THE HEART SKILLS STUDY

HEALTH LITERACY AND HEALTH LITERACY RESPONSIVENESS IN CARDIAC DISEASE PREVENTION AND REHABILITATION

PhD dissertation

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Oplysning være skal vor lyst,
er det så kun om sivet,
men først og sidst med folkerøst,
oplysningen om livet;
den springer ud af folkedåd
og vokser, som den vugges,
den stråle i vort folkeråd,
til aftenstjernen slukkes.

(N.F.S. Grundtvig)
The Heart Skills Study would never have come to be had it not been for my main supervisor Helle Terkildsen Maindal. You have encouraged and inspired me from the day I first knocked on your door and I hope will continue to do so in the future. There is still much to do!

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Preface
Over the past decades, social inequity in health has been high on the international as well as the Danish health agenda. With concern, researchers, leaders, and decision makers have observed the impact of socio-economic conditions on health outcomes, use of healthcare systems, and eventually mortality. In Denmark, 41.8% fewer deaths from ischaemic heart disease would occur among men if the total population followed the mortality pattern of people with intermediary or long educations (1).

Health literacy and health literacy responsiveness (i.e. the way in which systems make health information and resources available to people regardless of their health literacy level) is increasingly emphasized as an important intermediary goal of health promoting initiatives and as a means of enhancing equitable distribution of health and well-being.

In a recent editorial (2019) Zsuzsanna Jakab, the then World Health Organization Regional Director for Europe, reflects on the potential of health literacy in public health, stating that: ‘Acknowledging people for what they are able to do contrary to what they carry with them in terms of personal, social and cultural challenges not only appear to be a potential key strategy in improving equitable distribution of health and well-being, but may also reduce the stigmatization related to the experience of social exclusion.’ (2)

The Heart Skills Study examines the role of health literacy in relation to long-term illnesses and cardiac conditions. This thesis reports on the Heart Skills Study based on four embedded scientific papers. In relation to studies I-III, I hypothesize, that:

i. In a general Danish population, long-term illness and multimorbidity are associated with specific health literacy challenges (study I).

ii. In a Danish population with self-reported cardiovascular disease, limited health literacy is associated with adverse health behaviour and poor health-related quality of life (study II).

iii. In a Danish population of people referred to municipal cardiac rehabilitation, limited health literacy is associated with low participation and poor health-related quality of life (study III).

Taking off from our results, I also report on the application of a co-design development methodology (the OPtimising HEalth Literacy and Access (Ophelia) approach) to improve health literacy responsiveness in a municipal cardiac rehabilitation unit, and I evaluate the organizational impact of applying this methodology.

Reflecting the explorative nature of this process, I hypothesize in relation to study IV that:

Organizational changes aimed at improving organizational health literacy responsiveness in a municipal cardiac rehabilitation unit can be developed and
integrated using a systematic intervention development methodology based on local needs assessments, co-design methodologies, and pragmatic intervention testing (study IV).

OUTLINE OF THE THESIS

This thesis follows the natural chronology of the Heart Skills Study. It begins with the conceptualization of health literacy and health literacy responsiveness (chapter 1). Health literacy is then positioned in relation to central determinants of health and health outcomes, first in relation to general populations and people suffering from long-term illness (chapters 2 and 3), and secondly within the context of cardiovascular disease and cardiac rehabilitation (chapters 4, 5, and 6). Then, the thesis accounts for the current evidence on effective health literacy interventions and reports on the development process and pilot testing of a co-designed intervention in cardiac rehabilitation (chapters 7 and 8). Lastly, a general discussion summarizing the main findings and reflecting on methodological issues, results, and implications for future research and practice is provided (chapter 9). The thesis ends with our summarizing conclusions (chapter 10), and finally, an English and a Danish summary is provided (chapters 11 and 12). References are listed after each chapter. A list of abbreviations, a list of included figures and tables, and an overview of appendices are provided below.

Four scientific papers, all published in peer-reviewed journals, are embedded within the thesis (chapters 3, 5, 6, and 8). Collectively they constitute the Heart Skills Study. Their interrelationship is illustrated in figure 0.1. Links to the original papers are provided in the front page of the relevant chapters. Reflections on the study rationales and methodologies are included in chapters prior to each study (chapters 2, 4, and 7). The first three studies focus on the identification of health literacy challenges among people with long-term conditions and cardiovascular diseases in particular, while the fourth study comprises an attempt to respond to these challenges in cardiac rehabilitation.
Several central methodologies and measures are introduced early in the thesis and reintroduced in connection with later chapters. I have tried to avoid too many repetitions and instead consistently referred to previous chapters and sections when these overlaps occur.

Throughout the thesis, I generally use the pronouns we and our when referring to my personal choices and reflections. This is to ensure homogeneous language, adhering to the format of the four embedded studies (chapters 3, 5, 6, and 8), which all refer to a team of authors. However, all text contained in other chapters of the thesis is my own original work.

I wish you happy reading,

Anna Aaby
<table>
<thead>
<tr>
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<th>Description</th>
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<tbody>
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<td>CVD</td>
<td>Cardiovascular disease</td>
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<tr>
<td>CR</td>
<td>Cardiac rehabilitation</td>
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<tr>
<td>HAYS</td>
<td>‘How Are You?’ Survey (a regional health survey in Central Denmark Region)</td>
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<tr>
<td>HLS-EU</td>
<td>The European Health Literacy Survey (conducted in 2011 in 8 European countries)</td>
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<td>HLS-EU-Q</td>
<td>The European Health Literacy Questionnaire</td>
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<tr>
<td>HLQ</td>
<td>The Health Literacy Questionnaire</td>
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<tr>
<td>HRQoL</td>
<td>Health-related quality of life</td>
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<tr>
<td>MCS</td>
<td>Mental component summary (summary measure of the SF-12)</td>
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<tr>
<td>Ophelia</td>
<td>The OPtimising HEalth Literacy and Access (approach to health literacy intervention development and testing)</td>
</tr>
<tr>
<td>Org-HLR</td>
<td>The Organizational Health Literacy Responsiveness (a framework, process and tools for assessing and improving organizational health literacy responsiveness)</td>
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<tr>
<td>PCS</td>
<td>Physical component summary (summary measure of the SF-12)</td>
</tr>
<tr>
<td>PDSA</td>
<td>Plan-Do-Study-Act (a framework for quality improvement testing)</td>
</tr>
<tr>
<td>REALM</td>
<td>Rapid Estimate of Adult Literacy in Medicine</td>
</tr>
<tr>
<td>SBSQ</td>
<td>Set of Brief Screening Questions (3-item questionnaire assessing health literacy)</td>
</tr>
<tr>
<td>SF-12</td>
<td>12-item Short Form Health Survey (questionnaire assessing HRQoL)</td>
</tr>
<tr>
<td>TOFHLA</td>
<td>Test of Functional Health Literacy in Adults</td>
</tr>
<tr>
<td>WHO</td>
<td>World Health Organization</td>
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Chapter 1: Health literacy and health literacy responsiveness
WHAT IS HEALTH LITERACY?

