyone’s unique experiences as a result of our pre-existing mental models and as a tool for predicting future process outcomes (Perla et al., 2013).

There are several similarities between pragmatism and the concept of co-production (Allemang et al., 2022). Pragmatism and co-production both align with democratic values including collaboration, citizen engagement, promoting a sense of community and relationship-building (Allemang et al., 2022; Coldham, 2018). Shared problem-solving is a central guiding principle in both pragmatism and co-production (Allemang et al., 2022; Coldham, 2018). Furthermore, both pragmatism and co-production aim at generating knowledge that

promotes social justice, action and change (Allemang et al., 2022; Coldham, 2018).

Rationale

The promotion of the best possible health and care is challenging to healthcare organizations worldwide. Healthcare organizations' capabilities to improve the quality of care are therefore crucial to the sustainability of the future welfare state. Research implies that co-production of healthcare services, involving persons with disease, their families and healthcare professionals, has the potential to promote the best possible health and care. However, although co-production is underpinned by international and national healthcare policies, it still is a novel approach to healthcare QI and the best possible health, and has not yet been fully adopted by healthcare organizations. Thus, there is a lack of knowledge about how co-production could be applied in practice and how healthcare organizations should be organized to promote high-quality co-produced patient-centered care, particularly for persons with cardiac care needs. Furthermore, patients, their families and healthcare professionals lack knowledge about how to work together with shared power, co-learning about each other's needs. This indicates that healthcare organizations, patients, families and healthcare professionals are faced with challenges and opportunities, and that there is a need for extended knowledge within this field. Drawing from these gaps in knowledge, it is important to explore the prerequisites for and the value of co-production and to provide lessons for future co-produced healthcare QI initiatives in cardiac care.

Aim

The overall aim of this thesis was to explore the prerequisites for and the value of co-production and to provide lessons for future co-produced healthcare QI initiatives in cardiac care.

Research questions

- What experiences can be identified from the pilot testing of a LC, aimed at increasing the sense of security in everyday life among PWA? (Paper 1)
- What are the perceived barriers to and facilitators of co-production among PWHF, their family members, and professionals? (Paper 2)
- What matters to PWHF and their family members and what changes to HF care do they propose based on their experiences? (Papers 3 and 4)
- What experiences can be identified from EBCD participation? What factors influenced the stakeholders' participation in the EBCD process? (Papers 3 and 5)

Research methods

Overview of and relation between included papers

Table 1 provides an overview of the included papers in this thesis. The papers aimed at gradually generating knowledge on the prerequisites for and the value of co-production and to provide lessons for future co-produced healthcare QI initiatives in cardiac care.

To start building knowledge on co-production in a cardiac care context, drawing on QI tools suggesting small iterative changes, a small-scale model for co-production for and with PWAF was tested (paper 1). This meant conducting healthcare QI work by planning, doing, studying, and acting on the results of the work together with a few individuals in the LC initiative in a cardiac care CMS setting. During this project, I and the research participants started to explore how co-production might work in the research context. To be able to promote further co-production for and with persons with cardiac care needs, perceived barriers and facilitators affecting co-production of healthcare services were explored (paper 2). To overcome the barrier of not understanding the concept of co-production and how this concept might be applied in practice, EBCD, a step-by-step model for co-production, was tested to guide stakeholders' co-learning about co-produced healthcare QI. The experiences of PWHF and family members, identified during the EBCD process, were the starting point of a co-designed improvement initiative (papers 3 and 4). To guide future co-production initiatives, paper 5 reported on the participants' experiences of the EBCD process and factors influencing their participation.

The research process

Figure 3 offers a visual presentation of the research process and its timeline.

Table 1.

Overview of papers and study designs, participants, data collection and data analysis and theoretical frameworks.

	Paper 1	Paper 2	Papers 3 + 4	Papers 3 + 5
Design	Organizational case study	Qualitative design with focus groups	Case study	Qualitative design with focus groups
Participants	PWAF ¹ (n=10) Family members (n = 3) Professionals ² (n=7)	PWHF ³ (n=5) Family members (n=5) Professionals ² (n=4) Professionals ⁴ (n=7)	PWHF (n = 17) Family members (n=4)	Family members (n=4) Professionals ² (n=3)
Data collection	PWAF ratings Project documents FGIs ⁵	FGIs ⁵	Field notes from observations Meeting minutes Individual interviews	FGIs ⁵
Data analysis	Descriptive statistics Qualitative content analysis	Qualitative content analysis with a deductive approach	Reflexive thematic analysis	Reflexive thematic analysis
Theoretical framework	SDT ⁶	COM-B ⁷		MUSIQ ⁸
Use of theoretical framework	Retrospective reflection	Development of interview guides and data analysis		Development of interview guide

¹Persons with atrial fibrillation. ²Professionals in cardiac care. ³Persons with heart failure. ⁴Professionals in primary care. ⁵Focus group interviews. ⁶Self-determination theory. ⁷Capability, Opportunity, Motivation, Behavior. ⁸Model for understanding success in quality improvement.

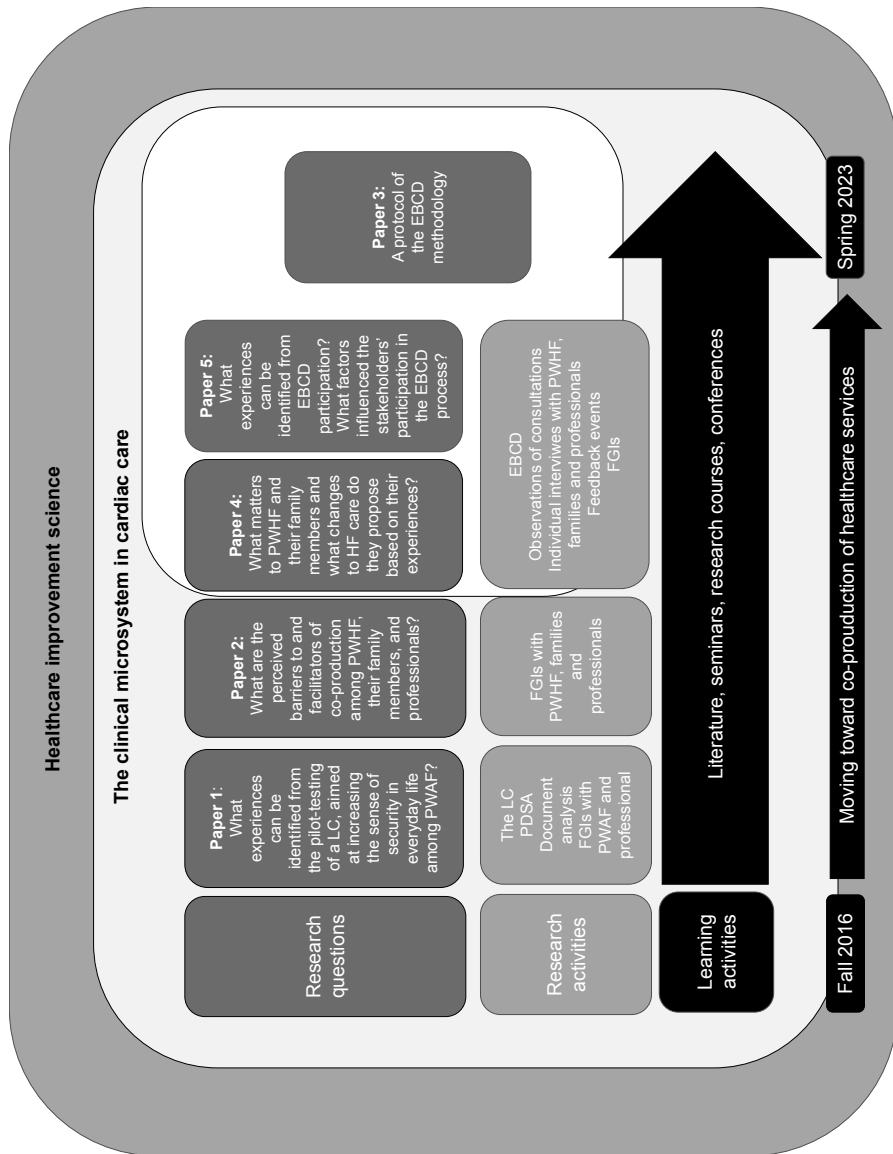


Figure 3. The research process and its timeline in the cardiac care microsystem, underpinned by healthcare improvement science. LC = Learning Café; PDSA = Plan, Do, Study, Act; PWAF = Persons with atrial fibrillation; PWHF = Persons with heart failure; FGI = Focus group interview. EBCD = Experience-Based Co-Design.

A practice-oriented interactive research approach

This thesis applied healthcare improvement science with a practice-oriented interactive research approach (Hermans & Schoeman, 2016). Practice-oriented research is here understood as research with goals originating from a practice in which the created learning contributes directly to improvements (Hermans & Schoeman, 2016; Hummelvoll et al., 2015). This understanding of practice-oriented research and development aligns with the thesis's pragmatic epistemology focusing on "useful knowledge" (Perla et al., 2013).

The interactive research approach can be understood as "a collaborative research approach characterized by recurrent interactions and joint learning activities between researchers and practitioners in commonly agreed upon efforts to study change and innovation in organizations" (Ellström et al., 2020, p. 1520). Interactive research contributes to theory development, to organizational innovation and to change processes (Ellström et al., 2020). The focus lies on conducting research with the participants throughout the research process (Ellström et al., 2020).

Empirical context at the regional and the local levels

The research in this thesis was set in Region Jönköping County (RJC) in the southeastern part of Sweden (figure 4). The region, serving approximately 365 000 citizens, has a long tradition of healthcare QI (Andersson Gäre & Neuhauser, 2007; Baker et al., 2008; Ovretveit & Staines, 2007; Staines et al., 2015). Co-production of healthcare services has evolved and grown over time in the RJC context (Persson et al., 2021). However, the involvement of persons living with disease, family members, healthcare professionals and citizens in service improvement and research is not yet routinely spread within the research context. The region-wide "Tillsammans" initiative ("*Together*") draws on the Swedish health strategy "Nära Vård" ("*Closer Care*"). "Tillsammans" aims at promoting co-produced healthcare and at shifting care from acute care in hospitals to planned and person-centered primary care closer to the citizens (Region Jönköpings län, 2023).



Figure 4. Sweden (to the left) and Region Jönköping County with its three health districts and municipalities (to the right).
Source: <https://www.google.com/maps>.

RJC is divided into three healthcare districts. The Highland health district consists of PCCs organized around the Highland district hospital, serving approximately 115 000 citizens. Heart disease, including AF and HF, accounts for a major part of the disease burden in the district's aging population. Patients with heart disease receive care mostly in PCCs, with access to emergency care and specialized cardiac care in the Highland district hospital as needed. The local context for this thesis consists of the hospital's cardiac ward and a PCC in the southern part of the Highland health district. This research is a part system-wide efforts to promote the best possible co-produced health (Region Jönköpings län, 2023).

Designs, settings, participants, data collection methods and analysis

Paper 1

An organizational case study

Paper 1 reports on an organizational case study (Baker, 2011). This design combines qualitative and quantitative data when exploring how organizational improvement interventions work (Baker, 2011). This study design was deemed to be appropriate for the study pilot testing a small-scale model for co-production, the LC.

The Learning Café

The LC is a group education program for involving individuals who live with the same disease (Vifladt et al., 2010). The LC is led by healthcare professionals. It usually consists of four sessions scheduled three to four weeks apart. During the first session, patients', and family members' questions regarding living with disease are solicited. Those questions are then passed on to expert professionals, such as physicians, nurses, physical therapists, pharmacists, and curators. The experts are invited to answer the participants' questions at subsequent LC sessions, during which new questions may arise and need to be discussed. The participants are encouraged to share their experiences of and advice regarding living with disease. Thus, the LC provides an opportunity for individuals to support each other in life with disease. In terms of co-producing health and healthcare, the LC can be seen as a model for co-designing and co-delivering an education program based on the patients', and family members' needs.

Cardiac care with PWAF, family members, and professionals

The study was set at the cardiac ward, Department of Internal Medicine and Geriatrics, the Highland district hospital (Höglandssjukhuset), RJC, Sweden. Between September 2016 and January 2017, I formed an improvement team with five volunteering professionals (two nurses, one cardiologist, one resident physician and one administrative assistant) working in specialty cardiac care. The professionals were

eligible for participation if i) they were working in the study context, and ii) they were interested in improving patients' knowledge about AF.

The improvement team planned and tailored the LC to the local context as an additional follow-up program after a hospital admission or after an outpatient clinic visit due to AF. Ten volunteering Swedish PWAF (seven men, three women) and three of their family members joined the LC. The PWAF were in the age range of 50-80 years and had different professional and educational backgrounds. To be eligible for LC participation, the PWAF needed i) an AF-related hospital admission or AF-related visit to the outpatient clinic and ii) willingness to share knowledge and learn more about AF with fellow PWAF, family members and professionals. The PWAF were not asked to join the LC if they were unable to communicate with others. Since the aim of this study was to pilot test the LC, a convenience sampling was used. Convenience sampling is a non-probability sampling strategy in which participants are selected for study participation if they are part of a target population and meet certain practical criteria (Jager et al., 2017). Convenience sampling is a proper sampling method within pilot testing and developmental science research and is widely used in clinical research where participants who meet the inclusion criteria are recruited to the study (Jager et al., 2017).

The LC intervention consisted of four 2.5-hour sessions organized and led by the improvement team's two nurses who were trained to facilitate the LC. During the first LC session, PWAF and family members had their questions and concerns about living with AF solicited. During this first session, the PWAF and their family members sat in small groups discussing what mattered to them and what they needed to know more about to be able to feel secure in everyday life living with AF. These questions were written down in notes. Those notes were then shared with professionals (a physician, a nurse, and a physiotherapist) who were invited to the subsequent sessions to answer the participants' questions and to interact with them. The administrative assistant documented the questions and answers and shared them with the participants as a record of the LC sessions.

Qualitative and quantitative data

Both quantitative and qualitative data were collected to inform the organizational case study. Quantitative data consisted of the ratings of sense of security in everyday life with AF (main outcome measure) and the satisfaction with the LC intervention among PWAF. The ratings were self-assessments by the PWAF after each LC session using a non-validated form developed by the professionals and piloted with the PWAF. The ratings were made on a scale of 0-10, 10 representing “completely secure” or “completely satisfied”.

Qualitative data consisted of documents (the project plan and notes from project meetings), my field notes reflecting the improvement efforts and focus group interviews (FGIs). At the end of the last LC session, I invited all participants to participate in an FGI, one each for the PWAF and professionals, respectively. The interviews aimed at exploring experiences from pilot testing the LC. FGIs are useful when, as here, the intention is to explore participants’ needs, thoughts, feelings and perceptions about a phenomenon, in this case LC participation (Wibeck, 2010). Five PWAF and five professionals agreed to FGI participation. Five individuals is an appropriate number to include in FGIs (Wibeck, 2010). I conducted the interviews (duration approximately 60 min) guided by a semi-structured interview guide focusing on experiences from LC participation. The interviews were audio-recorded, anonymized, and transcribed verbatim by an administrative assistant employed by RJC.

Descriptive statistics and qualitative content analysis

Quantitative data were visualized graphically in chronological order using descriptive statistics. These graphs were discussed with participating PWAF to make sense of the data. FGI transcripts were analyzed using qualitative content analysis with an inductive approach (Krippendorff, 2004; Lundman & Hällgren Graneheim, 2008). The inductive approach was deemed appropriate since there was no pre-existing framework that was expected to fit the results (Bengtsson, 2016). The transcripts were read through several times to obtain a sense of the whole. The transcripts were then divided into meaning units. Next, the meaning units were organized into codes. The various codes were compared based on differences and similarities and sorted into

subcategories and categories. Finally, the latent content of the categories was organized into a theme (Lundman & Hällgren Graneheim, 2008). Table 2 exemplifies a meaning unit, code, subcategory, category and a theme.

Table 2.

An example of a meaning unit, code, subcategory, category and theme.

Meaning unit	<i>“I am, basically, a thinking and worrying person, a bit anxious you know. [--] So, when I was diagnosed with atrial fibrillation, I felt quite clearly that there is too little information about what it means, what the risks are, how am I supposed to handle it, is it something that comes and goes, or will it remain forever and so on, so there was a lot of information that I missed. So, this has really been a wonderful thing, I think.”</i> [FGI with PWAF]
Code	Need for information
Subcategory	Meet the information needs
Category	Facilitation of coping strategies
Theme	PWHF: Quality of life

Quantitative data and qualitative data were then related to each other to explore the main outcome of the intervention (i.e., the change regarding the sense of security in everyday life) and potential mechanisms for the outcome. To make sense of the results and to deepen the understanding of them, they were retrospectively related to the theoretical concept of co-production and Self-determination theory (SDT) (Batalden et al., 2016; Bradbury-Jones et al., 2014; Ryan & Deci, 2000).

Paper 2

A qualitative design with focus groups

Paper 2 reported on a qualitative study with focus groups (Wibeck, 2010).

Cardiac care with PWHF, family members, and professionals

The study was set at the cardiac ward in the Highland district hospital and in a PCC in RJC, Sweden, between November 2019 and February 2020. Four stakeholder groups were invited to participate: (1) PWHF; (2) family members of PWHF; (3) professionals working in specialized cardiac care; and (4) professionals working in primary care. A convenience sampling strategy was used (Jager et al., 2017). A HF primary care nurse suggested eligible PWHF and family members for study participation. Then I contacted them by phone to provide further information and obtain their consent to participate. PWHF and family members were excluded from study participation if they were (i) under 18 years of age; (ii) unable to consent to study participation due to acute illness, cognitive impairment, or lack of proficiency in the Swedish language; or (iii) had received care with me as their cardiologist. Five PWHF (three men, two women, median age 74 years) and five family members (one man, four women, median age 83 years), participated in this study. I recruited healthcare professionals, working at the cardiac ward in the Highland district hospital or in the PCC in RJC, during workplace meetings and through e-mailed information letters. Seven primary care professionals (three physicians, three nurses, one physiotherapist) and four specialty care professionals (one physician, one nurse, one physiotherapist and one assistant nurse) consented to participation. Participant characteristics are shown in tables 3 and 4.

Qualitative data

Qualitative data was gathered through four separate FGIs with all stakeholder groups. I conducted the FGIs, assisted by semi-structured interview guides, and explored capabilities, opportunities and motivation to co-produce healthcare. The interview guides were piloted with two PWHF and two professionals prior to the data collection and revised accordingly – the word “co-production” was deemed unclear

and replaced by “cooperation”. This reflects the difficulty in translating the word “co-production” into Swedish, both semantically and as a previously unfamiliar phenomenon. All interviews were audio-recorded, anonymized, and transcribed verbatim by an administrative assistant employed by RJC. After the FGI, and as a complement to it, the PWHF wrote diaries as often as they wanted during a two-week period about their views on co-production of healthcare. Data collection through patient diaries has previously been used to involve patients in healthcare QI (Engström & Elg, 2015).

Table 3.
Participating PWHF and family members, paper 2.

Study participants	Gender	Age (years)
PWHF		
#1	Male	77
#2	Male	66
#3	Male	70
#4	Female	81
#5	Female	76
Family members		
#1	Male	85
#2	Female	83
#3	Female	89
#4	Female	67
#5	Female	45

Table 4.

Participating professionals, paper 2.

Study participants	Gender	Age (years)	Profession
Primary care professional			
#1	Male	43	Physician
#2	Female	23	Physiotherapist
#3	Female	49	Nurse
#4	Female	46	Nurse
#5	Female	54	Nurse
#6	Female	31	Physician
#7	Female	44	Physician
Cardiac care professionals			
#1	Male	38	Physician
#2	Male	37	Physiotherapist
#3	Female	50	Nurse
#4	Female	57	Assistant nurse

Qualitative content analysis

A latent content analysis was used to analyze transcripts from the FGIs and diaries written by participating PWHF (Elo & Kyngas, 2008). First,

I read the transcripts and diaries several times. Next, I made notes and headings in the transcripts representing perceived prerequisites for co-production. The notes and headings formed codes that were categorized into two subcategories: 1) barriers to, and 2) facilitators promoting, co-production of healthcare. Applying a deductive approach, the barriers and facilitators were then coded into a categorization matrix developed from the Capability, Opportunity, Motivation COM-B model (Michie et al., 2011). Table 5 shows an example of the analysis. The first draft of the analysis was discussed in depth with my main supervisor, then further revised before being discussed by all supervisors until consensus was reached. During these discussions, the initial codes were revised to fit the COM-B categories.

Table 5.

Example from text – analysis, paper 2.

Text from empirical data	<i>“I mean, before we can say that we have patients involved in making decisions concerning their own care, first we must have a good concept to deliver to them and we are not there yet.”</i> [FGI with professionals in cardiac care]
COM-B category	Psychological capability
Barriers	Lack of knowledge about co-production

The COM-B model describes what influence behavior change: *Capability* (physical and psychological), *Opportunity* (physical and social) and *Motivation* (reflective and automatic) (Michie et al., 2011). Physical capability refers to physical ability, strength, and skills. Psychological capability includes comprehension, knowledge, engaging in thought processes, memory, and cognition (Ayakaka et al., 2017; Holland-Hart et al., 2019; Michie et al., 2011). Physical opportunity describes environmental opportunities. e.g., time, facilities, resources, and availability. Social opportunity refers to cultural norms

and roles, interpersonal influences, and inequalities, e.g., the opportunity presented by the milieu (Ayakaka et al., 2017; Holland-Hart et al., 2019; Michie et al., 2011). Reflective motivation refers to intentions, plans, convictions, and considerations whereas automatic motivation refers to wishes, needs, feelings and habits (Ayakaka et al., 2017; Michie et al., 2011).

Previous research indicates that the COM-B model is useful to identify barriers and facilitators affecting co-production of healthcare (Addis et al., 2019; Holland-Hart et al., 2019), patient participation in healthcare safety promotion (Schildmeijer et al., 2018), patients planning advance care (Peck et al., 2018) and shared decision-making (Dimopoulos-Bick et al., 2019).

Paper 3

A protocol of the EBCD methodology

Paper 3 was a protocol of the EBCD methodology reported on in papers 4 and 5 (Suutari et al., 2022). EBCD is a step-by-step participatory healthcare QI process in which patients', family members' and professionals' experiences are solicited and used to redesign healthcare services (Donetto et al., 2015). Since the EBCD methodology is extensive, the protocol gave me an opportunity to elaborate on the methodology.

During the EBCD process, experiences of healthcare services are gathered using observations of healthcare consultations, individual narrative-based filmed or audio-recorded stakeholder interviews, as well as stakeholders' feedback events. The patients' interviews are edited into a 20-30 minute "trigger" film highlighting the service touchpoints identified from their interviews. Touchpoints are emotionally significant positive or negative events, situations or key resonating themes that shape patients' overall service experience and that may have arisen in several interviews (The Point of Care Foundation, 2021; Varnali, 2019). Based on the recognized touchpoints, patients, family members and professionals jointly discuss and propose priorities for healthcare service improvements. Those proposed service changes are then designed, planned, implemented, and

evaluated by small improvement teams that include patients, family members and professionals. Figure 5 visualizes the EBCD process and how it unfolded “in real-life”.

Paper 4

A case study

Paper 4 reported on the experience gathering phases of the EBCD process. A case study design is useful when exploring complex issues in real-life settings (Crowe et al., 2011). Paper 4 aimed at exploring what matters to PWHF and their family members and what changes to HF care they propose based on their experiences.

The EBCD process “in real-life”

To fit the real-life circumstances of the research context, the EBCD process described in paper 3 needed to be adjusted. Figure 5 offers a visual presentation of the EBCD process “in real-life”.

The EBCD process was guided by the EBCD toolkit (The Point of Care Foundation, 2021). First, a steering group with PWHF, family members and professional representatives was formed. The experiences of the PWHF were then gathered through field notes from non-participant observations of their healthcare consultations. Next, filmed or audio-recorded individual interviews with PWHF solicited their experiences. The interviews were guided by a semi-structured interview guide developed by the authors to mirror different experiences of life with HF and of HF care, as well as proposed improvements to HF care (Anne-Marie Suutari et al., 2023). These interviews were edited into a 30-minute “trigger film” mirroring the experiences of the PWHF. Next, family members’ experiences were gathered through semi-structured interviews guided by the same interview guide but focusing on their experiences of HF and its care. The following step, the PWHF feedback event, aimed at validating their experiences. The “trigger film” was used to prompt the discussions during this event. Preliminary key themes, developed during data analysis by me, were discussed with the participants during the event. A similar feedback event was held with family members to solicit their experiences.

After completing the gathering of the professionals' experiences through individual interviews and a feedback event, a joint feedback event with all participating stakeholders was held. Again, the “trigger film” prompted the discussions. During the joint stakeholder event, participants jointly agreed on improvements to information about HF. Next, a small team with patient, family member and professional representatives co-designed an educational video about HF.

Online communication tools were used to facilitate data collection and stakeholder interaction during the covid-19 pandemic meeting restrictions. The adjustments to the planned EBCD process (paper 3) are further discussed in the ‘Discussion’ section.

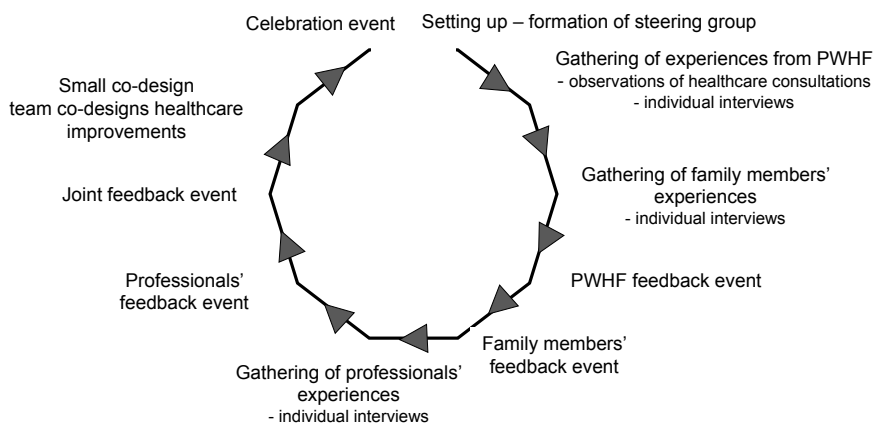


Figure 5. The EBCD process “in real-life” (Suutari et al., 2023).

Cardiac care with PWHF, family members, and professionals

Between September 2021 and December 2022, I led the EBCD process in the Highland health district, RJC. Included organizations were the cardiac ward, the Department of Internal Medicine and Geriatrics, Highland district hospital (Höglandssjukhuset) and a PCC, RJC, Sweden. The project was deemed to be in line with the quality strategy in RJC and was initiated in collaboration with the managers of the included operations.

Inclusion and exclusion criteria and the recruitment procedures were identical to those in reported in paper 2. Nine PWHF (three women and six men) participated in observations of healthcare consultations. No demographics, other than gender, were collected from these PWHF so as not to interfere with the consultations. One man, participating in observations of healthcare consultations, agreed to participate in subsequent steps of the EBCD process. The rest of the PWHF, who participated in observations, declined further study participation.

Eight PWHF (three women and five men, age range 68-86 years) participated in the interviews exploring experiences of living with HF, HF care and areas for service improvement. Five PWHF (two women and three men, age range 72-82 years) agreed to participate in a separate PWHF feedback event to validate the identified key themes. Five PWHF (two women, three men, 72-83 years) participated in the joint stakeholder event. Tables 6 and 7 show participant characteristics for those PWHF and family members who participated in the initial individual interviews.

Qualitative data

Qualitative data was collected to inform the case study. The data consisted of:

- field notes from non-participant observations of healthcare consultations with PWHF
- filmed or audio-recorded individual interviews with PWHF and family members
- meeting minutes from stakeholders' individual and joint feedback events

Reflexive thematic analysis

Latent reflexive thematic analysis (TA) with an inductive approach was used to develop themes from the collected data (Clarke & Braun, 2017). The analytical process followed the guidelines for reflexive TA (Clarke & Braun, 2017) and the development of themes with use of specific questions (Braun & Clarke, 2022). The analysis started with me listening to the filmed or audio-recorded interviews several times. After this, the interviews were transcribed verbatim. Familiarization included

reading the transcripts multiple times, during which I highlighted important passages and made notes on first impressions related to the research questions.

Table 6.

Participating PWHF, individual interviews, paper 4.

Study participants	Gender	Age (years)	HF diagnosis	Previous profession
PWHF				
#1	Male	86	Several years ¹	Farmer
#2	Female	83	4	Teacher, principal
#3	Male	68	1.5	Not applicable
#4	Male	76	Several years ¹	Entrepreneur
#5	Female	85	2	Cemetery worker, maid
#6	Male	72	2	Construction industry
#7	Male	76	9	Painter
#8	Female	82	0.5	Kitchen, daycare

¹PWHF unable to tell.

Table 7.

Participating family members, individual interviews, paper 4.

Study participants	Gender	Age (years)	Profession	Relation to PWHF
Family member				
#1	Female	46	Assistant nurse	Daughter
#2	Female	69	Assistant nurse	Wife
#3	Female	71	Assistant nurse	Wife
#4	Female	55	Assistant nurse	Daughter

The next phase, generating codes, included inductively organizing text passages with similar meanings and denoting them with labels. During the third phase, constructing initial themes, preliminary themes were constructed using codes as building blocks. This was done on a sheet of paper with two columns, one for the codes and one for the preliminary themes. Next, themes were revised, guided by literature to deepen the understanding of the analysis process (Braun & Clarke, 2022). Codes and themes were re-organized and redefined or removed if they did not add knowledge about the research questions. Themes were then defined and named. This phase included shaping a story around a central organizing concept within themes and involved going back and forth between previous phases of the analysis. During the writing-up phase, the story around the central organizing concepts was further re-shaped and abstracted beyond the simple description of the themes. Codes, subthemes and themes were continually discussed, reflected upon and revised among the co-authors during the process. The study participants reflected on the content and meaning of the themes during the EBCD feedback events. The story about data was discussed and re-shaped by the co-authors together. Table 8 shows an example of the analysis.

Table 8.

Example from text – analysis, paper 4.

Text from empirical data	<i>“I don’t want to put any burdens on my daughter because I want to try to ease things for her instead if possible. And my husband and my sister, no, we do not talk about illnesses.” [PWHF5]</i>
Codes	Lack of support networks
Subthemes	PWHF: Experiences of living with HF
Theme	Theme 1: I struggle every day

Paper 5

A qualitative design with focus groups

Paper 5 reported on a qualitative study with focus groups (Wibeck, 2010).

Cardiac care with PWHF, family members, and professionals

The study was conducted between November 2022 and December 2022 at the cardiac ward, Department of Internal Medicine and Geriatrics, Highland district hospital (Höglandssjukhuset) and in a PCC in RJC, Sweden.

With the exception of those two PWHF who had declined further participation during earlier steps of the process, all EBCD participants were invited to participate in the FGIs, one with PWHF and family members and one with professionals. Four PWHF, four family members and three professionals agreed to participate. Tables 9, 10 and 11 show characteristics of the participants in the study reported in paper 5.

Table 9.

Participating PWHF, paper 5.

Study participants	Gender	Age (years)	HF diagnosis	Previous profession
PWHF				
#1	Female	83	4	Teacher, principal
#2	Male	76	Several years ¹	Entrepreneur
#3	Male	76	9	Painter
#4	Female	82	0.5	Kitchen, daycare

¹PWHF unable to tell.

Table 10.

Participating family members, paper 5.

Study participants	Gender	Age (years)	Profession	Relation to PWHF
Family				
#1	Female	46	Assistant nurse	Daughter
#2	Female	69	Assistant nurse	Wife
#3	Female	71	Assistant nurse	Wife
#4	Female	55	Assistant nurse	Daughter

Table 11.

Participating cardiac care professionals, paper 5.

Study participants	Gender	Age (years)	Profession	Years in profession
Cardiac care professionals				
#1	Female	32	Nurse	8
#2	Female	52	Nurse	16
#3	Female	52	Assistant nurse	6

Qualitative data

Qualitative data was gathered through two separate FGIs, one with PWHF and family members and one with professionals, respectively. The semi-structured interview guides were developed to mirror the experiences of and individual conditions for participation in the EBCD process. The guide directing the professionals' FGI was inspired from a framework, the Model for Understanding Success in Quality (MUSIQ), to mirror the roles of, and inter-relationships between, contextual factors within QI initiatives (Reed et al., 2018). Participants were then encouraged to elaborate on their experiences and on individual or organizational conditions for re-designing HF care. The interviews took place in a conference room in a PCC or in the hospital. All interviews were audio-recorded and transcribed verbatim.