The concept of health literacy has developed over the past decades from a narrow term focusing on the association between literacy and health outcomes, which is still widely adopted particularly in the United States, to a broader term concerned with the collective abilities to access, understand, appraise, apply, and communicate information about health at an individual level (1). Recently, also the contextual resources needed to apply these abilities have been included in some definitions (2), reflecting the dynamic nature of health literacy and its application under diverse circumstances.

Individual health literacy is dependent on personal factors and social circumstances (cf. chapter 2) and is created and developed throughout the life course (3,4). However, particular events such as the occurrence of specific health challenges as well as individual contexts such as the cultural and political environment and health institutions surrounding the individual affect the need and opportunity to apply individual health literacy capabilities (3). Figure 1.1 illustrates this balance and shows how the complexity and demands placed upon the individual, e.g. by the health system, are crucial in determining the significance of health literacy strengths and limitations in relation to health promotion, prevention, and care (3).

Multiple definitions of health literacy are available in the literature, most of which include variations of accessing, understanding, analysing, and using information about health (1). In the Heart Skills Study, we adhere to the 2018 International Union for Health Promotion and Education (IUHPE) definition of health literacy as:

‘the combination of personal competencies and situational resources needed for people to access, understand, appraise and use information and services to make decisions about health’ (2).

Study II precedes the publication of this definition and uses:

‘people’s knowledge, motivation and competences to access, understand, appraise and apply health information in order to make judgements and take decisions in every-day life concerning health’

Figure 1.1. The role of individual characteristics and contextual factors in determining the effect of health literacy on health outcomes (extended version from Kickbusch et al. (3)).

Perspectives on health literacy

The conceptualization of health literacy is ongoing and occurs in very diverse settings with very different aims in view (5). In clinical settings (and studies) focusing on improving individual care, health literacy is often perceived as a risk factor of poor health (6). This perspective is profoundly supported in the epidemiological literature associating health literacy with health outcomes, adherence, and use of healthcare services (cf. chapters 2 and 4) and has led to the development of health literacy interventions focusing on health-literacy sensitive information, client-provider communication, and self-management (cf. chapter 7) (7,8). The perspective is summarized in a model developed by Paasche-Orlow et al. (2007) highlighting three factors claimed to connect health literacy with health outcomes: (i) access to healthcare, (ii) the interaction between patients and their healthcare professionals, and (iii) self-care (figure 1.2) (9). The model not only ascribes these factors to individual patient characteristics such as skills, motivations, and beliefs, but also introduces the healthcare system, health providers, and society as mediators or moderators of the effect of health literacy on health outcomes (9).
**Figure 1.2. Causal pathways between limited health literacy and health outcomes (adapted from Paasche-Orlows et al. (9))**

<table>
<thead>
<tr>
<th>Access and Utilization of Health Care</th>
<th>System Factors</th>
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<td>Patient Factors</td>
<td>System Factors</td>
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<tr>
<td>- Navigation skills</td>
<td>- Complexity</td>
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<tr>
<td>- Self-efficacy</td>
<td>- Acute care orientation</td>
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<td>- Perceived barriers</td>
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<th>Provider-Patient Interaction</th>
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<tr>
<td>Patient Factors</td>
<td>Provider Factors</td>
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<td>- Knowledge</td>
<td>- Communication Skills</td>
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<td>- Beliefs</td>
<td>- Teaching ability</td>
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<td>- Participation in decision making</td>
<td>- Time</td>
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<th>Self Care</th>
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<td>Patient Factors</td>
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<td>- Motivation</td>
<td>- Support Technologies</td>
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<td>- Problem solving</td>
<td>- Mass media</td>
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<tr>
<td>- Self-efficacy</td>
<td>- Health education</td>
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<tr>
<td>- Knowledge/skills</td>
<td>- Resources</td>
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*The box is a summary of the characteristics included in the original model.

In contrast, health literacy interpreted from a public health perspective represents an individual asset to be developed and targeted through health education at both individual and population levels, with the ultimate goal of empowering the individual to act upon his/her health situation or health concerns within his/her community or society (6,10). Health literacy and empowerment are thus closely related but do not need to be understood in a linear correlation with one (health literacy) leading to the other (empowerment). Rather, they are interconnected qualities that are both needed for effective self-management (11). In this view, health literacy becomes an approach rather than an end goal, and health literacy interventions are set in different arenas focusing on capacity building in a life course perspective (12,13). This approach to health literacy is much less explored, and there is a paucity of intervention strategies in the area (13,14). However, some of the thinking is reflected in Don Nutbeam’s three theoretical levels of literacy, which he has applied to health literacy thinking (10). Slightly rephrased, they comprise:

i. **Functional health literacy**, i.e. basic skills in reading and writing in relation to health. This level is generally covered in the narrow definitions of health literacy.

ii. **Communicative (or interactive) health literacy**, i.e. skills which can be used to actively participate in everyday activities concerning health.
iii. **Critical health literacy**, i.e. skills which can be applied to critically analyse information, and to use this information to exert greater control over life events and situations.

While the first level is broadly a cognitive ability to understand and act upon health information such as prescribed medical regimens, the following two levels also involve executive and social skills, which increasingly empower the individual to control and change his health behaviour or the health discourse of society (10).

In the Heart Skills Study, we integrate elements from both health literacy perspectives by adhering to a complex interpretation of health literacy as an omnipresent but dynamic phenomenon in every-day life continuously changing in and between individuals (5). All four studies collectively constituting the Heart Skills Study relate to people diagnosed with long-term conditions (study I) and cardiac conditions in particular (studies II-IV). In that respect, we take a clinical approach, examining health literacy as a risk factor among people already diagnosed. However, our intervention development process (study IV) is not primarily aimed at improving individual health literacy but rather focuses on the system level factors of Paasche-Orlow’s model (9), and throughout the four studies, we use a comprehensive health literacy measurement tool (cf. the section ‘How is health literacy measured’ below) covering all Nutbeam’s three health literacy levels (10). This allows us to also examine and respond to the executive and social aspects of health literacy affecting the individual’s health beyond the clinical setting such as the ability to navigate the health system, interact with health providers, or self-manage health.

**Health literacy across different arenas**

As new perspectives on health literacy have emerged and developed so have the arenas in which health literacy is created, applied, and responded to. Information about health is communicated, exchanged, and discussed throughout the health system and in society as a whole.

Figure 1.3 illustrates how different manifestations of health literacy may affect the impact of health promoting factors on the distribution of health and well-being.
While the majority of the available literature is concerned with individual health literacy, studies have also shown that the adequate health literacy of relatives or peers can mitigate the consequences of limited health literacy (16–18) and so may the health literacy-related knowledge of health professionals (19) and their ability to recognize and respond to the health literacy challenges of their clients (20,21). Little evidence is yet available regarding the role of other professions such as teachers and social workers, although the area is being given increasing attention as a consequence of the wide spreading recognition of health literacy as a health determinant developed throughout the life course (22–26).

In a wider perspective, the abilities of healthcare professionals are just one aspect of an institution’s or a service provider’s organizational health literacy (27). In relation to the Heart Skills Study, organisational health literacy is of particular importance and is therefore more thoroughly elaborated on below.
Especially in relation to health promotion and prevention, the way in which health information is shared and handled within a community, e.g. in schools and at workplaces, may be defining for the health literacy of community members and thus affect their health behaviours, health risks, and their abilities to cope with health challenges (13,28). Likewise, the media and commercial industry possibly affect the level of critical health literacy required to navigate public health information by presenting health information in a more or less transparent and understandable way (29,30).