Reflexive thematic analysis

Reflexive TA was used to analyze data. Data analysis entailed the same procedure as in paper 4. Table 12 shows an example of the analysis.

Table 12.

Example from text – analysis, paper 5.

Text from empirical data	<i>"It becomes so much more real... when you meet patients and family members then it becomes more real, right."</i> [Professional]
Codes	Seeing individuals as human beings, not as patients
Subthemes	To acknowledge and to be acknowledged
Theme	It's a win-win! The value of being involved in an EBCD process

Ethical considerations

All studies were conducted according to the Declaration of Helsinki and had ethical approval from Swedish ethical authorities prior to the data collection.

Ethical values in co-production of healthcare

Ethical frameworks derived from co-production research can be employed to help make ethical considerations in co-production explicit (Australian Healthcare and Hospitals Association, 2018; Holland-Hart et al., 2019). Ethical values put forward by these frameworks include non-maleficence, beneficence, benefit and welfare, justice, autonomy, respect for individuals, health maximization, solidarity, proportionality, efficiency, and effectiveness (Page, 2022). In the next sections, these values are reflected upon and related to the research in this thesis.

Non-maleficence, beneficence, benefit, and welfare and solidary

Non-maleficence refers to “not doing harm” (Page, 2022). Non-maleficence in research means that no harm should come to the research participants as a result of study participation (Gelling, 1999).

Research participation was not anticipated to cause any physical harm. Precautions were taken to prevent emotional distress, for example, when participating in conversations about previous experiences of AF, HF, or healthcare services. These individuals would have been offered individual support (a patient supporter or counselor) or a referral to their regular healthcare team. Professionals in need of support would have been advised to see an occupational healthcare professional. A non-participant observer was employed during the data gathering phase in the EBCD process (paper 4) to minimize the interference during healthcare consultations (Ciesielska et al., 2018). I had the role of a participating observer during steering group meetings and EBCD feedback events. Although my researcher’s role and the professional’s role was sometimes difficult to separate, participant observations

offered the advantage of collecting information about social practices and topics during the interviews (Ciesielska et al., 2018).

Beneficence promotes the good in society and also in research (Pieper & Thomson, 2016). In research, beneficence can be understood as when research participants experience benefits from their research participation (Pieper & Thomson, 2016). *Benefit and welfare* point at health services research being beneficial to the participants in terms of outcomes related to improved health and well-being (Page, 2022). *Solidary*, a collective commitment to equitably sharing costs and benefits for the good of a population, is a prerequisite for benefit and welfare (Page, 2022).

The research in this thesis is deemed to be beneficial to persons with heart disease, their family members, healthcare professionals and to the welfare state. Through participation, persons with heart disease and their family members had the opportunity to contribute to knowledge that will improve healthcare and future healthcare co-production initiatives. These individuals also had the opportunity to share experiences about life with disease with each other, which proved valuable to participating PWAF, PWHF and their family members. Participating professionals had the opportunity to learn more about healthcare QI and co-production of healthcare QI, thus experiencing professional development. Ultimately, this research aimed to encourage the best possible health and care, therefore aligning with the principle of benefit and welfare.

Autonomy, respect for individuals and proportionality

The concept of *autonomy* comprises several different concepts such as privacy, voluntariness, self-mastery, free choice, choosing one's own moral position and accepting responsibility for one's own choices (Gelling, 1999).

All research participation was voluntary. Informed consent was obtained prior to the data collection from those who agreed to participate. Participants were informed about the possibility of withdrawing their participation at any time during the research process. The individual's choice was respected throughout the process.

Participants were encouraged to share both positive and negative experiences of life with heart disease and its care. However, there might be a risk of participants choosing not to report all personal experiences, particularly during the filmed or audio-recorded individual EBCD interviews which were edited into a trigger film and presented to the other participants. This represents an ethical issue when it comes to data collection during the EBCD process.

Proportionality is positioned between autonomy and beneficence. Proportionality means that the individual freedom is balanced against public good (Page, 2022). This ethical value can be understood as a subjective trade-off among potential research participants. It is not further explored in this thesis.

Justice

The research principle of *justice* refers to health-equity, including a just and equal access to healthcare across populations (Page, 2022). Aligning with this ethical principle in healthcare research means putting the needs of the research participants before the objectives of the research (Gelling, 1999).

Ethical issues associated with the principle of justice relate to selection bias and the exclusion of vulnerable groups (Gelling, 1999). For this particular research, study participants were recruited among persons living with heart disease, their family members and healthcare professionals in RJC. An ethical issue might be that participants unable to consent to study participation due to acute illness, cognitive impairment or language barriers were excluded from study participation. This may have generated a selection of participants limited to persons that are easy to co-produce healthcare with, thus limiting the transferability of the study findings. However, being pragmatic about involving frail individuals in research a convenience sampling strategy seemed appropriate to use in this research (Jager et al., 2017; Ludwig et al., 2020). The inclusiveness of the research is further elaborated on under the ‘Discussion’ section.

Health maximization, efficiency, and effectiveness

Health maximization refers to maximized health at a population level (Page, 2022). This thesis, focusing mainly on healthcare QI and co-production on a CMS level, does not address outcomes on a population level. However, if the LC and the EBCD process and co-production of healthcare QI spread to a wider context, positive health effects may be seen on the population level.

Efficiency refers to using health resources efficiently and to avoid waste (Page, 2022). Efficiency can further be understood as a sustainable use of health resources (Stacey & Stacey, 2012). Here, sustainability is understood as when the research projects are designed to address the research context's real-life healthcare needs taking its prerequisites and resources into consideration. This research is conducted in a cardiac care setting involving persons living with heart disease, their families and healthcare professionals working in RJC. Cardiovascular disease leads to approximately 18 million deaths each year worldwide (World Health Organization, 2021). This makes cardiovascular disease the number one cause of death and indicates an ever-increasing need of high-quality patient-centered cardiac care. Thus, the research in this thesis addressed the real-life needs of the research context.

The research was carried out between the years 2016 and 2023. Staff shortages and a high workload characterized the research context during this period. From March 2020 onwards the covid-19 pandemic further added to the workload and limited the patients', family members' and professionals' opportunities to participate in research activities. Therefore, it was necessary to adjust the research activities to current organizational resource constraints. An ethical issue related to the choice of research context would be if this context required unique processes when involving families, healthcare professionals, and persons living with disease, making it difficult to transfer the results to other contexts. By aiming for transferable knowledge about how to co-produce healthcare QI, the research in this thesis is deemed sustainable.

Effectiveness covers continuous healthcare QI and innovation, taking limited resources and reduction of waste into consideration (Page,

2022). Effectiveness means that the intended or desired results are produced. The overall aim of this thesis was to explore the prerequisites to and the value of co-production and to provide lessons for future co-produced healthcare QI initiatives in cardiac care. I claim that these desired outcomes have been achieved.

Main findings

Paper 1: Promoting a sense of security in everyday life

Paper 1 aimed at testing a small-scale model promoting co-production and a sense of security in everyday life among PWAf in a cardiac care setting – the LC (Suutari et al., 2019).

The results indicate that the LC pilot test generated positive outcomes for participating PWAf, professionals, and the healthcare organization. The main outcome, the sense of security in everyday life among PWAf, seemed to improve when participating in subsequent sessions of the LC (figure 6). The satisfaction with the LC was high throughout the program (figure 6).

Participating PWAf reported strengthened coping strategies when sharing experiences with peers and when learning more about AF and its care.

"I am, basically, a thinking and worrying person, a bit anxious you know. [--] So, when I was diagnosed with atrial fibrillation, I felt quite clearly that there is too little information about what it means, what the risks are, how I am supposed to handle it, is it something that comes and goes, or will it remain forever and so on, so there was a lot of information that I missed. So, this has really been a wonderful thing, I think." [FGI with PWAf]

Participants appreciated the opportunity to share knowledge and concerns with family members and fellow PWAf, since such opportunities are not common in traditional care. The findings further indicated that when the sense of security increases, the need for emergency care among PWAf may decrease. On the organizational level, this indicates a promising future shift from emergency care to planned care.

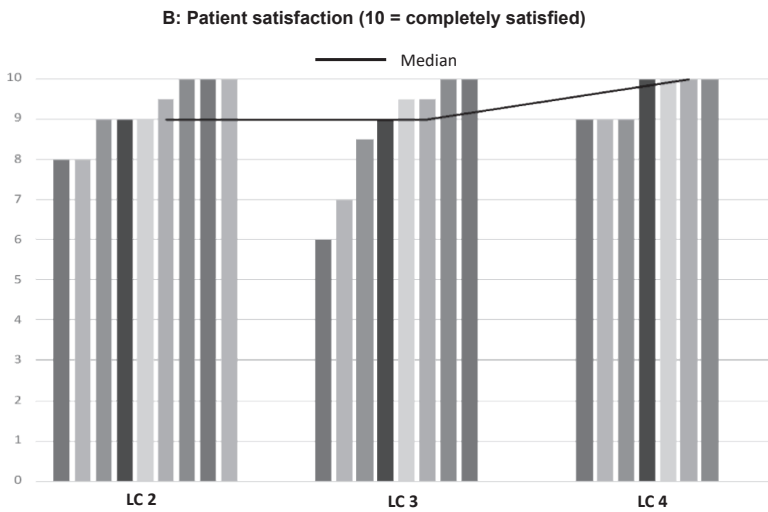
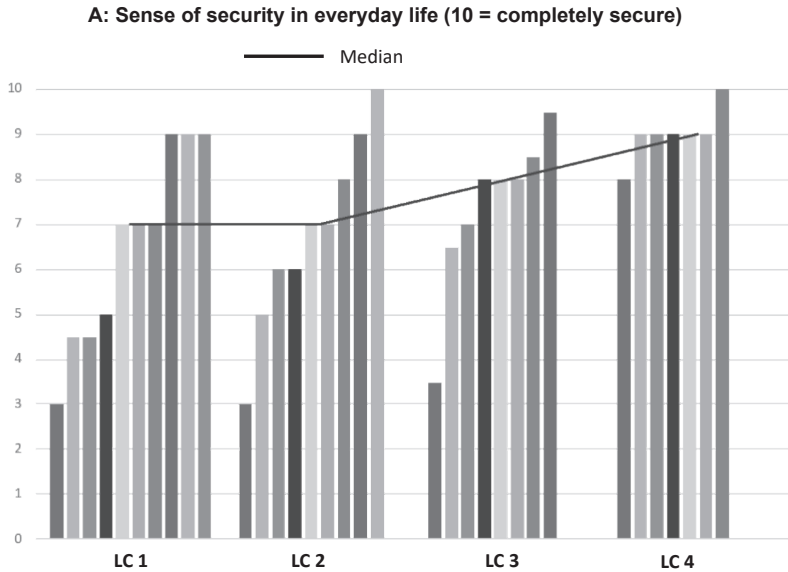


Figure 6. (A) Sense of security in everyday life. (B) Patient satisfaction. Each bar represents a patient in the Learning Café (LC) group education program. The black line represents the median ratings. The rating for the sense of security at the first Learning Café session was considered to be the baseline rating. Patient satisfaction was only rated after Learning Café sessions 2-4, with invited healthcare professionals, to evaluate the patients' experience of the format used, then to discuss the participants' questions (Suutari et al., 2019, p. 1243).

Participating professionals reported enhanced professional development, when learning more about the persons behind the disease and their needs.

“We’ve had the chance to see them not as patients, but as persons”. [FGI with professionals]

The professionals said that they felt they could take greater control of their own work situation when working with healthcare QI within existing organizational resource constraints. In addition, the professionals gained new understandings concerning patient and family member involvement in healthcare QI. To start with what mattered to the patients and family members shifted the focus from the information that healthcare professionals wanted to convey, to what patients sought and needed.

I reflected on the findings from the LC pilot test after the conclusion of the data analysis and found that the innate psychological intrinsic motivators included in SDT - autonomy, competence, and relatedness - can link the execution of the LC program to its results (Bradbury-Jones et al., 2014; Ryan & Deci, 2000, 2017). Autonomy refers to individuals’ need to feel that they have choices and that their behaviors are self-endorsed (Ryan & Deci, 2017). Competence refers to individuals’ need to develop mastery and to operate effectively within their own lives (Ryan & Deci, 2017). Relatedness concerns individuals’ need to care about, and be cared for by others (Ryan & Deci, 2017). According to SDT, individuals, in this case PWA and professionals, will naturally engage in interesting, challenging, and enjoyable activities that satisfy the innate psychological intrinsic needs (Lohmann et al., 2016). Thus, patients’ and professionals’ motivation to collaborate in the LC to promote self-management, well-being, and work satisfaction can be understood in terms of SDT.

Combining existing QI models with SDT components and participants’ experiences of piloting the LC, a conceptual model that explained the case study was developed (figure 7) (Batalden & Davidoff, 2007; Batalden, 2018; Ryan & Deci, 2017). The link between co-production and SDT is further elaborated on in the ‘Discussion’ section.

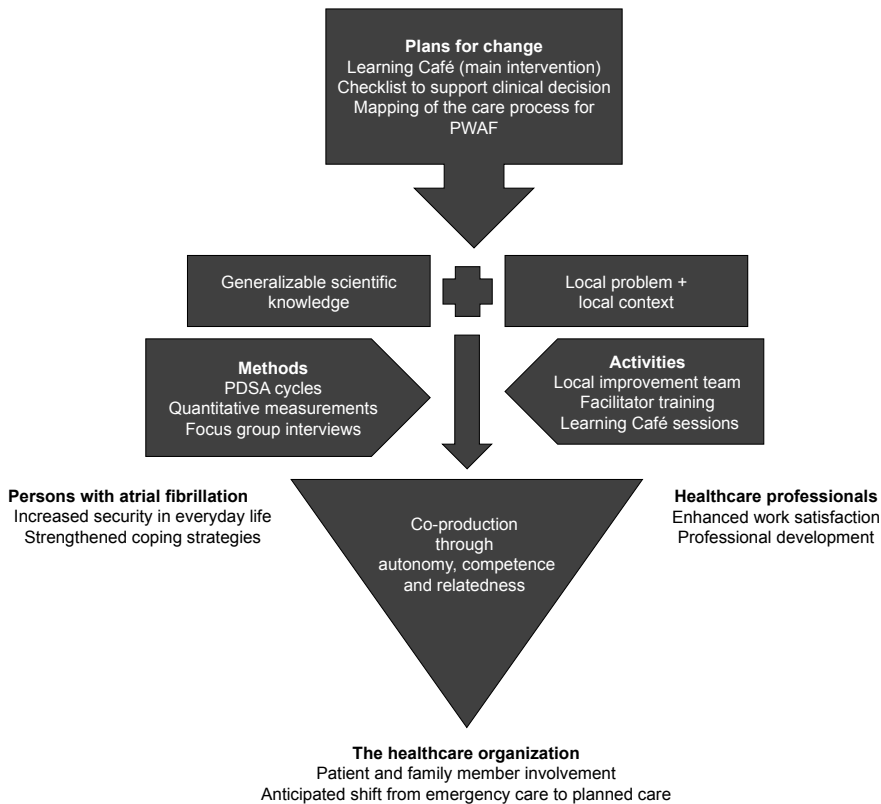


Figure 7. The Learning Café pilot test – exemplifying early steps on the way toward co-producing healthcare through stakeholder autonomy, competence, and relatedness – generating positive outcomes for persons with atrial fibrillation (PWAF), professionals and the organization (modified from Batalden & Davidoff, 2007) (Suutari et al., 2019, p. 1246).

Paper 2: Improving health for people living with heart failure

Paper 2 aimed at exploring the perceived barriers to and facilitators of co-production of healthcare among PWHF, their family members, and professionals (Suutari et al., 2021).

The barriers and facilitators are summarized in table 13 and elaborated on in detail below.

Capabilities to co-produce healthcare

The most barriers to co-production of healthcare were found in the domain of capabilities. Participants acknowledged that PWHF had varying and sometimes impaired physical health, which was a real-life challenge to being engaged in healthcare. In terms of psychological capabilities, PWHF and family members assumed that they needed more knowledge about how healthcare organizations work to be able to design healthcare processes. Furthermore, PWHF assumed that their lived experiences would not be useful when designing care.