To comply with these multifaceted implications of health literacy in the individual and its context, many countries have already or are integrating health literacy into their national health policies and strategies or are developing specific health literacy action plans (31). In a Danish context, this is, however, not yet the case. Although the Danish Health Authorities have elaborated on the concept of health literacy in a brief from 2009 (32), no specific political action was taken on that occasion. Consequently, the term health literacy is not yet integrated into most Danish healthcare settings, although attention towards the concept has lately been on the rise (33).

**Organizational health literacy responsiveness**

*Organizational health literacy* states the degree to which an organization makes it easier for people to navigate, understand, and use information and services. The concept of organizational health literacy has developed over the past decade. Already in 2007, Andrulia and Brach envisioned a healthcare system in which providers and their organizations worked to integrate health literacy into the improvement of healthcare quality (34). In 2012, the same Brach developed the more operationalized *Ten Attributes of Health Literate Health Care Organizations* (35), widely cited in later papers on organizational health literacy. Since then, several other frameworks and guides have been developed (27), emphasizing focus areas such as organisational priority, commitment and leadership in health literacy, organisational culture, strategies and routines in being health literacy responsive, resource allocation, available health literacy related tools and guides, as well as staff competences and general health literacy awareness, as playing a central role in the development of organizational health literacy (27,36).

*Organizational health literacy responsiveness* is a newer term similar to organizational health literacy, but with specific emphasis on the acknowledgement and response to diverse health literacy challenges faced by individuals within a population. It was first defined by Dodson et al. in 2015 (37) and then later modified by Trezona et al. (2017)
In the Heart Skills Study, we adhere to the International Union for Health Promotion and Education (IUHPE) definition (2018) (2):

‘the way in which services, organizations and systems make health information and resources available and accessible to people according to health literacy strengths and limitations.’

The political and scientific call for initiatives targeting organizations and aimed at improving or responding to individual health literacy is increasing (2,3,39–41). So far, there is little evidence on the effectiveness of specific frameworks and guides although many of them have demonstrated their ability to identify health literacy barriers (27). Chapter 7 elaborates further on this subject.

### HOW IS HEALTH LITERACY MEASURED?

There is a large number of health literacy measures available to estimate individual health literacy (42). Overall, they can be divided into instruments assessing health literacy in an objective (e.g. reading comprehension) or subjective (e.g. self-reported abilities) manner. Also, they can relate to more or less narrow definitions of health literacy, measuring only some aspects of the concept such as functional health literacy alone or attempting to cover a broader understanding. Table 1.1 provides examples of some of the most used health literacy measures.

Throughout the Heart Skills Study we use parts of (study II) or the full (studies I, III, and IV) Health Literacy Questionnaire (HLQ) to measure individual health literacy.

The HLQ was developed and tested in 2013 by Professor Richard Osborne and colleagues, Melbourne, Australia, using a validity-driven grounded psychometric approach (52). The questionnaire has been translated into several languages and used in different cultures and has shown strong psychometric properties both in (54,55) and outside (56–58) the Australian context in which it was developed. The HLQ has also been translated and validated in a Danish context by Maindal et al. (59).
<table>
<thead>
<tr>
<th>Instrument</th>
<th>Author (year)</th>
<th>Mode of assessment</th>
<th>Short description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Rapid Estimate of Adult Literacy in Medicine (REALM)</td>
<td>Davis et al. (1991, 1993) (43,44)</td>
<td>Objective</td>
<td>A test of literacy in clinical practise. Subjects are scored based on the number of listed words that are correctly pronounced. Available in long and short versions.</td>
</tr>
<tr>
<td>Set of Brief Screening Questions (SBSQ)</td>
<td>Chew et al. (2014) (47,48)</td>
<td>Subjective</td>
<td>3-item questionnaire for use in clinical practice. Subjects rate their perceived abilities on a 5-point scale.</td>
</tr>
<tr>
<td>Newest Vital Sign (NVS)</td>
<td>Weiss et al. (2005) (49)</td>
<td>Objective</td>
<td>Test of comprehension, evaluation and application of health information in clinical practice. Based on six questions relating to a nutrition label.</td>
</tr>
<tr>
<td>Functional Communicative and Critical Health Literacy measure (FCCHL)</td>
<td>Ishikawa (2008) (50)</td>
<td>Subjective</td>
<td>14-item questionnaire for use in clinical practice covering functional (5 questions), communicative (5 questions) and critical (4 questions) health literacy. Subjects rate their perceived abilities on a 4-point scale.</td>
</tr>
<tr>
<td>European Health Literacy Questionnaire (HLS-EU-Q)</td>
<td>Sørensen et al. (2013) (51)</td>
<td>Subjective</td>
<td>47-item questionnaire for use in general populations. Subjects rate their perceived abilities to access, understand, appraise, and apply health information on a 4-point scale. The questionnaire is available in short form (Q16, Q12 and Q6).</td>
</tr>
<tr>
<td>The Health literacy Questionnaire (HLQ)</td>
<td>Osborne et al. (2013) (52)</td>
<td>Subjective</td>
<td>44-item questionnaire divided into 9 separate scales. Can be used in clinical practice as well as general populations. Described in further detail below.</td>
</tr>
<tr>
<td>The Information and Support for Health Actions Questionnaire (ISHA-Q)</td>
<td>Osborne et al. (2015) (53)</td>
<td>Subjective</td>
<td>60-item questionnaire divided into 14 scales. 10 optional supplementary scales (43 questions) are available for specific health challenges. The questionnaire is developed for low- and middle-income settings.</td>
</tr>
</tbody>
</table>
The questionnaire consists of 44 items divided into nine scales, independently measuring the following aspects of health literacy:

1. Feeling understood and supported by healthcare providers (4 questions)
2. Having sufficient information to manage my health (4 questions)
3. Actively managing my health (5 questions)
4. Social support for health (5 questions)
5. Appraisal of health information (5 questions)
6. Ability to actively engage with healthcare providers (5 questions)
7. Navigating the healthcare system (6 questions)
8. Ability to find good health information (5 questions)
9. Understand health information enough to know what to do (5 questions)

A license must be obtained to be allowed to use the HLQ. However, details on the content and scoring procedures available in the original publication on the development of the tool (52) is reproduced in appendix I.

To connect the HLQ to existing health literacy theory, each of the HLQ scales were already during their development linked to one or more of Nutbeam’s three health literacy levels (52). The categorization is reported in table 1.2.