“I mean, if you don’t have the knowledge you can come up with any kind of claim, which there is no value in [...] To participate in designing the health care services [...] My views obviously wouldn’t be worth anything.” [FGI with PWHF]

Professionals understood co-production as a service to be offered to patients on top of traditional healthcare rather than as an approach to improved healthcare services. When talking about co-production, a fear of patients taking control over medical decisions was voiced by the professionals. Still, they predicted that there would be growing expectations and willingness to co-produce in the future among patients and family members.

However, the professionals agreed that patients and family members needed more organizational and medical knowledge to be able to participate in co-production of healthcare. In particular, the limited capability to understand and apply health information among PWHF was highlighted by the professionals as a major barrier to their co-production capabilities.

Not being invited to co-produce care was acknowledged as hindering co-production. Family members, in particular, described how they were often overlooked as a natural part of the CMS.

Table 13.

Barriers to and facilitators of co-production.

COM-B category	Barriers	Facilitators	
Capability			
	Physical capability	Impaired physical strength	Physical strength to engage in co-production
Psychological capability	Lack of knowledge about co-production	Capability to understand health information	
	Impaired mental health	Adequate communication skills	
	Insufficient coping strategies	Existing working practices that promote co-production	
	Difficulties understanding health information	Capability to adapt to new work methods	
	Difficulties applying health information	Family member support	
	Difficulties among professionals in handling persons with limited HL		
	Inadequate communication skills		
Opportunity			
	Physical opportunity	Fragmented healthcare system	Accessible healthcare support
		Insufficient leadership support	
	Time and resource constraints		

Social opportunity	Expectations of the patients' role	
	Expectations of the professionals' role	
	Family members' role variations	
Motivation		
Reflective motivation	Belief that co-production is unachievable	Belief that co-production improves care Belief that co-production leads to efficient use of resources
Automatic motivation		Plans for how to co-produce
	Reluctance to co-produce	Wish to co-produce

Opportunities to co-produce healthcare

Participants perceived co-production to be more time- and resource-intensive compared to traditional care. These constraints might reduce our willingness to listen to and involve patients and family members during healthcare visits, physicians reasoned. Patients agreed:

“I think that they [the health professionals] would be happy to know more about how we feel, but the question, obviously, is whether they have the time to sit and listen to us?” [FGI with PWHF]

Both professionals and participating PWHF expected professionals to be in charge of healthcare processes. PWHF revealed a feeling of inferiority in their role relative to that of professionals and imagined that professionals would not appreciate their opinions about organizational and medical matters. Family members expressed uncertainty over when and how to co-produce healthcare, putting them

in a difficult position. Old traditions but also professionals' discomfort with allowing patients to have more influence over their own health and care were reasoned to cause this uneven power balance between PWHF and clinicians.

“It is known that heart failure patients want to take more responsibility for their own illness, that they want to be involved, and it may be we who think that this is our responsibility and may not dare to hand it over to the patient.” [FGI with professionals in primary care]

Motivation to co-produce healthcare

All participating stakeholder groups said that they were motivated to co-produce healthcare. The motivation to co-produce healthcare services was promoted by perceived co-production benefits. Participants talked about how cooperation within the CMS could promote patients' and family members' sense of security in everyday life and improve the quality of healthcare. Co-production was further believed to promote professionals' learning about life with a chronic disease, thereby improving their capabilities to design appropriate care. In addition, professionals thought that co-production could potentially encourage patients to conduct better self-care management if supported by improved team communication and a person-centered approach focused on the patients' needs. All participants assumed that healthcare visits focusing on cooperation to meet patients' care needs would be more time-consuming compared to the traditional care provided today. Still, cooperation and co-production were perceived to be worthwhile in the long run. However, not everybody has the wish or the capabilities to be involved, participants reasoned.

Paper 3: Using stakeholders' experiences to redesign health services

Paper 3 described the EBCD process with PWHF, their family members, and professionals (Suutari et al., 2022). The EBCD process is described in detail under 'Methods' and further elaborated under 'Discussion'.

Paper 4: Improving heart failure care with an EBCD approach

Paper 4 aimed at identifying the experiences of life with HF and its care among PWHF and their family members. Furthermore, paper 4 aimed at understanding how these experiences translate into proposed HF care changes (Anne-Marie Suutari et al., 2023). Five overarching themes, with 12 service touchpoints, emerged (table 14).

Theme 1: I struggle everyday

Being diagnosed with HF was a life-changing event accompanied by constantly being worried and anxious. Shortness of breath and a lack of physical strength were described by PWHF as having a particularly negative impact on everyday life. “Water pills”, aimed at decreasing HF symptoms, were experienced to be “a necessary evil”, further adding to a poor quality of life.

Still, PWHF tried to cope with HF by maintaining a positive attitude toward life and by living normal lives, despite the HF. The closest family members, i.e., the spouse or children, were the main support system for the PWHF, although they did not want to be a burden to their family.

"I don't want to put any burdens on my daughter because I want to try to ease things for her instead if possible. And my husband and my sister, no, we do not talk about illnesses." [PWHF5]

PWHF missed the support from others living with HF and lacked opportunities to relate to peers.

Family members of PWHF experienced worry as ever-present in their daily lives. A particularly difficult aspect of family members' life was trying to create a balance between being worried and trying to put on a brave face for their loved ones. To cope, most family members turned to healthy family members for support. They seemed reluctant to seek support from healthcare professionals or other people outside the closest family circle.

Table 14.

Service touchpoints and themes.

Service touchpoints to be addressed during future HF ¹ care improvements	Themes
<p>Lack of support when diagnosed with HF</p> <p>Lack of support networks to assist PWHF</p> <p>Lack of support networks to assist family members</p>	Theme 1: I struggle every day
<p>Inappropriate timing for information to PWHF</p> <p>Inadequate strategies for communication with PWHF</p> <p>Inappropriate timing for information to family members</p> <p>Inadequate strategies for communication with family members</p>	Theme 2: I don't understand HF
<p>Patient-professional interactions: lack of acknowledgment</p> <p>Lack of care continuity</p> <p>Family member-professional interactions: lack of acknowledgment</p>	Theme 3: Please, do not ignore me!

Professionals do not invite PWHF to be involved in healthcare

Theme 4: How can I get involved?

Professionals do not invite family members to be involved in healthcare

Theme 5: HF care can improve!

¹HF = heart failure; ²PWHF = persons with heart failure

Theme 2: I don't understand HF

The professionals' use of medial language was a barrier to PWHF understanding information about HF and its care. Health-related information seemed difficult to get across to some PWHF, leaving them unsure of treatment and next steps.

"They have probably tried to give me information, but I have not been able to take it in [...] I do not really understand what it [heart failure] means." [PWHF5]

Not being able to understand what was happening during emergencies, was a particular source of anxiety and stress among participating family members. In certain situations, family members felt excluded and not a priority to healthcare professionals, leaving them with a sense of being uninformed. Furthermore, not knowing who to turn to and when, made family members feel unsure about how to provide support to their sick loved ones.

Theme 3: Please, do not ignore me!

PWHF had great confidence in the professionals who they had met during healthcare consultations and who they experienced as knowledgeable and easy to interact with. Being able to trust the professionals made PWHF feel safe. However, PWHF had experienced

not being listened to during healthcare visits. Participating PWHF thought that not being listened to was due to professionals feeling overwhelmed and stressed out, thus not having the time to listen to their patients. Not being listened to made PWHF feel stressed and not welcome to contact care.

"I made a visit here [to the primary care center] because I felt very sick... And then I got another doctor who almost scolded me for coming here and disturbing him." [PWHF6]

The lack of care continuity, experienced by both PWHF and their family members, forced them to recapitulate the medical history to previously unknown professionals during each healthcare visit. Family members felt that they constantly had to stand up for themselves and their sick family members to get sufficient attention from the professionals. Having to repetitively rebuild relationships all over again made the PWHF and family members feel insecure.

Theme 4: How can I get involved?

Observations of healthcare consultations revealed how professionals were usually in charge during consultations and did not always listen to the family member's perspective. Still, family members felt highly motivated to be involved in the care of their loved ones. However, family members experienced that their loved ones did not want to involve them or inform them about what was said during healthcare visits. Furthermore, not being explicitly invited by professionals to be involved in the care of their loved ones was challenging to family members. Thus, family members found it difficult to be involved in a balanced way, i.e., to be involved without being too protective or interfering with the integrity of their loved one.

Not all PWHF considered themselves to be capable of being involved in healthcare. Sometimes PWHF simply were not at all interested in being involved. Others thought that their experiences would not be interesting or important enough to inform care improvements. Yet others explained that they did not find it appropriate to tell professionals how to run healthcare.

“I am not the kind of person who wants to intrude. You accept things as they are.” [PWHF8]

Theme 5: HF care can improve!

Drawing from their experiences, PWHF and family members suggested a range of improvements to HF care (table 15). They also suggested improvements to information about HF, indicating that they felt that they had difficulties in understanding health-related information. PWHF wanted to know more about HF symptoms, treatment, and physical activity to treat HF and to prevent HF from worsening. PWHF wanted access to written information in plain language – to have something to go back to after healthcare consultations. Participants also suggested group activities with others in a similar situation, for the opportunity to exchange experiences about life with HF, for support and for co-learning about HF.

“It might be a little easier to open up if you are with others who have the same medical condition. If you are the only one living with a disease, then you do not really talk about it.” [PWHF7]

The *timing*, i.e., when health-related information is provided, was experienced to influence the understanding of HF and its care. Optimally, information should be repeated during planned healthcare visits, participants said.

To be able to build trustful relationships during healthcare visits, PWHF and family members suggested that the continuity of HF care should improve. To be treated well and to be taken seriously by professionals, and to improve communication during healthcare visits were other improvements suggested by both PWHF and professionals. It was suggested that this could be accomplished by providing professionals with communication training. Family members wanted professionals to clearly invite them to be involved in healthcare, for example by including this request in invitations to healthcare consultations.

Table 15.

Proposed improvements to HF care.

Improvements proposed by PWHF	Improvements proposed by family members
Improved information about HF Symptoms Treatment (medicines and physical activity) Timing of HF information	Improved information about HF Self-management of HF Who to contact and when Timing of HF information
Improved continuity in care	Improved continuity in care
Improved relations and communication	Improved relations and communication
	Invitation to be involved in healthcare

Paper 5: Experiences of and conditions for redesigning HF care

Paper 5 aimed at exploring PWHFs', family members' and professionals' experiences of and conditions for EBCD participation in a Swedish cardiac care setting (A-M. Suutari et al., 2023). Table 16 summarizes the subthemes and themes that emerged from the data.

Table 16.

Subthemes and themes, paper 5.

Subthemes	Themes
To gain new knowledge about HF To acknowledge and to be acknowledged To learn to improve HF care together	It's a win-win! The value of being involved in the EBCD process
Barriers and facilitators on the individual level - Varying capabilities and motivations	To be or not to be involved? Conditions for EBCD participation on different levels
Barriers and facilitators on the project level – Constraints and inclusiveness	
Barriers and facilitators on the organizational level – organizational culture, management and the covid-19 pandemic	

It's a win-win! The value of being involved in an EBCD process

PWHF experienced the EBCD process to be a win-win situation with opportunities to gain knowledge about HF and to relate to peers and knowledgeable professionals. To professionals, the narratives, i.e., the “trigger film” and the participants’ stories during the joint EBCD feedback event, were particularly powerful for improving their understanding of life with HF.

*"It becomes so much more real... when you meet patients and family members then it becomes more real, right."
[FGI with professionals]*

Thus, the EBCD process seemed to form a new social space giving the professionals’ opportunities to relate to their patients as fellow human beings, and not as patients, in a non-clinical setting. The professionals anticipated that they would be more responsive to their patients’ and family members’ needs in the future based on their experiences of the EBCD process.

Varying physical and mental capabilities due to HF made it difficult for PWHF to fully engage with the EBCD process. Thus, their EBCD participation was facilitated by having a family member who could offer their assistance during EBCD events. Furthermore, various motivations for EBCD participation were revealed. The choice to be involved in order to help others by sharing their experiences of life with HF was one motivation found among PWHF. Driven by self-centered motivations, PWHF essentially intended to be involved to gain knowledge about HF and its treatment. Thus, PWHF participated to improve their understanding of HF, rather than to improve HF care.

"Well, it was actually a little bit selfish - now I'm going to learn more about my disease." [FGI with PWHF]

Family members, too, wanted to learn more about HF. However, they also wanted to put forward their experiences to improve HF care. Their motivations drew on experiences of not being listened to or invited to

be involved in healthcare. The professionals' involvement was underpinned by their desire to improve healthcare processes.

Family members and professionals found themselves having to work around their busy work schedules to be able to participate. However, PWHF were not at all bothered about the EBCD process being time intensive. What mattered to them was to be able to participate on their own terms. Being able to have the project venue close to home and not feeling obligated to participate in every step (for example, they might wish to decline due to health issues) facilitated their participation.

Professionals recognized that those in the greatest need from medical and emotional points of view might not have been invited to participate.

"Those who choose not to come are perhaps the ones who in fact need it the most." [FGI with professionals]

However, PWHF and family members simply seemed to think that EBCD participation was not for everyone. Although inclusiveness might have been problematic in this particular EBCD process, no easy solutions for how to promote inclusiveness in future initiatives was put forward by the professionals.

Constraints due to the covid-19 pandemic forced the organization and the professionals to re-direct time and resources to clinical work. Thus, professionals felt that the EBCD participation was something they needed to squeeze in between clinical duties. Still, driven by their own personal motivation to improve HF care, the professionals managed to make time to participate. The professionals argued that managers should at all times encourage healthcare QI, create the conditions for participation in healthcare quality improvement, and make sure that all new employees are introduced to QI.

Summary of main findings

This research exemplifies a learning journey in a Swedish cardiac care setting – from the first steps of patient, family member and professional collaboration in the LC group education program to explicitly aiming

at co-production of healthcare in the final EBCD project. A pragmatic approach, grounded in healthcare improvement science, guided the construction of useful knowledge in all papers.

Barriers to and facilitators of co-production were identified on different levels – the individual, the relational and the systemic levels. Individual factors influencing co-production included motivation to co-produce, self-efficacy, health status and HL. Both self-centered and community-centered motivations to co-produce were identified among the research participants. Relational factors influencing co-production included communication and being invited to co-produce. Both PWHF and family members occasionally felt excluded from healthcare, which was a barrier to co-production. A facilitator on the contextual and systemic levels included the context-specific organizational culture promoting healthcare QI. Systems barriers included resource constraints due to the covid-19 pandemic.

The LC and the EBCD process created value for participating PWAF, PWHF, family members, professionals and the health system. The PWAF and PWHF improved their knowledge of AF and HF when participating in the LC and the EBCD process. Participation enabled patients' interactions with peers, family members and knowledgeable healthcare professionals, thus promoting their relatedness. The improved disease knowledge and relatedness were, in turn, understood to improve the sense of security in everyday life with disease. This was believed to improve coping, thus promoting a shift from emergency care to planned care. Professionals reported enhanced professional development, learning more about person-centeredness and feeling in greater control of their own work situation when trying to improve healthcare despite resource constraints. The health system gained knowledge about what needs to change in HF care. Suggested areas of improvement included improved information about HF, improved continuity of care, improved relations and communication between patients, family members and professionals, and inviting patients to be involved in healthcare.

Discussion

Moving toward co-production in cardiac care – a learning journey

This research exemplifies a learning journey – from the first steps of patient-family member-professional collaboration in the LC to explicitly aiming at co-production of healthcare in the final EBCD project.

Healthcare improvement science guided the construction of useful knowledge in all research studies (Perla et al., 2013). In line with the foundations of healthcare improvement science, QI methodologies and tools were employed to facilitate learning cycles about how to co-produce healthcare QI (Perla et al., 2013). Improvement activities were practice-oriented, whereas data analysis and writing up the research papers were research-oriented (Ellström et al., 2020). All steps focused on joint learning about how to co-produce healthcare QI and better care (Ellström et al., 2020). A multidisciplinary research team, persons living with heart disease, their family members and healthcare professionals worked in partnership and brought different perspectives to the QI projects and research (Perla et al., 2013). Furthermore, pragmatism guided this research. There are several implications of pragmatism on organizational processes, such as co-production of healthcare QI (Kelly & Cordeiro, 2020):

- The focus on useful knowledge. Pragmatism focuses on useful knowledge. Thus, pragmatism enabled me to design research studies based on stakeholders' experiences and real-life problems. This warranted a research agenda of practical relevance.
- Acknowledging experiences as knowledge. According to pragmatism, knowledge is created from different stakeholders' experiences. This research focused on producing useful and practical knowledge through the interconnectedness of different stakeholders' experiences.
- The focus on consequences of different choices of action. Pragmatism acknowledges that different actions can lead to

different consequences for different stakeholders. Thus, this research focused on questions like “what is the best thing to do in this particular context?”

From the Learning Café to Experience-Based Co-Design

The co-production pathway, described in detail in the ‘Background’ section (p. 20), provides a framework for assessing the level of patient and family member involvement in healthcare QI. This framework can also be used to visualize the learning journey toward co-production in the research context. The levels of patient and family member involvement for each paper are indicated in figure 8 and are further discussed below.

Paper 1 reported on the pilot test of the LC group education program aimed at increasing the sense of security in everyday life among the PWAF. Participating PWAF, family members and professionals had no previous knowledge or experience of how to involve persons with disease in healthcare and healthcare QI. Thus, co-production was not explicitly discussed during the LC project.

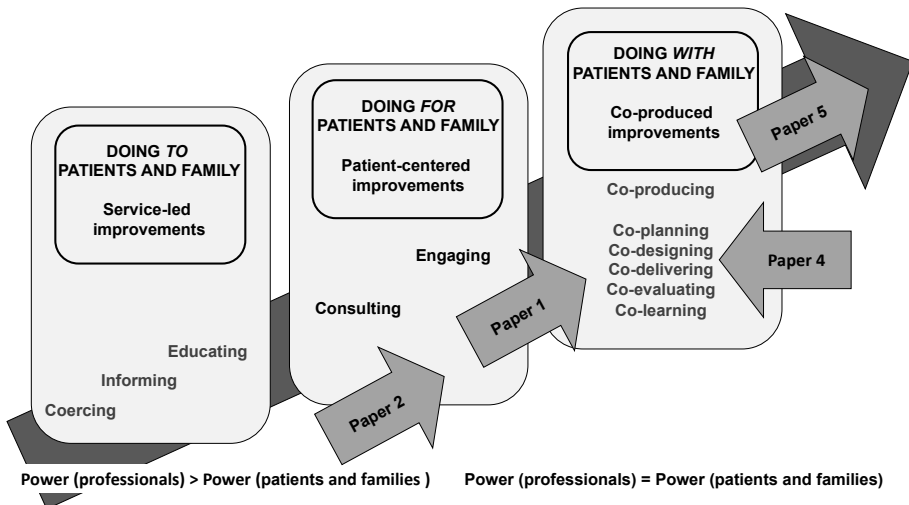


Figure 8. Levels of patient and family member involvement in the research papers, indicated by arrows. Paper 3 was a protocol of the EBCD methodology and is therefore not included here (modified by author A-MS after Arnstein (Arnstein, 1969); Williams & Caley (Williams & Caley, 2020)).

However, reflecting retrospectively on this project and the level of patient and family member involvement (paper 1), the LC can be understood to be a small-scale model exemplifying a movement toward joint learning about co-production of healthcare (figure 8) (Perla et al., 2013). The project was initiated by the professionals who felt that PWAF struggled to understand AF. Only professionals were involved in the planning phase of the LC, and they invited PWAF and their family members to collaborate with them after the initial phases of the project. In fact, patients are rarely the initiators of co-production (Voorberg et al., 2015). However, through their questions, the PWAF and their family members shaped the content of the sessions, exemplifying co-design and co-delivery of the LC sessions. By rating the sense of security in their everyday life and their satisfaction with LC sessions, and by discussing these ratings with the professionals, the PWAF were involved in co-evaluation of the LC program. By asking new questions and by sharing knowledge with professionals and fellow participants, there was co-learning among the PWAF, family members and professionals regarding what matters when living with chronic AF and how to handle the condition in everyday life. No reflections regarding shared power were made in this project. Thus, it remains unclear whether the project aligned with the co-production principle of shared power (Coldham, 2018).

To be able to co-produce healthcare more explicitly, I thought that it would be helpful to understand what perceived barriers to and facilitators of co-production needed to be managed in my research context. Thus, paper 2 reported on the perceived preconditions for such co-production. Here, the level of patient and family member involvement is on the level of “consulting” i.e., to obtain the stakeholders’ feedback on co-production (figure 8).

To overcome the difficulties in understanding co-production and how to apply the concept in practice, I decided to test the EBCD approach in the next phase of the research. EBCD, with its step-by-step approach was deemed appropriate to guide the stakeholders through a

collaborative process that was not previously familiar to them (Donetto et al., 2015).

Paper 4 reported on the first parts of the EBCD process that aimed explicitly at co-production of healthcare QI. The EBCD process aligned with several principles of co-production (Coldham, 2018). The principle of reciprocity was fulfilled through joint discussions and co-learning about each other's needs during the EBCD feedback events. The principles of including all perspectives and respecting and valuing the knowledge of those working together meant that all the necessary views, experiences, skills, and knowledge were included in the project and that the skills and experiences of those involved were respected (Coldham, 2018).

The roles of PWHF and their family members in the EBCD process, included:

- Study participation: PWHF and their family members participated in observations of healthcare consultations, individual interviews, EBCD feedback events and co-design meetings.
- Research management: One PWHF representative and one family member representative participated in the steering group of the research project. These representatives co-planned and co-led the feedback events together with the project leader and health professional representatives to ensure that all stakeholder perspectives were acknowledged throughout the process.
- Research design: PWHF and family members were involved in choosing, planning and designing an intervention aimed at improving HF care, i.e., the educational film about HF.
- Development of interview guides: Prior to the data collection, two PWHF and two family members were asked to review the interview guides used for individual interviews and FGIs. This ensured interview questions were clear and easy to understand.
- Data analysis: PWHF and family members were involved in sense-making of study results during EBCD feedback events.
- Dissemination of research findings: PWHF and their family members were offered the opportunity to be involved in a joint presentation of the study results at seminars and conferences.

Paper 5 reported on the experiences that can be identified from EBCD participation and the factors that influenced the stakeholders' participation in the EBCD process. The findings from paper 5 can further promote future co-production initiatives. This paper provides knowledge on how a co-design process is experienced by the participating stakeholders, thereby supporting the feasibility of such processes. Paper 5 reports on barriers to and facilitators of a co-design process in a Swedish cardiac care setting. These conditions might also apply to other chronic care contexts, thereby being helpful when planning for other healthcare co-design initiatives. Furthermore, the findings demonstrate the value of a co-designed process in terms of patients' improved social relationships, sense of belonging and peer support networks and the professionals' improved understanding about the patient and family member perspective. These benefits might further promote the wide adoption of co-production and co-design in practice.

Inclusiveness

The co-production principle of including all perspectives and respecting and valuing the knowledge of all those working together embraces diversity and inclusiveness (Coldham, 2018). External exclusion focuses on who is included in the co-production activity itself (Eriksson, 2022). To avoid external exclusion, societal groups should have a say about matters concerning them (Amann & Sleight, 2021). Including disadvantaged groups in co-production is vital since they might have different interests or perspectives that will not be targeted otherwise. They may also bring new knowledge and experiences to the table (Amann & Sleight, 2021). Research indicates that personal attitudes, prejudices and doubts influence the willingness to participate in co-production (Rantamäki, 2017). Furthermore, persons with low motivation, trust and self-efficacy are less likely to participate in co-production (Sicilia et al., 2019). Empirical evidence suggests that women are more likely to volunteer than men (Galende-Sánchez & Sorman, 2021). However, sometimes the characteristics of the persons participating in co-production are not even explored or reported on. This raises the question: What are the characteristics of people who are not co-producing? (Loeffler & Bovaird, 2016).

To fully promote inclusiveness in co-production initiatives, internal exclusion should likewise be addressed. Internal exclusion refers to the interactions during which the disadvantaged may not be listened to (Booth, 2019). Not being met in a professional or caring way and not experiencing trust in healthcare professionals are common issues put forward by patients and family members (Matarozzi et al., 2017; Skar & Soderberg, 2018). Not being met in a professional or caring way may in turn reinforce existing power structures and stereotypes (Eriksson, 2022). An EBCD project in a mental health care context recently indicated that patients and family members do want to be acknowledged and validated in healthcare (McAllister et al., 2021). Another EBCD project in a cancer care context revealed similarly that communication and relationships between stakeholders mattered to the overall experiences of care (Tsianakas et al., 2012). This implies that the quality of interactions between patients and professionals is crucial to good quality care. This thesis resonates with these earlier EBCD projects, suggesting that the way you are acknowledged and listened to during healthcare consultations matters for the overall experience of healthcare services and the feeling of being acknowledged. Thus, healthcare organizations should not strive for excellence only in adhering to guidelines recommended for disease management but also when it comes to the quality of human interactions.

Feeling excluded during healthcare consultations may reinforce existing power structures and stereotypes (Eriksson, 2022; Pirinen, 2016). Pirinen (2016), exploring the barriers and enablers to service co-design, reported that it could be difficult

to persuade doctors to commit to a co-design project where the benefits were uncertain. It was difficult to introduce new roles to the strong professional power hierarchy in healthcare. Hierarchic relations affected the social dynamics and willingness to bring forth problems in the co-design sessions (Pirinen, 2016, p. 35)

These findings resonate with physicians being found to perceive themselves as holding power when interacting with their patients (Nimmon & Stenfors-Hayes, 2016). Although some participating physicians found it natural to empower their patients, others experienced that their power weakened when patients were involved in

care processes (Nimmon & Stenfors-Hayes, 2016). Thus, uneven power dynamics between stakeholders within healthcare contexts still seem to represent a barrier to the co-production of healthcare processes, and stand in opposition to the co-production principle of shared power among stakeholders (Coldham, 2018).

The prerequisites for co-production in a cardiac care setting

The research participants spoke about co-production in terms of a “dream scenario”. Within this conceptualization lies the understanding of co-production as being something good that is difficult or even impossible to achieve. In fact, the research findings indicate that barriers, hindering the wide adoption of co-production of healthcare in the cardiac care research context, still exist. Expanding the understanding of facilitators and how to manage the barriers is therefore helpful when co-learning how to co-produce in the wider context.

The facilitators of and barriers to co-production in this thesis can be categorized into the individual level (motivation, self-efficacy, health status, HL); the relational level (communication, being invited to co-produce); and the contextual and systemic levels (understanding co-production, organizational culture and the influence of the covid-19 pandemic).

Individual and relational factors influencing co-production

Motivation as a facilitator to co-production

PWHF, family members and professionals all said that they felt motivated to co-produce healthcare services due to perceived co-production benefits. Participants perceived that co-production could improve the quality of healthcare by considering patients’ and family members’ experiences during the design process of healthcare services. Furthermore, co-production was believed to promote patients’ self-care capabilities and thus potentially reduce the need for emergency care. Other motivations put forward by PWHF and family members included the opportunity to gain new knowledge about their disease, to be able

to improve one's own health, to meet others with similar experiences and to be able to contribute to the best possible healthcare for others in society.

Intrinsic motivators are yet another aspect of motivation. I reflected on the findings from the LC pilot test after the conclusion of the data analysis and found that the innate psychological intrinsic motivators included in SDT – autonomy, competence, and relatedness – might link the execution of the LC to its results (Bradbury-Jones et al., 2014; Ryan & Deci, 2000, 2017). Autonomy refers to individuals' need to feel that they have choices and that their behaviors are self-endorsed (Ryan & Deci, 2017). Competence refers to individuals' need to develop mastery and to operate effectively within their own lives (Ryan & Deci, 2017). Relatedness concerns individuals' need to care about, and be cared for by, others (Ryan & Deci, 2017). According to SDT, individuals, in my case PWAF and professionals, will naturally engage in interesting, challenging, and enjoyable activities that satisfy the innate psychological intrinsic needs (Lohmann et al., 2016). Thus, stakeholders' motivation to collaborate in the LC to promote self-management, well-being, and work satisfaction might be understood in terms of SDT. A growing body of literature has explored the association between SDT and motivation to engage in various activities. However, few previous research studies have explored the link between co-production of healthcare services and SDT. A study by Engström (2015), conducted within a lung cancer service, implies that the drive to satisfy the innate needs stipulated by SDT greatly influences if and how patients participate in service development within healthcare (Engström & Elg, 2015). Thus, SDT might offer an underlying mechanism to co-production that needs to be further explored in future research.

Furthermore, the motivations to co-production can be understood in terms of self-centered or community-centered motivations (Van Eijk & Steen, 2016; Van Eijk & Steen, 2014). People with self-centered motivations are passive actors who engage in co-production to get something back after putting something in. These individuals might feel motivated by self-development, gaining self-confidence, feeling acknowledged or meeting others to share experiences with (Steen,

2021; Van Eijk & Steen, 2016; Verschuere et al., 2012). Furthermore, intrinsic rewards, such as personal enjoyment, are powerful self-centered motivators for being engaged in healthcare co-production (Verschuere et al., 2012). Participants' engagement in co-production initiatives may also be promoted by payment for their participation, indicating that monetary rewards may be a motivational tool in some cases (Dimopoulos-Bick et al., 2018). Others have community-centered motivations to be engaged in healthcare co-production. These individuals engage in co-production more actively to improve how healthcare organizations operate (Dimopoulos-Bick et al., 2018; Van Eijk & Steen, 2016; Van Eijk & Steen, 2014). Furthermore, they want to do good for the benefit of society in general and feel that their efforts are making a difference (Van Eijk & Steen, 2016; Van Eijk & Steen, 2014; Voorberg et al., 2015). An altruistic desire, i.e., the wish to give something back when receiving help, is yet another community-centered motivation (Steen, 2021).

The salience of a service is yet another perspective on motivation to co-production of healthcare. People consider active engagement in a service only when a service is perceived as salient (Steen, 2021). Hence, citizens will more easily participate in co-production when they find the outcome preferable, when they trust their goals will be reached and when they perceive that they can make a difference (Bovaird et al., 2016; Parrado et al., 2013). However, participating professionals in my research acknowledged that not all patients and family members have the motivation to participate in co-production. These variations in motivations are a challenge to the standardization of co-production (Batalden et al., 2016).

Whether people engage in co-production for self-centered or community-centered reasons depends on the stakeholders' and the organization's maturity and receptiveness to co-production and co-design (Vennik et al., 2016). Stakeholders' motivations usually progress from self-centered to community-centered motivations as they learn what co-production is all about and how co-production might play out in practice (Vennik et al., 2016). The PWAF, PWHF and family members in our study had no previous experience of being involved in healthcare co-production. Mirroring previous research, PWHF

demonstrated a low self-efficacy in co-producing healthcare services, assuming that their lived experiences would not be useful when re-designing care (Holland-Hart et al., 2019). Furthermore, PWHF felt that they would interfere with the professionals' domains, if expressing their own thoughts and wishes regarding healthcare services. Therefore, it is not surprising that PWHF mainly talked about self-centered motivations for being engaged in the EBCD process. The professionals' community-centered motivations indicate that they understand how the co-production of healthcare services might improve healthcare on a systems level.

Since various motivations can influence the level of involvement and the outcomes of co-production, future initiatives should explore the stakeholders' motivations to co-produce, and should use the identified motivations as driving forces for co-production (Steen, 2021; Virlée et al., 2020). No monetary compensation was offered to the participants in my research. How monetary compensation might influence participation in future co-production initiatives in the Swedish cardiac care setting is yet to be explored.

Poor physical and mental health as barriers to co-production

HF is associated with poor physical and mental health, with a negative influence on HRQoL (Johansson et al., 2021). Poor health is known to be a barrier to co-production of healthcare (Holland-Hart et al., 2019). When participating in co-production, participants put in time and effort, and they may refrain from co-producing when a poor health condition restricts the effort they can make (Steen, 2021). PWHF in this research talked about various health issues, such as fatigue and shortness of breath, which prevented them from fully engaging in everyday activities and also in co-production of healthcare.