Table 1.2. Linkage between the Health Literacy Questionnaire (HLQ) and Nutbeam’s three health literacy levels after Osborne et al. (2013) (52)

<table>
<thead>
<tr>
<th>Health Literacy Questionnaire Scale</th>
<th>Nutbeam’s health literacy levels</th>
</tr>
</thead>
<tbody>
<tr>
<td>9. Understand health information enough to know what to do</td>
<td>Functional health literacy</td>
</tr>
<tr>
<td>2. Having sufficient information to manage my health</td>
<td></td>
</tr>
<tr>
<td>8. Ability to find good health information</td>
<td></td>
</tr>
<tr>
<td>1. Feeling understood and supported by healthcare providers</td>
<td>Communicative/interactive health</td>
</tr>
<tr>
<td>3. Actively managing my health</td>
<td></td>
</tr>
<tr>
<td>4. Social support for health</td>
<td>Critical Health literacy</td>
</tr>
<tr>
<td>6. Ability to actively engage with healthcare providers</td>
<td></td>
</tr>
<tr>
<td>7. Navigating the healthcare system</td>
<td></td>
</tr>
<tr>
<td>8. Ability to find good health information</td>
<td></td>
</tr>
<tr>
<td>5. Appraisal of health information</td>
<td></td>
</tr>
<tr>
<td>3. Actively managing my health</td>
<td></td>
</tr>
<tr>
<td>4. Social support for health</td>
<td></td>
</tr>
</tbody>
</table>
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Chapter 2: Health literacy in the adult Danish population and beyond
THE PREVALENCE OF LIMITED HEALTH LITERACY

In accordance with the more complex interpretations of health literacy (cf. chapter 1), one could argue that it is often inappropriate to make a sharp distinction between high and low health literacy and thereby disregard the dynamic and multifaceted nature of the concept (1). None-the-less, the majority of the studies referred to in this chapter do relate to health literacy as a polarized phenomenon in an attempt to examine its predictors and outcomes.

The prevalence of limited health literacy differs substantially between countries as a consequence of diverse cultures, societies, educational systems, and health systems (2–6). Furthermore, the use of different definitions and measures makes it difficult to compare studies on the prevalence of limited health literacy – a challenge the ‘Action Network on Measuring Population and Organizational Health Literacy’ (M-POHL) initiative under the auspices of the WHO is attempting to address in a European context (7).

That said, the European Health Literacy Survey (HLS-EU) carried out in 2011 across eight European countries (N = approx. 8,000) found the prevalence of limited health literacy to be between 28.7% and 62.1%, depending on the country in question (3). Denmark was not part of the HLS-EU. However, a large Danish population-based study from 2014 (N = 29,473) reported on HLQ scale 6 (engaging actively with healthcare providers) and HLQ scale 9 (understanding health information well enough to know what to do) (8). At item level, 14.5% to 18.3% and 8.8% to 20.2% perceived the health literacy task in question as difficult or very difficult in each scale respectively (8).

CAUSES AND CONSEQUENCES OF HEALTH LITERACY CHALLENGES

In the following sections, we review the evidence on critical health determinants and health outcomes associated with health literacy. The literature in this field is extensive, thus our assessment is not exhaustive. Since the Heart Skills Study concerns the Danish healthcare context, we have focused our evaluation as much as possible on research from similar contexts, i.e. European and Danish studies. We mainly address studies focusing on determinants and outcomes relevant in relation to the studies embedded in this thesis, and when possible, we have preferred studies based on broad health literacy measures such as the HLS-EU and HLQ. We have focused on literature based on general populations and, in anticipation of study I (cf. chapter 3), studies on
populations with long-term illness or multimorbidity. Chapter 4 provides a thorough review of literature on health literacy specifically concerned with cardiovascular diseases (CVD) and cardiac rehabilitation (CR).

**Health literacy and health determinants**

One of the reasons health literacy has risen so quickly on the international agenda is its claimed role in relation to the social inequity in health observed in many countries including Denmark (9–12). The pathways are not entirely mapped; however, it is quite indisputable that health literacy is associated with a number of sociodemographic and socioeconomic determinants of health (3,13,14). In a European context several larger studies using the HLS-EU-Q have emerged in the wake of the HLS-EU confirming these tendencies (3,15–21), and the previously described Danish population-based study does the same (8).

The most pronounced associations seem to be between limited health literacy and financial deprivation (3,8,14,16,17,19–22), low educational attainment (3,8,13,14,17–20,22), and low (self-perceived) social status (3,15,17,19,20). The HLS-EU identified several vulnerable groups based on percentage of people with limited health literacy and found this to be 73.9% in people with very low self-perceived social status, 68.0% in people with low education, and 67.1% in people suffering from financial deprivation as compared to 47.6% in the total population. Other frequently reported social health determinants associated with limited health literacy include single living (8,13,14,23), and belonging to ethnic minority groups or being migrant (13–15).

Health literacy may also be associated with gender, although the evidence is less unequivocal and may depend on the health literacy measure in question (3,8,13,14,22). An Australian study based on the HLQ found that health literacy was higher among men than women in some aspects of health literacy (13), while the opposite was true in the HLS-EU using an overall health literacy score based on the HLS-EU-Q47 (3).

Something similar may be the case regarding age. Some studies suggest an association between limited health literacy and high age (3,14,15,19,22,23). However, in studies based on the HLQ, the tendency is less clear (8,13). For example, the earlier mentioned Danish study on national health literacy indicators reports higher mean scores among 65- to 85-year-olds than the 25- to 44-year-olds in HLQ scales 6 and 9 (8).

Almost all studies regarding the association between health literacy and health determinants are cross-sectional. However, both a Danish (24) and two Dutch (25,26) studies confirm health literacy as a possible mediator between educational attainment
and health outcomes, and based on studies mainly from the United States, the role of health literacy in relation to racial/ethnic disparities seems to be relatively well-supported (27,28).

Health literacy and health outcomes

Risk factors and prevalence of long-term illness. A large quantity of literature reports on the association between limited health literacy and risk factors of long-term illness. In the Danish context alone, several studies on general populations as well as in people with long-term conditions suggest a relationship between health literacy and preventive health behaviours such as physical activity (24,29,30), dietary habits (24,29–31), and obesity as a proxy for long-term health behaviour (24,30), while findings on smoking habits (24,29,30) and alcohol consumption (29,30,32) are less clear. The HLS-EU (3) and other large studies (22,33–35) confirm many of the Danish tendencies. Across diagnostic groups, there is also a growing body of evidence suggesting an association between limited health literacy and the prevalence of long-term illness (3,20,36,37) and multimorbidity (13,16,37,38). In a Danish study, Friis et al. (2016) showed an increased prevalence of health literacy challenges among people with different long-term conditions, especially CVD and mental disorders, compared with the general population. The study also found that having more than one long-term condition tended to aggravate the associations (36).

Health, self-care, and quality of life. A large quantity of research is available examining health literacy and global measures of health status. Some address the overall health status (3,22,27,52,53), while others use more comprehensive measures of health-related quality of life (HRQoL) such as the 12-item Short Form Health Survey (SF-12) (30,33,35,54,55). Independent of measure, the referred studies generally find positive associations between health literacy and the outcome in question.