Even though no participating PWHF mentioned feeling depressed, all participating PWHF talked about being worried and anxious. Research suggests that PWHF have a high prevalence of anxiety and of depression (Celano et al., 2018). Poor mental health may be a barrier to co-production if causing lack of insight, lack of verbal ability and difficulty cooperating with others (Solbjør et al., 2013). Mental health

issues may further impair co-producers' social skills, i.e., how easily they can socialize with others, thus making it difficult to interact and co-produce healthcare with others (Steen, 2021).

If individuals with poor physical and mental health are to be included in co-production, a pragmatic approach to participation should be applied. Being pragmatic about participation in co-production means making it easy for people to participate. Participants need to be involved on their own terms, and sometimes participation must be redefined due to health issues (Ludwig et al., 2020; Solbjør et al., 2013; Steen & Tuurnas, 2018). These adaptations might include professional facilitators providing persons with information to help them make decisions more easily, to reduce the demands for choice and to enhance participation (Solbjør et al., 2013).

Limited health literacy as a barrier to co-production

My findings suggest that PWHF have limited HL. HL includes (a) knowledge of health and healthcare; (b) ability to apply health-related information; and (c) ability to self-manage disease and partner with healthcare professionals to improve one's health (Liu et al., 2020). Thus, PWHF and other populations with limited HL may struggle to actively participate in everyday activities and to apply new information to new circumstances (Brabers et al., 2017).

Previous research studies have revealed the effect of the patients' HL on healthcare behaviors. For example, limited HL may have a negative influence on engagement in self-management activities (Matsuoka et al., 2016; Son et al., 2018; Wu et al., 2017). In addition, limited HL may negatively influence patients' decision-making capabilities (Noordman et al., 2022). There is also an association between limited HL and poor medication adherence (Lee et al., 2017). Having a limited HL may also indicate a lack of competencies that are valuable in co-production, such as social skills or knowledge about the service (Van Eijk & Steen, 2014). Given that HL is associated with a variety of participative abilities, it can be argued that limited HL is a barrier to co-production (Virlée et al., 2020).

Several actions need to be taken to overcome the barrier of limited HL during co-production initiatives. The PWHF and family members who participated in my EBCD project talked about having the reassurance of each other's company during the process, making it easier for them to participate. Inviting family members to co-produce health and care might therefore compensate for patients' limited HL levels (Cameron et al., 2016). Although not explicitly expressed by participating professionals in the research, an overestimation of their patients' HL levels might explain their struggle to convey health information to their patients (Goggins et al., 2016). Thus, professionals need to approximate the patients' HL levels to be able to adjust the language they use when collaborating with these patients. In addition, professionals need to learn new communication skills and strategies to be able to convey information to persons with limited HL (Nutbeam & Lloyd, 2021; Saunders et al., 2019). Strategies to help patients and family members ask questions, should also be developed and tested to further strengthen the communication within healthcare contexts and to overcome the barrier of limited HL among persons with disease.

Feeling excluded as a barrier to co-production

Family members were highly motivated to be involved in the care of their sick parents or partners and to be involved in healthcare processes. However, sometimes they felt excluded from participation by both their loved ones and the healthcare professionals. Similarly, other research studies have reported that caregivers felt excluded by PWHF, who refused to talk about their current health situation or future care plans (Wingham et al., 2017). Furthermore, sometimes caregivers felt being ignored by healthcare professionals during consultations, thereby feeling excluded from being involved in healthcare processes (Wingham et al., 2017). PWHF in this particular research admitted that they occasionally refrained from involving their family members in their health and care issues. They did not want to worry their family members or be a burden to them.

In line with family members, PWHF sometimes felt ignored in healthcare settings. They wanted to be validated and listened to by the professionals. The professionals said that they could improve their

willingness and capabilities to invite patients and family members to co-produce health and care. The professionals acknowledged that old traditions but also their unease with allowing patients to have more influence over their own health and care, represented a barrier to inviting patients and family members to co-produce healthcare. Physicians have previously been reported to perceive themselves to hold power when interacting with their patients (Nimmon & Stenfors-Hayes, 2016). Research reveals that professionals may occasionally withhold important information from PWHF, for example information about HF prognosis, thus preventing PWHF from seeing the whole picture. Furthermore, clear explanations about HF were sometimes not provided due to the patients' perceived mental and emotional conditions (Mangolian Shahrababaki et al., 2017). Whether these international findings can be translated into Swedish healthcare contexts needs further exploration. However, with the cultural diversity among patients and healthcare professionals in Sweden, this approach to illness and healthcare may well exist among both patients, family members and professionals. If patients and family members do not have access to the same information available to the professionals, there is a risk of an uneven power distribution hindering the co-production of healthcare. On the other hand, if patients and family members are provided with information that they do not want to hear, trust issues between stakeholders in the CMS or negative psychological consequences might hinder further co-production of healthcare. This implies that finding out about each other's expectations is a vital prerequisite for co-production of healthcare services.

Not being invited to be involved in healthcare at all, or being invited but not listened to, implies that both external and internal exclusion in addition to uneven power structures, discussed earlier in this chapter, are barriers to co-production (Eriksson, 2022). The principles of co-production challenge old traditions and it takes effort to change established power structures (Batalden et al., 2016). However, over time, the professionals included in this research anticipated that patients would demand to be more actively involved in their care. These demands would then also shift the professionals' idea of how to interact with their patients, they thought. This shift represents understanding co-production as a social innovation with services, change processes and

social outcomes at center stage (Choi & Majumdar, 2015; Evers & Ewert, 2021).

Contextual and systemic factors influencing co-production

Organizational culture as both a facilitator of and a barrier to co-production

The research in this thesis was conducted in the Highland health district, RJC, Sweden. Various contextual features can be understood to facilitate this research projects on healthcare QI and co-production of healthcare. Co-production, exemplified by initiatives defined as strategies, projects, QI programs or other efforts, which included persons with patient experience and/or their family members or carers, has evolved over time within RJC (Persson et al., 2021). The RJC context has a long tradition of continuous healthcare QI and has used “quality as strategy” as a guiding principle for public health and healthcare services for many years (Andersson Gäre & Neuhauser, 2007; Bodenheimer et al., 2007; Staines et al., 2015). All RJC healthcare leaders support this guiding principle, thus promoting healthcare QI among their employees. Furthermore, RJC employees gain knowledge and training in QI tools and methodologies as well as person-centered practices as a part of their employment. This training is supported by Qulturum, a center for the development of improvement knowledge and innovation in healthcare (Region Jönköpings län, 2022). Leaders and employees align with the understanding of everybody having two tasks – to do the job they are trained for and to improve the job they are doing. These contextual circumstances formed the prerequisites for conducting the research. These contextual circumstances in the RJC context align with the MUSIQ framework, putting forward QI knowledge on different organizational levels as key contextual factors to successful healthcare QI initiatives (Reed et al., 2018). Reed (2018) proposes that both the external and the organizational contexts influence the effective use of structured healthcare QI tools and methodologies in the CMS (Reed et al., 2018). The research, presented in this thesis, adds to the MUSIQ framework by proposing bidirectional relationships between the context and the CMS – lessons from co-production of healthcare QI in a cardiac care

CMS can increase the knowledge about co-production and healthcare QI in the wider context. This puts a focus on organizational learning also in a bottom-up perspective.

However, there are contextual and cultural aspects within my research context that can be perceived as barriers to co-production. One barrier refers to the contextual understanding of what co-production means. The research findings revealed the patients', family members' and professionals' limited understating of co-production and how to apply this concept in practice. The stakeholders understood co-production of healthcare as an addition of something "new" on top of traditional healthcare. Similarly, researchers have reported that citizen and patient involvement in shared decision-making, a key component in co-production, was understood as a theoretical idea rather than a current practice in healthcare (Alami et al., 2018). Co-production can further be understood from either an individual or an organizational perspective. The individual perspective focuses on patients, family members and professionals interacting around clinical issues in the CMS. The organizational perspective focuses on multiple stakeholders from different organizations interacting on many organizational levels in various service delivery phases (Gilardi et al., 2016). The research participants mainly discussed co-production in terms of one-on-one interactions in the CMS and rarely as an approach for improving healthcare on system level, even after receiving an explanation of co-production as an approach to healthcare QI on different organizational levels. These findings resonate with existing co-production literature and indicate that the system perspective on co-production was not yet established among the research participants (Holland-Hart et al., 2019). As earlier discussed, motivation to co-produce usually progresses from self-centered motivations to community-centered motivations as stakeholders learn more about co-production and how this concept might apply in practice. A similar progression, from an individual to an organizational focus for co-production, should be anticipated over time.

Another contextual barrier to co-production might be a hierarchic healthcare culture. The Swedish study participants told of a rather traditional "doctor-knows-best" healthcare context with professionals being in charge. Time and resource constraints and old traditions, with

professionals having a fear of losing control over healthcare visits and processes, may preserve the unequal power balance between stakeholders, professionals reasoned. These reflections are not unique but seem to remain in the ever-increasing volume of co-production literature (Masterson et al., 2022).

Co-production research during the covid-19 pandemic

Papers 1 and 2 reported on studies that were conducted in the pre-pandemic era between the years 2016 and 2020. The FGIs for paper 2 were conducted in February 2020. One month later, in March 2020, the Swedish covid-19 restrictions came into effect. The pandemic and the restrictions due to the pandemic influenced the design, participant enrollment and execution of the EBCD process.

I applied for ethical approval for the EBCD process in spring 2021. The EBCD methodology includes activities that entail interactions between individuals or groups, such as workshops and co-design meetings. To be able to put social distancing during the covid-19 pandemic into practice, online tools enabled the collection of interview data and facilitated participants' interactions during the initial stages of the EBCD process (Kjellström, 2021; McDermott & Newman, 2020). In this sense, the pandemic promoted new approaches to research participation (Tuttle, 2020).

The EBCD process was initially planned to start in June 2021. However, since the pandemic caused staff shortages and aggravated pre-existing resource constraints in the research context, the EBCD process and participant enrollment was postponed to September 2021. Similarly, the rest of the research community experienced research project delays due to the pandemic (Fleming et al., 2020; Tuttle, 2020). With the pandemic causing further staff shortages and a heavy workload in late 2021, some professionals initially hesitated to get involved in the research process. Likewise, there were leaders within the research context who were unsure of whether they could let employees participate in activities not directly related to patient care. For example, the nurse improvement advisor, who we had arranged to facilitate the EBCD process, had to prioritize clinical work. PWHF and

family member enrollment was further delayed when the primary care nurse, who suggested eligible PWHF and family members for study participation, did not have the time to engage in the research.

Despite the challenges due to the covid-19 pandemic, we still managed to complete the EBCD process. When I reflect retrospectively on the EBCD process, it seems that the challenging times helped us to focus on the core of healthcare improvement science – the pragmatic values of “what works” and “what is useful”. The pragmatic approach offered a flexibility regarding the who, when and how of participation in the EBCD process. Participants were those who wanted to and could participate – they were able to participate on their own terms. They could choose which EBCD steps to participate in. PWHF and family members confirmed that they appreciated not feeling forced to participate in all steps of the EBCD process. Every workshop and co-design meeting was documented, and that documentation was shared with everybody, even those not present at that particular meeting. I, the facilitator, prepared all meetings in advance and initiated all EBCD workshops and co-design meetings with a summary of the work so far. This helped the participants keep track of work progress. The individual interviews were conducted online only. However, after that initial phase of the process, the participants could choose whether to participate online or in person during the subsequent steps when the pandemic restrictions eased. These success factors made it possible to conduct the EBCD process even during the pandemic.

The value of co-production in a Swedish cardiac care setting

Value for persons with heart disease and their family members

Improved disease knowledge

Participating PWAF, PWHF and family members said that they gained new knowledge about AF and HF when participating in the LC or in the EBCD process. The LC conveyed clinical information about AF, addressed emotional needs, and corrected AF-related misconceptions, known to be important elements of the disease education for PWAF (Salmasi et al., 2019). Including patient testimonials or stories in the education, as was the case with the LC, can further promote knowledge about AF among PWAF (McCabe, 2011; Salmasi et al., 2019). Although the EBCD process is not primarily an education program, the process still offered opportunities for asking medical questions and sharing experiences with others (Ramfelt et al., 2020).

Gaining new knowledge about a disease, its treatment and its self-management is associated with positive outcomes. The fear and uncertainty among PWAF can be reduced when healthcare professionals have time to explain AF and support self-management capabilities among PWAF (McCabe et al., 2015; McCabe et al., 2020). Furthermore, PWAF with a good understanding of their AF report fewer symptoms and fewer AF-related negative emotions (McCabe et al., 2011). Likewise, patient education among PWHF might improve HRQoL, reduce hospital admissions and readmissions, and strengthen their self-management capabilities (Cui et al., 2019; Dessie et al., 2021; Rice et al., 2018).

Relatedness

Loneliness and lack of support networks are common among persons living with chronic conditions (Petitte et al., 2015). Both the LC and the EBCD process enabled interactions with peers, family members and knowledgeable healthcare professionals, thereby promoting the relatedness among participants. The PWAF and PWHF said that they

appreciated sharing experiences and advice with each other – “it feels good to know that you are not alone”, participants said. Although peer support for individuals living with chronic conditions is hard to evidence due to methodological challenges, potential positive outcomes have been reported (Thompson et al., 2022). Group-based learning and peer support have been proved to be valuable approaches to education for PWA (Ferguson et al., 2022). Likewise, PWHF value being part of a group in which they feel understood by others with the same condition and where they can share their experiences and challenges (Lockhart et al., 2014). Furthermore, peer support can improve self-management capabilities and provide the confidence to engage in day-to-day activities among PWHF (Lockhart et al., 2014).

Family members in this research reported feeling distressed and lacking support networks helpful for them when trying to cope with their partner’s or parent’s HF. These findings resonate with earlier research indicating that caregivers of PWHF often feel alone and burdened (Wingham et al., 2015). Caregivers might also feel that they should be able to cope, and thus refrain from asking for help (Wingham et al., 2015). Access to social support is associated with positive emotional outcomes whereas negative emotional outcomes among carers, such as depression and anxiety, are associated with less involvement in the care of PWHF (Grant & Graven, 2018; Grigorovich et al., 2017). This, in turn, might impair the self-management capabilities among PWHF (Trivedi et al., 2019). The family members who participated in my EBCD process said that they felt empowered by having the opportunity to share experiences with others with similar experiences, thus promoting their sense of relatedness.

Strengthened coping strategies and improved self-efficacy

The overall sense of security in everyday life among PWA increased with successive LC sessions. One explanation for this might be that the program provided an opportunity to share knowledge and personal experience, serving to increase competence regarding the disease and its treatment. Another explanation might be that the program strengthened the self-efficacy in self-managing AF. Researchers have previously described the positive link between co-production and

improved self-efficacy levels (Fledderus, 2015; Thomsen, 2015). Furthermore, the LC created conditions for interacting with or relating to fellow patients, family members and knowledgeable healthcare professionals. Competence and relatedness can facilitate coping and promote patient autonomy (Wingham et al., 2014), aligning with SDT (Ryan & Deci, 2000).

Participating PWAFF reported actual or anticipated changes in their patterns of healthcare utilization, expecting that they would refrain from going to the emergency room so quickly, due to the LC experience. This indicates that the LC strengthened the coping strategies among PWAFF which, in turn, might reduce their demand for emergency care. This aligns with research suggesting that patient support, one of the components of integrated AF care, can reduce the demand for emergency care among patients with AF (Hindricks et al., 2020; Rush et al., 2019).

Value for the healthcare professionals and the health system

Enhanced work satisfaction

Participating healthcare professionals, working in a context suffering from resource constraints, appreciated gaining control of their own work situation and reported enhanced work satisfaction when working with the LC program and EBCD process. The enhanced work satisfaction can be understood in terms of SDT, which proposes that there is an improved motivation when working with tasks that promote autonomy (Ryan & Deci, 2000). Furthermore, professionals experienced enhanced work satisfaction from positive patient feedback, which indicates the importance of interaction and relatedness. Previous research supports the idea that organizations benefit from creating working environments that promote intrinsic motivators. Promotion of intrinsic motivators in the context of work includes focusing on the meaningfulness of work, on personal mastery, on providing positive feedback, on learning opportunities, and on contributing to QI (Areskoug Josefsson et al., 2018; Kjellström et al., 2017).