Less clear associations are found in studies on clinical health outcomes (27) although several studies suggest associations between limited health literacy and worse control of long-term illnesses such as diabetes and hypertension (56–63). There does, however, seem to be a fairly consistent association between limited health literacy and increased mortality in general populations above 50 years of age (27,64–68). Other possible associations between limited health literacy and health outcomes include non-adherence to prescribed medication (69,70), lower disease knowledge (61,71–75), lower self-efficacy (56,71,73), and poorer self-care (56,73–76).
**Navigation health systems.** The association between health literacy and use of healthcare services is complex. Evidence emanating mainly from the United States suggests that limited health literacy may be associated with increased use of emergency services (27,39–45), increased frequency and/or length of hospitalizations (27,42–45), and decreased use of preventive services such as screenings (27,46,47), while the frequency of physician visits shows less clear results (40–42). The tendencies are confirmed in European studies (17,48–50). Thus, individuals with limited health literacy tend to use available healthcare services in an inappropriate way. Consequently, it is reasonable to assume that limited health literacy may have a negative impact on healthcare cost. This is confirmed in a recent review by Palumbo (2017) (51). However, since most included studies were carried out in a non-European context generalizability to the Danish setting is questionable.

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**RATIONALE AND METHODOLOGY IN STUDY I**

In study I (chapter 3) (37), we aim to (i) explore the health literacy of people with long-term illness or multimorbidity, and (ii) describe the health literacy strengths and weaknesses of a general Danish population. We hypothesize that in a general Danish population, long-term illness and multimorbidity are associated with specific health literacy challenges (cf. preface).

The study provides details on the diversity of health literacy strengths and weaknesses of a general population, deepening the understanding of health literacy as a complex phenomenon consisting of many capacities (1) that are not equally important when examining associations or developing interventions in different target groups.

Below the study population and methodologies are described and will be further discussed in chapter 9. For details on design and measures, please refer to the publication (cf. chapter 3) (37).

**The data collection and study population**

In total, 490 individuals were included in study I. The data were originally collected as part of the Danish validation study of the HLQ (77) and not for the Heart Skills Study. As described in the original paper, the data were collected through face-to-face interviews carried out by students and health professionals using a standardized protocol. The interviews included the full HLQ and a range of sociodemographic and health-related questions. The majority of participants were recruited in community health centres and in waiting rooms of general practices, although some participants were also
approached in workplaces and public places. No data are available regarding individuals declining participation.

**Design, measures, and methodologies in study I**

*Design.* Study I is a cross-sectional study based solely on interview data.

*Measures.* In this study, we used the full HLQ (cf. chapter 1) to measure health literacy. The HLQ scales constituted the independent variables of the regression analysis (first part of the study aim). For the descriptive analysis (second part of the study aim), participating individuals were grouped by means of cluster analysis based on the HLQ scales (see below). Each cluster represented a unique health literacy profile in the population.

Dependent variables in the regression analysis included (i) the presence of any long-term illness and (ii) the presence of ≥3 illnesses (multimorbidity). Sociodemographic measures (age, gender, mother tongue, cohabitation, and educational attainment) were used to characterize the clusters of the descriptive analysis as was health measures including self-perceived general health status (1 question), self-perceived general well-being (1 question), and presence of long-term illness and multimorbidity.

In this chapter we have described the associations between health literacy and a range of demographic and socio-economic factors. Many of these factors may also be associated with specific long-term illnesses and/or multimorbidity (11,78). Age, gender, mother tongue, cohabitation and educational attainment were therefore included as covariates in the regression analysis.

*Statistical analyses.* For each health literacy scale separately, simple and multiple logistic regression analyses were used to examine the association between health literacy and long-term illness as well as multimorbidity (first part of study aim). The design of the regression analysis is illustrated in figure 2.1.

In the descriptive analysis (second part of the aim), we conducted a hierarchical cluster analysis. This allowed us to identify a range of different health literacy profiles characterized by a unique combination of health literacy strengths and weaknesses within the population and examine their socio-demographic and health characteristics. The cluster analysis is a simple explanatory technique grouping individuals based on predefined variable in such a way that individuals within clusters are more similar than individuals in different clusters (79). We used the nine HLQ scales to define clusters and examined solutions ranging from 2 to 15 clusters. The optimal number of clusters was selected based the variance in and between clusters when comparing different
solutions, and on our judgement regarding the level of detail relevant in relation to the study aim. Further details on the statistical methodology are given in chapter 3.
Figure 2.1. Model of the regression analysis in study I

Independent variables:
- The health literacy questionnaire:
  - Feeling understood and supported by healthcare providers
  - Having sufficient information to manage my health
  - Actively managing my health
  - Social support for health
  - Appraisal of health information
  - Ability to actively engage with healthcare providers
  - Navigating the healthcare system
  - Ability to find good health information
  - Understand health information enough to know what to do

Potential confounders:
- Age
- Gender
- Mother tongue
- Cohabitation
- Educational attainment

Dependent variables:
- Having a long-term illness
- Having ≥3 current illnesses (multimorbidity)
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Chapter 3: Health literacy and long-term illness

Study I: Large diversity in Danish health literacy profiles: perspectives for care of long-term illness and multimorbidity.

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Alison Beauchamp
Jonathan O'Hara
Helle Terkildsen Maindal

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https://academic.oup.com/eurpub/article/30/1/75/5541024
Abstract

Background. Health literacy is an important, modifiable, social determinant of health. This study aims to explore health literacy challenges of people with long-term illness or multimorbidity and provide detailed profiles revealing health literacy strengths and weaknesses within a Danish population.

Methods. In this cross-sectional study among Danish individuals (n= 490), health literacy was assessed using the nine-scale Health Literacy Questionnaire (HLQ). Using multiple logistic regression and hierarchical cluster analysis, we estimated the association between HLQ scale scores and the likelihood of long-term illness and multimorbidity, and identified socio-demographic and health characteristics related to profiles of health literacy strengths and weaknesses.

Results. An increase in ‘actively managing my health’ and ‘social support for health’ decreased the odds of having a long-term illness [odds ratio, OR 0.53 (0.31–0.9); OR 0.43 (0.24–0.74)] and multimorbidity [OR 0.51 (0.26–0.98); OR 0.33 (0.17–0.62)], respectively. Conversely, an increase in ‘healthcare provider support’ increased the odds of having long-term illness [OR 2.97 (1.78–5.08)] and multimorbidity [OR 2.94 (1.53–5.87)], respectively. Five profiles were identified based on the cluster analysis. Each cluster was characterized by specific health characteristics, e.g. Cluster A by better health status ($\chi^2 = 39.976 (4), P< 0.001$) and well-being ($\chi^2 = 28.832 (4), P< 0.001$) and Cluster D by poor health status ($\chi^2 = 39.976 (4), P< 0.001$) and increased likelihood of long-term illness ($\chi^2 = 18.641 (4), P< 0.001$).

Conclusions. The association of health literacy with long-term illness and multimorbidity in combination with the health literacy profiling based on cluster analysis provides a comprehensive needs assessment and a promising starting point for the development of health literacy responsive interventions.
Introduction

Health literacy is the combination of personal competencies and situational resources needed for people to access, understand, appraise and use information and services to make decisions about health. It also includes the capacity to communicate, assert and act upon these decisions (1). The concept of health literacy thus imply a broad spectrum of dynamic individual skills but is operationalized through the individual’s interaction with healthcare systems and services. The demands and complexity placed upon the individual by these systems are therefore critical to the health impact of health literacy individual challenges (2).