Awareness about the patient and family member perspective

Several similarities between the life with AF and HF were revealed. Both the PWAF and the PWHF told a story of their heart disease having a negative influence on everyday life, causing insecurities, physical and emotional distress, and a longing to be able to share their lived experiences with others. Professionals' statements about seeing participating patients as persons indicated an improved awareness about the patient perspective. Both the LC and the EBCD project gave the professionals the opportunity to learn from the patients' and the family members' experiences and stories. Patients' illness narratives provide valuable information that supports person-centered care across the illness trajectory (Gidman, 2013). The purpose of these stories is to give the patients and family members a voice that tells about everyday life with a disease. Understanding the illness process from the patient's perspective provides important information on how to best support the patients and the family members (Schwind et al., 2016). Narrative medicine is medicine combined with a narrative competence (Charon, 2017). With a narrative competence, healthcare professionals can learn to interpret patients' stories to grow an understanding of their perspective and their life with disease (Charon, 2017).

Current evidence states that narrative medicine is an effective pedagogical tool (Milota et al., 2019). Patients' narratives help healthcare professionals to discover that their patients are more than their disease, thus aligning with the experiences of the professionals who participated in the LC (Chretien et al., 2015). Narrative medicine has also been proven to promote professionals' satisfaction with their work and sense of wellness, thereby further validating the positive findings from the LC and the EBCD experience (Komlos-Hrobsky, 2019).

Knowledge about what needs to improve in HF care

On the organizational level, the EBCD process provided knowledge about what healthcare areas need to improve. The study findings validate the findings from earlier EBCD projects with proposed improvements such as improved information about HF, improved

continuity of care, improved relations and communication between patients, family members and professionals, and the need of inviting patients and family members to be involved in healthcare. Within the mental healthcare context, patients and carers have suggested streamlining clinicians' working practices to free up time for interaction with their patients (McAllister et al., 2021). Furthermore, more patient-led training for nurses on how to address the patients' problems and taking a non-judgmental approach to patients and carers has been previously reported (McAllister et al., 2021). Patients and family members within palliative care proposed improvements to how they are acknowledged, communicated with, and validated by healthcare professionals (Blackwell et al., 2017). Similar to the PWHF and family members in my research, persons with lung cancer expressed their frustration with changing care providers and put forward their wish for improved continuity of care (Tsianakas et al., 2012). To receive health-related information in groups with others has been proposed by participants in previous EBCD projects (Tsianakas et al., 2012), which strengthens the positive findings from the LC pilot test and the EBCD process.

With similar results from EBCD projects in various contexts, it is reasonable to assume that the proposed improvements to HF care reported in this thesis are transferable to other chronic care contexts. Thus, the findings could be used as a starting point for future healthcare QI initiatives within the chronic healthcare context.

Joint value - the “trigger film” and an educational video about HF

A “trigger film” was edited from individual interviews with PWHF in line with EBCD methodology. The film was used during the EBCD process to promote discussions about experiences of life with HF and its care and facilitated the prioritization of areas for healthcare improvement. All PWHF approved the use of the film for future educational purposes.

Based on their experiences revealed during the EBCD process, the PWHF, their family members and professionals agreed that information about HF needed to improve. Thus, a small team comprising patients,

family members and professional representatives co-designed an educational video about HF. The video addressed HF and its symptoms, causes, treatment, and self-management strategies. The film is planned to be available to the public.

Measurement of co-production outcomes

A considerable proportion of all co-production initiatives do not report on outcomes of co-production, which further blurs the evidence base for co-production (Loeffler & Bovaird, 2018). To be able to determine whether co-production of healthcare leads to the best possible health and care, the outcomes of such co-production should be measured (Loeffler & Bovaird, 2018). With the exception of measuring the change regarding the sense of security in everyday life and patient satisfaction with the LC (paper 1), the outcomes of the co-produced healthcare QI were not measured in my research studies. Considering the short time frame for the research studies, it is not clear whether we would have seen the long-term effects if we had measured outcomes.

Future research studies on co-production should include outcome measures over time. The clinical value compass is a model that facilitates the development of outcome measures in different perspectives: (1) functional status; (2) satisfaction with healthcare and perceived benefit; (3) costs; and (4) clinical outcomes (Nelson et al., 1996). Figure 9 proposes outcome measures for future research on co-produced initiatives in the context of HF.

Functional status in the clinical value compass might include measurements regarding physical and mental well-being (Nelson et al., 1996). In HF care QI, the context of papers 3-5 in this thesis, measurements on HRQoL might be included.

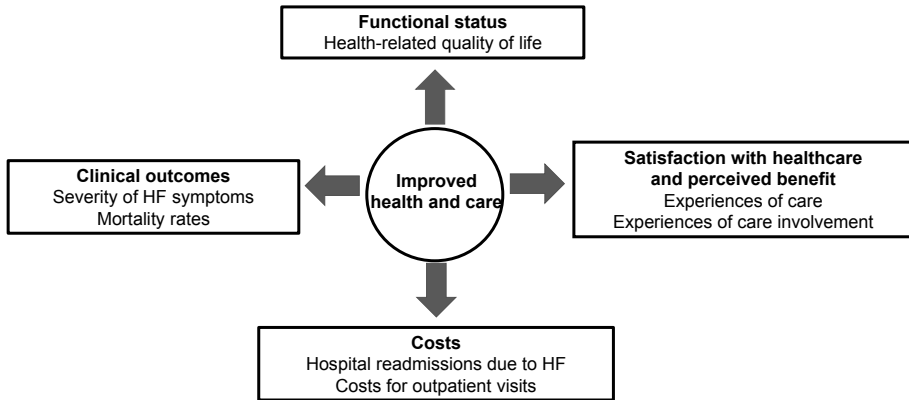


Figure 9. A proposed clinical value compass with outcome measures for future co-production research, an example in the context of HF.

When it comes to satisfaction with healthcare and perceived benefit, outcome measures might include measurements of satisfaction with healthcare and level of participation (Nelson et al., 1996). In the context of HF care, measurements regarding experiences of care and healthcare involvement could be included. Consistent evidence that patients and family members value being involved in co-production is yet to be discovered (Loeffler & Bovaird, 2018).

Few case studies assess the costs of co-production (Loeffler & Bovaird, 2018). Outcome measures related to costs might include direct medical costs as well as measures reflecting the use of resources (Nelson et al., 1996). In the context of cardiac care, measurements reflecting the cost could, for example, include measurements on hospital readmissions due to HF and costs for outpatient clinic visits. Other measurements related to costs might include increased managerial inputs and increased investment in the infrastructure to allow citizens to make a greater contribution in co-production initiatives (Loeffler & Bovaird, 2018).

What outcome measures to use in the perspective of clinical status depends on the clinical process that is to be improved. Measures might for example include mortality rates and/or morbidity rates (Nelson et al., 1996). In the context of HF care, outcome measures related to

clinical status might include measurements of the severity of symptoms as well as mortality rates.

Methodological considerations

The quality and generalizability of case study research

This thesis employed a qualitative case study design. A critique, sometimes put forward regarding case study research, is that it lacks scientific rigor. There are, however, various ways to address these concerns (Flyvbjerg, 2011). Strategies to promote scientific rigor within case study research include respondent validation and transparency throughout the process (Crowe et al., 2011). Respondent validation refers to research participants checking emerging findings and researchers' interpretations and providing own explanations to data analysis (Crowe et al., 2011). In this thesis, PWHF, family members and professionals verified the researchers' preliminary research findings during EBCD feedback events (paper 4). To promote further scientific rigor, the findings in all papers could have discussed with the participants. Transparency throughout the research process can be achieved by in detail descriptions of the whole research process (Crowe et al., 2011). Participant selection, data collection procedures, reasons for choosing a particular method, the researcher's pre-understanding and how this pre-understanding is managed and used to inform data analysis and conclusions need to be thoroughly described (Crowe et al., 2011). This thesis provides information about these aspects.

Another critique to case study research is that it may provide little basis for generalization (Flyvbjerg, 2011). However, the concept of generalizability can be understood from different perspectives. In this thesis, generalizability aligns with the concept of naturalistic generalizability (Hays & McKibben, 2021). Naturalistic generalizability refers to the generalizability achieved through the reader's familiarity with similarities and differences to the case research findings (Hays & McKibben, 2021). The reader compares the findings to their prior understandings of reality and then concludes whether or not the findings can be applied to their specific contexts and situations. Thus, naturalistic generalizability puts the responsibility of

generalization of research findings on the reader and facilitates experiential learning (Wikfeldt, 2017). To promote naturalistic generalizability, researchers need to provide readers with empirical evidence (e.g., quotes from interviews) and rich contextual details to help readers judge whether or not the case provides insights into their own cases. In all papers in this thesis, quotes are presented. Furthermore, the research context is thoroughly reported upon.

Being an insider researcher

I was an insider researcher during the whole research process. An insider researcher is close to the subject being researched and has a pre-understanding of the organization or group in which the research is being conducted (Fleming, 2018). Pre-understanding refers to all previous knowledge that a researcher brings to the research project, such as academic and non-academic experience (Alvesson & Sandberg, 2022).

There are several advantages to using one's pre-understanding in research (Alvesson & Sandberg, 2022). The pre-understanding is helpful when formulating research questions that are significant to the organization (Alvesson & Sandberg, 2022; Fleming, 2018). Pre-understanding includes contextual knowledge, making it easier to adapt the research design to local conditions and its goals and values (Vindrola-Padros et al., 2019). Furthermore, the pre-understanding facilitates data collection since the researcher gets richer data by asking the right questions at the right time (Alvesson & Sandberg, 2022; Brannick & Coghlan, 2007). The use of pre-understanding "can enrich the analysis by enabling a much broader mobilization of judgement, including the consideration of multiple meanings of empirical events" (Alvesson & Sandberg, 2022). Finally, the pre-understanding provides a good understanding of the target group and what is relevant and interesting to them (Alvesson & Sandberg, 2022).

However, if not recognized and managed by the researcher, there is a risk of research primarily reflecting the researcher's pre-existing understandings. This can have a negative influence on research validity (Palmér et al., 2022). Others argue that the researcher's pre-

understanding can be used as a positive input in research (Alvesson & Sandberg, 2022). Several strategies have been proposed to manage pre-understanding in research, including reporting on roles in the study context (Malterud, 2009), dialog (Alvesson & Sandberg, 2022) and reflexivity (Dodgson, 2019).

My roles and their potential influence on my research

I am a pharmacist and a physician by training. Currently, I hold the position of cardiologist at the Department of Internal Medicine and Geriatrics, The Highland district hospital (Höglandssjukhuset), RJC, Sweden. I interact with persons with heart disease, their family members and healthcare professionals, as part of my daily clinical duties. I have participated in several healthcare QI projects at the local and regional levels. Thus, I have a network within the organization and an insider perspective on healthcare delivery in RJC. I was the project leader and facilitator of the LC and the EBCD process. My researcher's roles included formulating research questions (papers 1-5); research design (papers 1-5); field work (papers 1-2 and 4-5); analysis (papers 1-2 and 4-5) and contributing and writing (papers 1-5).

My roles and relationships might have led to social desirability, with these relationships influencing who chose to participate in my research studies (Fleming, 2018; Mortel & Thea, 2008). Persons with heart disease and their family members might have felt obliged to participate from fear of not being prioritized when in need of healthcare. Likewise, professionals might have felt obliged to participate, from fear of losing their employment. To minimize these risks, I emphasized that participation was voluntary, with no consequences for non-participation. Patients in treatment by me were excluded from participation.

My roles and relationships might also have influenced what information participants chose to share during interviews and research events. Due to social desirability, persons with heart disease and family members might have chosen to exclude negative experiences about care services (Mortel & Thea, 2008). Professionals might have been unwilling to share information about situations believed to reveal flaws in clinical practice (Holmes, 2020). However, to express opinions regarding

working practices and to suggest workplace improvements is welcomed from professionals in RJC. Both positive and negative experiences are reported in this thesis.

Participants might also have refrained from sharing all experiences when assuming that me, the insider, possess more or better insider knowledge than they do. Therefore, information which should be obvious to me as an insider, may not have been put forward by the participants (Holmes, 2020). To minimize this risk in my research, participants were encouraged to share both positive and negative experiences of all aspects of life with disease and its care.

A further risk of being an insider researcher is the desire for positive outcomes (Fleming, 2018). The insider may be too attached to his/her context, thus wanting to present the context in an overly positive light (Holmes, 2020). There might also be a risk of failing to properly interpret the results if the insider is not able to bring an external perspective to the research process (Holmes, 2020). To minimize these risks in my research, data analysis was validated by the research participants and discussed with research supervisors knowledgeable in healthcare QI and qualitative research in healthcare contexts but with no connection to the cardiac care context.

The management of my pre-understandings

A prerequisite for bringing forward pre-understanding as a positive input in research is that it is appropriately managed. Becoming aware of one's own pre-understanding can be achieved by dialog with others with views that are different from our own (Alvesson & Sandberg, 2022). Through dialog, either face-to-face or through texts, different views of the research subject become visible, thus offering an opportunity to reflect upon pre-understandings and their impact on the research (Alvesson & Sandberg, 2022). According to Alvesson & Sandberg (2022) the "key in this dialog is to be able to identify productive aspects of our pre-understanding and to differentiate them from constraining aspects, thereby weeding out fixed ideas, confirmation bias and other blinders" (Alvesson & Sandberg, 2022). This dialog promotes reflexivity. Reflexivity means critically questioning one's role in and impact on research (Dodgson, 2019). In

this research, analyses were reviewed with senior researchers (all supervisors) – a form of investigator triangulation – to strengthen the trustworthiness of the research (Noble & Heale, 2019). The research findings were discussed and reflected upon among researchers, so openness to understanding the research subject and controlling of the pre-understanding helped ensure objectivity. We reflected upon our roles and how these roles impacted the research.

Contextual considerations

The research in this thesis was limited to one particular setting. The prerequisites for similar healthcare QI initiatives and research might therefore be different from those in other healthcare contexts. For example, other contexts might have different previous knowledge about healthcare QI and co-production. The EBCD process was carried out during the constraints on resources caused by the covid-19 pandemic. This obviously influenced the contextual capacity to engage in healthcare QI, as previously discussed.

Considerations regarding sample size and inclusiveness

The research studies entailed small sample sizes. This might limit the generalizability of the research findings. Based on my clinical experience, the most multimorbid persons with complex health issues were not represented; nor were those with cognitive impairments or those not speaking Swedish. Thus, there is a risk of including persons who are considered easy to co-produce with. However, with healthcare QI focusing on “what is useful” and adopting a pragmatic approach to participation, the healthcare QI methodology supports the involvement of those who want to and can participate (Perla et al., 2013). Still, the research participants were a varied group in terms of sex, age, personality, years since diagnoses, previous employment, and personal experiences of cardiac care. Thus, the research offers useful knowledge that can guide future co-production initiatives.

A limitation to fulfilling the principles of diversity and inclusiveness of co-production in this research might be that a convenience sampling strategy was employed (Jager et al., 2017). This sampling strategy

might promote external exclusion. Persons with acute illness, cognitive impairments or language barriers were excluded from participation and also from co-production. No attempt was made to explicitly include persons from disadvantaged groups, which might have a negative impact on the generalizability of research findings. To minimize external exclusion in future co-production initiatives, other recruitment strategies than those used in our research need to be tested, such as a random selection of participants (Goldsmith et al., 2019), strategies that make it possible to reach out to the general public, i.e., to invite “everyone” (Eriksson, 2022), clear incentives for participation (Voorberg et al., 2015) or adapting the location and/or language for co-production (Røhnebæk & Bjerck, 2021).

Adjustments of the EBCD process

Paper 3 described how the EBCD process was planned to unfold (Suutari et al., 2022). Aligning with the pragmatic underpinnings of healthcare improvement science, changes to the EBCD process were necessary during the project to fit the real-life circumstances of the research context.

The first EBCD step included the formation of a steering group and a first steering group meeting (Suutari et al., 2022). The steering group involved PWHF, family members and professional representatives. Additional separate steering group meetings were planned to be held during the EBCD process. However, with the process already being time intensive due to multiple events, the steering group meetings were integrated within existing EBCD events.