‘The Shanghai Declaration on promoting health in the 2030 Agenda for Sustainable Development’ endorsed by World Health Organization (WHO) in 2016 recognizes health literacy as a critical determinant of health and a vital component of effective responses towards inequality in health (3). Health literacy has been on the international research agenda for more than two decades. The prevalence of low health literacy has been found to be as high as one in four depending on context and measurement instrument (4,5). Low health literacy has been associated with social determinants of health such as financial deprivation, low educational level, living alone and non-indigenous ethnicity (4–6) as well as health indicators such as self-assessed health, health behaviour and prevalence and effect of long-term illness and multimorbidity (5–9). Health literacy is an unequally distributed but modifiable determinant of prevention and treatment of major non-communicable diseases including cardiovascular conditions (10) and diabetes (11) making it an inevitable target of health inequality interventions (12,13).

Effective development of such interventions is dependent on detailed knowledge and qualification of the specific health literacy challenges within a target population when compared with other populations (13–17). The Australian Health Literacy Questionnaire (HLQ) was designed to capture both intrinsic and extrinsic dimensions of health literacy - that is, the ability of an individual to understand, engage with, and use health information and health services and the perceived ability of organizations to promote such activity. The questionnaire provides a comprehensive profile of a population’s health literacy strengths and challenges allowing in depth analysis and tailored intervention development (18–20).

This study aims to explore health literacy challenges of people with long-term illness or multimorbidity and provide detailed profiles of health literacy strengths and weaknesses within a general Danish population usable for comparison with other Danish or non-Danish populations.
Methods

Data collection

Data collection for this cross-sectional study was undertaken as part of the Danish adaption and validation of the HLQ and is described in detail elsewhere (21). The HLQ normally takes at least 20 min to administer face-to-face, but the interviews were longer (>30 min) since they also included socio-economic measures. In brief, health professionals and students collected data in face-to-face interviews using a standardized protocol. Data collection took place in a variety of settings including community health centres, general practices, work places and public fora by means of convenience sampling. As all Danes are affiliated to a primary care physician free of charge, and can be referred to e.g. rehabilitation, people in primary care waiting rooms represent a broad population. However, no data were collected regarding refusal rate or characteristics of non-participants.

Measures

Health literacy. Health literacy was measured using a Danish version of the original Australian HLQ. The HLQ was designed using a grounded, validity-driven approach and has shown strong construct validity, reliability and acceptability (18,22). The translation was validated using forward–backward translation, consensus conference and cognitive interviews (21). The questionnaire contains 44 questions covering the following nine distinct aspects of health literacy each represented by a scale:

1. Feeling understood and supported by healthcare providers;
2. Having sufficient information to manage my health;
3. Actively managing my health;
4. Social support for health;
5. Appraisal of health information;
6. Ability to actively engage with healthcare providers;
7. Navigating the healthcare system;
8. Ability to find good health information;
9. Understand health information well enough to know what to do.

Response options in scales 1–5 are on a four-point ordinal scale and include ‘strongly disagree’ (1), ‘disagree’ (2), ‘agree’ (3) and ‘strongly agree’ (4), while response options in scales 6–9 are on a five-point ordinal scale and include ‘cannot do’ (1), ‘very difficult’ (2), ‘quite difficult’ (3), ‘quite easy’ (4) and ‘very easy’ (5). For each scale, mean [standard deviation (SD)] score across the 4–6 included questions is calculated to
represent the scale score (range 1–4 in scales 1 through 5 and 1–5 in scales 6 through 9).

Socio-demographic measures. As part of each interview, data on the participant’s age, gender, educational level, cohabitation and mother tongue were collected. Educational level was categorized as ‘still in school’, ‘7 or fewer years of school’, ‘8–9 years of school’, ‘10–11 years of school’, ‘high school diploma’ and ‘other’. For analyses, any level below ‘10–11 years of school’ was considered ‘low education’. Cohabitation was dichotomized as ‘lives alone’ or ‘living with someone’ the latter being either spouse/common-law partner, parents, children below 16 years, youths 16–20 years, or other adults. Mother tongue was defined as the primary language spoken/learned during childhood and was dichotomized into the categories ‘Danish’ and ‘Non-Danish’.

Health measures. Participants were asked to evaluate their general health status according to the general health domain (GH) of the SF Health Surveys (23). Answers were categorized accordingly as ‘excellent’, ‘very good’, ‘good’, ‘less good’ and ‘poor’. For analyses, the categories ‘less good’ and ‘poor’ were considered low health status. Likewise, participants reported general well-being (‘How would you characterize your general well-being and quality of life?’) as ‘really good’, ‘good’, ‘fair’, ‘poor’ and ‘very poor’, and in the analyses we considered ‘poor’ and ‘very poor’ as poor well-being.

The presence of any long-term illness or disability (more than 6 month’s duration) as well as presence of a range of specific diseases were reported (17 disease categories). Prior to analyses, these data were used to define two health challenged subgroups comprising people reporting at least one long-term illness lasting >6 months (termed ‘long-term illness’), and people reporting three or more current illnesses (termed ‘multimorbidity’). Both subgroups are of high interest from a societal and health system perspective due to their relatively higher health care consumption and worse health outcomes compared with healthy individuals.

Statistical analysis

Hierarchical cluster analysis was conducted based on all nine HLQ scale scores using Square Euclidian Distance as the distance measure and Ward’s linkage as the clustering method (24). This explanatory technique was used to describe patterns of health literacy in the population. The optimal number of clusters was determined by considering the variance of HLQ patterns and dismissing cluster solutions with very small cluster sizes as described by Batterham et al (19). The method has been chosen because it is included in the well-validated Ophelia intervention development approach.
currently being tested in multiple European settings, including an ongoing health literacy initiative in Denmark (19,25).

Since the HLQ scales use two different response ranges (1–4 and 1–5), all scores were converted to z-scores prior to clustering. Unadjusted and adjusted multiple logistic regression methods were used to estimate the association between the health literacy scales and outcome variables. Adjusted regressions included age, gender, cohabitation, Danish mother tongue and education. All regression analysis results were presented with 95% confidence interval. Significance level was set at P<0.05. All statistical procedures were conducted using the R language and environment for statistical computing.

**Ethics and approvals**

The study was approved by the Danish Data Protection Agency (j.no: 2016-051-000001(1321)). According to Danish law, when survey-based studies are undertaken in accordance with the Helsinki Declaration, specific approval by an ethics committee and written informed consent is not required. Potential respondents were provided with information about the survey and its purpose, including that participation was voluntary. The completion of the survey by participants was considered implied consent.

**Results**

A total of 490 individuals provided data for this study. Table 3.1 describes the socio-demographic and health related characteristics of the total sample as well as by clusters and subgroups.

The population had a mean age of 50.5 years (SD 17.3), the majority were females (60%) and few (7%) had another language than Danish as their mother tongue. One in five (19%) lived alone and the same proportion (19%) had low education. Reflecting the recruitment at health facilities, 45% of the sample reported low health status and 41% and 19% reported long-term illness and multimorbidity, respectively.