Second, the initial plan was to enroll 10-12 PWHF, 10-12 family members and 10-12 professionals in the EBCD process. However, the number of participants needed adjustment. Professionals, including the improvement advisor who we planned would facilitate the EBCD process, were unable to participate due to their focus on clinical work during the covid-19 pandemic. Instead I took on the facilitator role. I contacted many PWHF before finding those who were interested in study participation. Some PWHF declined study participation due to health issues or because they felt they had nothing to offer. Some

PWHF refrained from research participation since they were uncomfortable with the study's use of online tools. Given the fact that HF is associated with comorbidities, such as cognitive impairments and limited HL, future EBCD initiatives need to take these difficulties into consideration.

Family members were particularly difficult to engage in the EBCD process. A primary care nurse suggested eligible family members for participation. This sampling strategy proved to be time-intensive, and many family members had to be asked to find persons interested in study participation. Recruitment through trusted caregiver agencies would probably have been more effective for family member recruitment (Leslie et al., 2019). Participating family members were all female healthcare professionals by training, indicating that the sample of family members was not as representative as we wanted.

The EBCD participants agreed that the information about HF needed to be improved. To address this gap, the stakeholders decided to make an educational film about HF. The filming proved to be a complex task involving various stakeholders. Therefore, this step of the process was more time-intensive than anticipated. In April 2023, this step of the process is still ongoing. Thus, the overall timeline for the EBCD process needed adjustments.

The initial plan was to end the EBCD process with FGIs, one with PWHF, family members and professionals, respectively. These FGIs were intended to explore how organizational conditions influenced the participants' co-design and implementation process (Suutari et al., 2022). In real-life, a joint FGI with PWHF and family members was conducted during the co-design process, since the PWHF preferred to have the support of their family members when participating. Instead of focusing on only organizational conditions influencing the co-design process, the FGIs focused on stakeholders' experiences of and conditions for EBCD participation. Aligning with this focus, the approach to the reflexive TA was changed from a deductive to an inductive approach (paper 5).

The outcomes of co-production

The value of co-production, put forward in this thesis, draws mainly upon qualitative data from small case studies. Paper 1 reports on quantitative measurements of the sense of security in everyday life and satisfaction with the LC (figure 6). This was done on a non-validated scale, specifically designed for the LC. A limitation is that I only measured the sense of security and satisfaction on a group level, not on an individual level. Thus, it is not possible to understand how each individual's ratings changed during the LC. Furthermore, I have not measured the sense of security in everyday life over time to see whether the effect of the LC was sustainable. These limitations would be addressed if I were to start the project again.

Power issues, central to a co-production process, were not objectively measured or explicitly discussed during the research projects. However, the EBCD participants said that they felt they were able to collaborate together on equal terms. A facilitator or project coordinator, might be useful to let everybody speak and contribute to the joint work (Donetto et al., 2014; Eriksson, 2022). Furthermore, employing a critical reflective practice and dialog has been suggested to promote more balanced power dynamics between stakeholders in healthcare co-production (Ärleskog et al., 2021).

Conclusions and implications

Conclusions

Co-production of healthcare services – involving patients, their family members and professionals in healthcare processes – has the potential to promote the best possible health. The overall aim of this thesis was to explore the prerequisites to and the value of co-production and to provide lessons for future co-produced healthcare QI initiatives in cardiac care. Five papers contributed to useful knowledge regarding the co-production learning journey, the barriers to and facilitators of co-production of healthcare and the value of co-production.

The Swedish national health strategy “Nära Vård” (“*Closer Care*”) emphasizes engaging patients and family members as active partners of healthcare processes, thereby improving care, self-care and quality of life (Swedish Association of Local Authorities and Regions, 2023a). Aligning with the national “Nära Vård” strategy, the research in this thesis proposes how the co-production of healthcare might be practiced, particularly in cardiac care contexts which have seen only limited implementation of such initiatives. These lessons are useful when aiming at overcoming the barrier of varying understanding of co-production among stakeholders in the CMS.

Furthermore, this research highlights that the process of co-production itself, i.e., participation in the LC or in the EBCD process, is valuable to its stakeholders. The value of co-production can be understood in terms of improved disease knowledge, relatedness, strengthened coping strategies, enhanced work satisfaction, awareness about person-centeredness and knowledge about what care areas to improve. Based on the research findings, this thesis expands the understanding of the value of co-production in a wider perspective, including all experiences and knowledge that are useful when improving healthcare services.

In the cardiac care context, various self-centered and community-centered motivations were recognized to be facilitators to co-production. This thesis indicates that co-production can be linked to

SDT, thus strengthening a potential underlying mechanism to why individuals engage in co-production. Future co-production initiatives should draw on these motivations. This thesis further grows the understanding of what barriers that need to be managed during future co-production initiatives. In particular, this research contributes to the understanding of the barriers on the individual level among persons living with a chronic disease. These barriers, i.e., poor physical and mental health and limited HL, can be overcome by involving these individuals on their own terms. Relational barriers, i.e., professionals not inviting patients and their family members to be involved in healthcare co-production, require a cultural change among healthcare professionals. Barriers on the contextual and system levels, i.e., aligning with the contextual QI culture despite existing resource constraints, challenge healthcare leaders and managers.

Implications

Implications for co-production theory

The theoretical contributions of this thesis are threefold. The thesis contributes to (1) the understanding of co-production as a situational and contextual phenomenon; (2) the acknowledgment of co-production as a phenomenon that can be understood through various theoretical lenses and (3) the understanding of co-production as an approach for individual and organizational learning.

First, this thesis provides empirical evidence for co-production as a situational and contextual phenomenon. Underpinned by healthcare improvement science and its pragmatic foundations, this research exemplifies how co-production needs to be adjusted to its participants and its context depending on the phase of the project and its prerequisites. Rather than understanding co-production as a fixed process, the dynamic nature of co-production should be appreciated and used to facilitate healthcare QI under real-life circumstances.

Second, this thesis adds to a deeper understanding of the concept of co-production through various theoretical lenses. SDT suggests that co-production can be understood as a behavior that is underpinned by

innate intrinsic motivators (Ryan & Deci, 2017). By relating co-production to the COM-B model, we understand that motivation to co-produce needs to be accompanied by capabilities and opportunities (Michie et al., 2011). Thus, the COM-B model offers a more solid theoretical explanation to why and if individuals participate in co-production initiatives. Capabilities, opportunities and motivation to co-produce can, in turn, be framed by MUSIQ to mirror the roles of, and inter-relationships between, contextual factors within QI initiatives (Reed et al., 2018). By applying a motivational, behavioral and a contextual theoretical frame to data, the thesis acknowledges co-production as a phenomenon that can be understood through various theoretical lenses.

Third, this thesis provides empirical evidence for co-production as an approach to individual and organizational learning. Previous co-production research rarely puts forward co-learning as a component of co-production (Osborne et al., 2016). In this thesis, co-learning is understood to be a key component of co-production, and also the key approach to ensure that PWAF and PWHF learn more about their disease and the perspectives of their peers, and to ensure professionals learn more about the patients' and family members' perspective. Furthermore, this thesis shows how stakeholders learn to co-produce over time – from the LC to the EBCD. This learning journey highlights how organizational learning about how to co-produce can be facilitated by the core principles of co-production and pragmatism.

Implications for healthcare practice

Guiding principles for future co-production

Drawing on existing co-production literature and the experiences of moving toward co-production in a cardiac care setting, this thesis suggests guiding principles for future co-production initiatives in healthcare practice. These principles are indented to guide reflections regarding when, with whom and how to co-produce healthcare QI.

Choose the appropriate approach for your project

A plethora of healthcare QI methodologies and tools are available. Co-production can be understood as yet another approach to healthcare QI, that is appropriate when aiming at improving patients' capabilities to self-manage their health or when designing or re-designing new services or healthcare processes (Gilardi et al., 2016; Robert, 2022). When choosing co-production as the healthcare QI approach, there should be reflection on whether a project aims for these kinds of outcomes.

Invite people to co-produce

The vast majority of co-production initiatives in healthcare settings are initiated by healthcare professionals or researchers. As exemplified by this research, one explanation for this might be that patients and family members do not want to interfere with the professionals' domains. Thus, the patients and the family members cannot be expected to take the lead and co-production still needs to be initiated by healthcare professionals and/or researchers.

Be inclusive

The co-production principle of including all perspectives and respecting and valuing the knowledge of all those working together embraces diversity and inclusiveness (Coldham, 2018). There should be reflection on participant recruitment strategies and on those who choose to participate. Recruitment strategies, such as a random selection of participants, strategies that make it possible to reach out to the general public, clear incentives for participation or adapting the location and/or language for co-production, might improve inclusiveness. The participants need to be able to participate on their own terms to ensure that everybody feels able to contribute. Data should be collected on participants' characteristics such as age, gender, education level, health status and socio-economic status. Thereby, the diversity and the inclusiveness of the co-production initiative can be reported on.

Ensure that the project brings value for the participants

Self-centered and/or community-centered motivations motivate people to engage in co-production and determine the outcomes of such engagement (Steen, 2021; Virlée et al., 2020). Co-production initiatives should draw on the participants' real-life problems and motivations. "What's in it for them" should be clearly communicated.

Explore how power can be shared

With shared power being an important principle of co-production, future co-production initiatives need to explore how power is shared during co-production initiatives (Coldham, 2018). To work toward shared power means that both professionals *and* the patients and their family members need to learn how to establish equal and reciprocal relationships. Furthermore, whether shared power between stakeholders might be associated with positive outcomes in terms of improved health is an area that needs to be explored. Different strategies should be tried to understand what works in different contexts. Strategies that might promote power sharing include using a facilitator to let everybody speak and contribute to the joint work (Donetto et al., 2014; Eriksson, 2022). Furthermore, employing a critical reflective practice and dialog among stakeholders has been suggested to promote more balanced power dynamics between stakeholders in healthcare (Ärleskog et al., 2021).

Involve the leaders and the wider healthcare context

Healthcare leaders and managers can facilitate and promote co-production within their organizations (Sicilia et al., 2019). Thus, to be able to secure the necessary resources for co-production initiatives and to help disseminate the work, leaders need to be kept updated on project progress. Leaders and managers might also be involved in the steering committee of the project or may be active participants during project meetings.

Measure the outcomes of co-production

To be able to determine whether co-production of healthcare promotes the best possible health and care, the outcomes of such co-production

should be measured (Loeffler & Bovaird, 2018). Appropriate measurements, for example according to the clinical value compass, should be co-produced during the project (Nelson et al., 1996). These measurements should then be collectively measured before, during and after the project to see whether positive project outcomes can be detected. Sense-making, i.e., “the processes by which people seek plausibly to understand ambiguous, equivocal, or confusing issues or events”, should guide the collective interpretation of data and the future implementation of research findings (Brown et al., 2015).

Future research

I have identified several objectives for future research while writing this thesis. Thus, I propose the following research questions for future research on co-production of healthcare:

- What are the outcomes of co-production and how can these be measured in cardiac care? What are the outcomes of co-production and how can these be measured in healthcare in general?
- What mechanisms link co-production to its outcomes in cardiac care? What mechanisms link co-production to its outcomes in healthcare in general?
- How should co-production of cardiac care services be managed? How should co-production of healthcare in general be managed?
- How can the knowledge about co-production be improved among persons living with heart disease? How can the knowledge about co-production be improved among patients, professionals and the public?
- What is the cost benefit of co-production of cardiac care services? What is the cost benefit of co-production of healthcare in general?
- How can lay people be engaged as co-researchers and co-authors of research papers?

Epilogue - My own learning

This thesis was finalized in April 2023. Next, I will reflect upon my own learning during my PhD journey.

My first reflections concern my learning regarding theory of science. Being a pharmacist and cardiologist by training, I have a strong background in the positivist paradigm. My clinical reality is all about evidence-based medicine and trying to figure out how the results from large randomized controlled trials can be implemented locally to promote the best possible healthcare and health. However, to be able to translate quantitative measures into good quality care for the patients, we need to turn our attention to how evidence is implemented and how quality of care can be improved. My personal learning journey has included the realization that just producing evidence in line with the positivist epistemology is by no means a guarantee that the evidence will be applied in practice. However, when applying healthcare improvement science methodologies in a healthcare context it is essential to consider the strong positivist paradigm in healthcare settings. Only by acknowledging the strong, obvious and usually implicit positivist paradigm within healthcare contexts, am I able to introduce other epistemologies to healthcare and to highlight the strengths of combining different ways of knowledge creation. Thus, as a result of critically thinking about various theories, my journey entails a shift from the positivistic paradigm to healthcare improvement science, supported by pragmatism and its situational theoretical standpoints.

My next reflections concern my learning regarding research methodologies. The case study design (papers 1 and 4) taught me to explore complex processes in my own healthcare organization. Using the interactive research approach trained me in reflecting upon and balancing my different roles during the research process. I have gained knowledge about how to conduct FGIs and individual interviews and how to integrate interviews with other data collection methodologies, such as field notes from observations and project documents, to address my research questions. This data was analyzed using qualitative

methodologies. As a novice qualitative researcher, I set out to learn more about how to use qualitative content analysis with an inductive approach (paper 1). Approaching transcripts from FGIs with a step-by-step approach helped me to understand how qualitative data could be used to address research questions. Next, I employed a qualitative content analysis with a deductive approach, underpinned by the COM-B model (paper 2). Here I further developed my knowledge regarding qualitative content analysis and how to relate data to a pre-existing theoretical framework. By combining FGIs with diaries written by participating PWHF, I developed a new data collection methodology that is useful for capturing information about a phenomenon both in groups and individually. Papers 4 and 5 employed reflexive TA for data analysis. Here, unlike with qualitative content analysis and its more straightforward procedure, I was challenged by trying to reach a level of abstraction and to let the analysis tell a story about the data. Furthermore, I had to understand how to make sense of my own pre-understanding as a tool for data analysis and how to manage it, rather than only understanding my pre-understanding as something that introduced biases to the research process. I have also gained knowledge about how to relate my research to pre-existing theories, such as SDT (paper 1), COM-B (paper 2) and MUSIQ (paper 3).

This thesis builds on my master's thesis on healthcare QI and leadership. When writing my master's thesis, co-production emerged as a concept that I wanted to explore further. Thus, my master's thesis was further developed through the lens of co-production (paper 1). During my PhD studies, I have gained a deeper understanding about the concept of co-production. I have grown to appreciate co-production as a phenomenon that aligns with the ethical concepts of autonomy and self-determination. To me, it makes sense to understand co-production as an approach to healthcare QI, rather than as the end outcome of such initiatives. By writing this thesis, I have gained knowledge about the prerequisites to co-production, how it might be promoted and what value it might bring to its stakeholders and healthcare organizations. Future research is warranted to explore what outcomes in terms of improved health and care can be associated with co-production.

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Co-producing healthcare quality improvement

– the prerequisites for, the value of and the lessons from co-production in a Swedish cardiac care setting

This thesis focuses on how persons living with heart disease, their family members and professionals can co-produce healthcare quality improvement and the best possible health and care. Underpinned by healthcare improvement science and its pragmatic roots, this thesis explores how a Learning Café (LC) and Experience-Based Co-Design (EBCD) work in a Swedish cardiac care setting. The overall aim of this thesis was to explore the prerequisites for and the value of co-production and to provide lessons for future co-produced healthcare quality improvement initiatives in cardiac care.

Barriers to and facilitators of co-production were identified on different levels – the individual, the relational and the systemic levels. Individual barriers to co-production included poor health and limited health literacy among persons with heart disease. Relational barriers included professionals not inviting patients and their family members to be involved in healthcare co-production. Barriers on the systemic level included time and resource constraints and varying understanding of how co-production might be applied in practice. Both self-centered motivations, such as wanting to learn more about a specific disease, and community-centered motivations, such as wanting to improve healthcare services, were identified to be facilitators to co-production. The LC and the EBCD process created value for its participants and the organization, including improved disease knowledge; relatedness; strengthened coping strategies and improved self-efficacy; awareness about the patient and family member perspective; and knowledge about what needs to change in heart failure care.

This thesis proposes how healthcare co-production might be practiced, particularly in cardiac care contexts which have seen only limited implementation of such initiatives. Future research is warranted to understand how co-production might be implemented and play out in various healthcare contexts and with other groups of persons living with chronic disease.



ANNE-MARIE SUUTARI is a pharmacist and a physician. She also holds a master's degree in Quality Improvement and Leadership in Health and Welfare. She is interested in how co-production can bring patients, family members and professionals together in healthcare quality improvement aiming at the best possible health and care. She works as a cardiologist in Region Jönköping County, Sweden.

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