In this sample, five clusters were selected as the optimal cluster solution for the sample, based on cluster size and health literacy pattern diversity. Cluster analysis revealed a pattern of high (Cluster A) through to low (Cluster E) overall health literacy based on overall mean of the nine HLQ scale scores. Nineteen respondents had one or more missing HLQ scores due to incomplete questionnaire data and were excluded from the clustering procedure.
The likelihood of having low education increased from Cluster A (representing highest overall health literacy) through Cluster E (representing lowest overall health literacy) ($\chi^2 = 4.08$ (4), $P = 0.395$). Cluster A was characterized by a significantly larger proportion reporting good health status ($\chi^2 = 39.976$ (4), $P < 0.001$) and well-being ($\chi^2 = 28.832$ (4), $P < 0.001$) than other clusters. Cluster B and C was characterized by a significantly higher number without a long-term condition ($\chi^2 = 18.641$ (4), $P < 0.001$) and Cluster D had a higher percentage of people with poor health ($\chi^2 = 39.976$ (4), $P < 0.001$) and long-term conditions ($\chi^2 = 18.641$ (4), $P < 0.001$). Cluster E was too small to produce significant differences but was generally characterized by poor health indicators.

Besides the expected high prevalence of poor health indicators, individuals in the two subgroups were on average older, more often lived alone and more often had low education than the total population.
Figure 3.1. Participant characteristics in total population, clusters and subpopulations

<table>
<thead>
<tr>
<th></th>
<th>All</th>
<th>Cluster A</th>
<th>Cluster B</th>
<th>Cluster C</th>
<th>Cluster D</th>
<th>Cluster E</th>
<th>Longterm illness</th>
<th>Multi-morbidity</th>
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</thead>
<tbody>
<tr>
<td></td>
<td>(N = 490)</td>
<td>(N = 91)</td>
<td>(N = 34)</td>
<td>(N = 193)</td>
<td>(N = 131)</td>
<td>(N = 22)</td>
<td>(N = 199)</td>
<td>(N = 91)</td>
</tr>
<tr>
<td>Socio-demographic factors</td>
<td></td>
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</tr>
<tr>
<td>Mean age (SD)</td>
<td>50.50 (17.34)</td>
<td>48.36 (15.05)</td>
<td>49.88 (18.55)</td>
<td>50.47 (17.99)</td>
<td>50.13 (16.78)</td>
<td>52.77 (17.93)</td>
<td>57.39 (15.12)</td>
<td>60.00 (12.98)</td>
</tr>
<tr>
<td>Old age (≥ 60 years), N (%)</td>
<td>151 (31)</td>
<td>23 (25)</td>
<td>10 (29)</td>
<td>64 (33)</td>
<td>38 (29)</td>
<td>8 (36)</td>
<td>90 (45)</td>
<td>45 (49)</td>
</tr>
<tr>
<td>Female gender, N (%)</td>
<td>293 (60)</td>
<td>53 (58)</td>
<td>23 (68)</td>
<td>108 (56)</td>
<td>86 (66)</td>
<td>8 (36)</td>
<td>131 (66)</td>
<td>62 (69)</td>
</tr>
<tr>
<td>Lives alone, N (%)</td>
<td>93 (19)</td>
<td>17 (19)</td>
<td>8 (24)</td>
<td>31 (16)</td>
<td>29 (22)</td>
<td>2 (9)</td>
<td>45 (23)</td>
<td>24 (26)</td>
</tr>
<tr>
<td>Non-Danish mother tongue, N (%)</td>
<td>36 (7)</td>
<td>6 (7)</td>
<td>5 (15)</td>
<td>11 (6)</td>
<td>11 (8)</td>
<td>0 (0)</td>
<td>12 (6)</td>
<td>5 (5)</td>
</tr>
<tr>
<td>Low education, N (%)</td>
<td>95 (19)</td>
<td>12 (13)</td>
<td>5 (15)</td>
<td>39 (20)</td>
<td>28 (21)</td>
<td>6 (27)</td>
<td>48 (24)</td>
<td>25 (27)</td>
</tr>
<tr>
<td>Health related factors</td>
<td></td>
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</tr>
<tr>
<td>Low health status (score 4 or 5), N (%)</td>
<td>222 (45)</td>
<td>29 (32)</td>
<td>10 (29)</td>
<td>72 (37)</td>
<td>86 (66)</td>
<td>14 (64)</td>
<td>143 (72)</td>
<td>78 (86)</td>
</tr>
<tr>
<td>Poor well-being (scoring 4 or 5), N (%)</td>
<td>95 (19)</td>
<td>7 (8)</td>
<td>4 (12)</td>
<td>28 (15)</td>
<td>43 (33)</td>
<td>6 (27)</td>
<td>70 (35)</td>
<td>45 (49)</td>
</tr>
<tr>
<td>Longterm illness, N (%)</td>
<td>199 (41)</td>
<td>38 (42)</td>
<td>8 (24)</td>
<td>62 (32)</td>
<td>69 (53)</td>
<td>11 (50)</td>
<td>199 (100)</td>
<td>76 (84)</td>
</tr>
<tr>
<td>Multimorbidity (3 or more), N (%)</td>
<td>91 (19)</td>
<td>14 (15)</td>
<td>4 (12)</td>
<td>32 (17)</td>
<td>34 (26)</td>
<td>4 (18)</td>
<td>76 (38)</td>
<td>91 (100)</td>
</tr>
</tbody>
</table>

(SD) standard deviation
Table 3.2 shows the result of a regression analyses, representing the associations between each HLQ scales and the subgroups.

In regression analyses adjusted for age, gender, cohabitation, ethnicity, and education, we found that a one-unit increase in mean scale score of ‘healthcare provider support’ (Scale 1) increased the odds of having a long-term illness [odds ratio, OR 2.97 (1.78–5.08)]. Conversely, a one-unit increase in Scale 3 ‘actively managing my health’ and Scale 4 ‘social support for health’ decreased the odds [OR 0.53 (0.31–0.9) and OR 0.43 (0.24–0.74), respectively] of having a long-term illness in both unadjusted and adjusted analyses.

Significant associations between multimorbidity and the same three HLQ scales (Scale 1, 3 and 4) were also seen in adjusted analyses [OR 2.94 (1.53–5.87), OR 0.51 (0.26–0.98) and OR 0.33 (0.17–0.62), respectively].

In unadjusted analysis ‘having sufficient health information’ (Scale 2) was significantly associated with both groups [OR 0.51 (0.36–0.72) and OR 0.55 (0.36–0.84)], while the result retained its directionality but failed to reach significance in adjusted analysis.

Table 3.3 shows the mean scale score and SD for each of the nine HLQ subscales upon which the cluster analysis is based. Results are given for the total population as well as for each cluster separately.

In all HLQ subscales, Cluster A scored well above the total population. The same was true of mean HLQ scale scores in Cluster B. However, for social and health care provider support as well as appraisal of health information and active management of health, mean scores dropped compared with Cluster A. Cluster C mean HLQ scale scores were very similar to those of the total population. Cluster D mean HLQ scale scores were lower than total population means and especially low with regard to social support, ability to engage with health care providers and ability to navigate the health system. The small Cluster E had very low mean HLQ scores in all scales.
### Figure 3.2. Associations between populations and HLQ scales

<table>
<thead>
<tr>
<th></th>
<th>Long-term illness [n = 199 (41%)]</th>
<th>Multimorbidity [n = 91 (19%)]</th>
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<tbody>
<tr>
<td></td>
<td>Unadjusted OR 95% CI Adj. OR 95% CI</td>
<td>Unadjusted OR 95% CI Adj. OR 95% CI</td>
</tr>
<tr>
<td>1. Healthcare provider support</td>
<td>1.29 0.95–1.76 2.97* 1.78–5.08 1.21 0.82–1.79 2.94* 1.53–5.87</td>
<td></td>
</tr>
<tr>
<td>2. Having sufficient health info.</td>
<td>0.51* 0.36–0.72 0.57 0.32–1.02 0.55* 0.36–0.84 0.59 0.29–1.19</td>
<td></td>
</tr>
<tr>
<td>3. Actively managing my health</td>
<td>0.60* 0.43–0.84 0.53* 0.31–0.90 0.61* 0.40–0.93 0.51* 0.26–0.98</td>
<td></td>
</tr>
<tr>
<td>4. Social support for health</td>
<td>0.46* 0.31–0.66 0.43* 0.24–0.74 0.39* 0.25–0.61 0.33* 0.17–0.62</td>
<td></td>
</tr>
<tr>
<td>5. Appraisal of health info.</td>
<td>0.65* 0.46–0.90 1.11 0.65–1.89 0.70 0.46–1.06 1.52 0.78–3.01</td>
<td></td>
</tr>
<tr>
<td>6. Ability to actively engage</td>
<td>0.97 0.71–1.33 0.90 0.51–1.59 1.06 0.72–1.59 1.42 0.71–2.88</td>
<td></td>
</tr>
<tr>
<td>7. Navigating the healthcare sys.</td>
<td>0.75 0.55–1.01 0.79 0.42–1.47 0.79 0.54–1.15 0.76 0.35–1.64</td>
<td></td>
</tr>
<tr>
<td>8. Ability to find good info.</td>
<td>0.72* 0.53–0.97 1.02 0.53–1.95 0.73 0.51–1.05 1.00 0.46–2.21</td>
<td></td>
</tr>
<tr>
<td>9. Understanding health info.</td>
<td>0.84 0.61–1.17 1.49 0.75–2.99 0.80 0.53–1.20 1.09 0.47–2.50</td>
<td></td>
</tr>
</tbody>
</table>

All analyses are adjusted for age, gender, cohabitation, mother tongue, and education.
*Ps<0.05. CI, confidence interval; HLQ, Health Literacy Questionnaire; OR, odds ratio.
Table 3. Mean HLQ scale scores of the total population and clusters

<table>
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<tbody>
<tr>
<td></td>
<td>N</td>
<td>Mean (SD)</td>
<td>Mean (SD)</td>
<td>Mean (SD)</td>
<td>Mean (SD)</td>
<td>Mean (SD)</td>
<td>Mean (SD)</td>
<td>Mean (SD)</td>
<td>Mean (SD)</td>
</tr>
<tr>
<td>All</td>
<td>481</td>
<td>3.00 (0.60)</td>
<td>3.06 (0.55)</td>
<td>2.83 (0.55)</td>
<td>3.14 (0.52)</td>
<td>2.75 (0.56)</td>
<td>3.99 (0.59)</td>
<td>3.69 (0.61)</td>
<td>3.99 (0.61)</td>
</tr>
<tr>
<td>Cluster A</td>
<td>91</td>
<td>3.77 (0.27)</td>
<td>3.58 (0.39)</td>
<td>3.38 (0.47)</td>
<td>3.62 (0.34)</td>
<td>3.35 (0.42)</td>
<td>4.52 (0.38)</td>
<td>4.23 (0.45)</td>
<td>4.5 (0.38)</td>
</tr>
<tr>
<td>Cluster B</td>
<td>34</td>
<td>2.81 (0.45)</td>
<td>3.57 (0.39)</td>
<td>3.04 (0.39)</td>
<td>3.12 (0.54)</td>
<td>2.99 (0.42)</td>
<td>4.39 (0.33)</td>
<td>4.43 (0.25)</td>
<td>4.68 (0.25)</td>
</tr>
<tr>
<td>Cluster C</td>
<td>193</td>
<td>2.94 (0.43)</td>
<td>3.08 (0.29)</td>
<td>2.82 (0.42)</td>
<td>3.21 (0.36)</td>
<td>2.67 (0.45)</td>
<td>4.07 (0.32)</td>
<td>3.77 (0.31)</td>
<td>4 (0.33)</td>
</tr>
<tr>
<td>Cluster D</td>
<td>131</td>
<td>2.69 (0.51)</td>
<td>2.68 (0.44)</td>
<td>2.57 (0.44)</td>
<td>2.79 (0.48)</td>
<td>2.54 (0.38)</td>
<td>3.51 (0.52)</td>
<td>3.19 (0.44)</td>
<td>3.66 (0.46)</td>
</tr>
<tr>
<td>Cluster E</td>
<td>22</td>
<td>2.38 (0.61)</td>
<td>2.11 (0.6)</td>
<td>1.95 (0.52)</td>
<td>2.61 (0.59)</td>
<td>1.76 (0.29)</td>
<td>3.25 (0.94)</td>
<td>2.54 (0.34)</td>
<td>2.51 (0.64)</td>
</tr>
</tbody>
</table>

(SD) Standard deviation
Health literacy scores are color coded from highest (light gray) to lowest (dark gray)
Discussion

In this study, we have provided evidence that long-term illness and multimorbidity is associated with specific health literacy challenges including lack of active self-management, and social support for health independent of age, gender, cohabitation, ethnicity and education. Further, we have provided a comprehensive profile showing health literacy strengths and weaknesses of a Danish population.

**Strengths and weaknesses**

To our knowledge, this is the first study to provide a comprehensive health literacy profile based on the HLQ of a Danish population and the first HLQ profile to compare the health literacy of a general population (i.e. not grouped based on health status) with those of people with long-term illness and multimorbidity. Our analyses allowed us to confirm the vulnerability of these subgroups and further characterize their specific health literacy assets and challenges.

Obviously, low health literacy decreases the respondents’ abilities to provide the data required in a questionnaire. Also, awareness of personal challenges may increase the likelihood to decline participation. The issue has been minimized by the supported data collection with face-to-face invitation and interview but may have led to an underestimation of the health literacy challenges in the population. The strength of our results has been affected by the relative low sample size resulting in small clusters and groupings, most prominently in Cluster E (n= 22). Also, since health literacy is a dynamic capacity affected by personal, environmental and health-related factors, knowledge about causal pathways and the experienced nature of the specific challenges are important information not obtained in this cross-sectional study.

Confirmatory studies using the same approach on larger populations in other similar contexts, as well as longitudinal or qualitative research prior to or as part of specific intervention development is warranted.

**Interpretations**

The association between poor health and low health literacy has been shown in multiple studies (5,7,26–28). Our regression analyses confirms these findings, and provides additional information as to what aspects of health literacy may be most severely challenged.

In our cluster analysis, we also found a strong tendency towards poor health indicators in clusters with poor health literacy profiles (Cluster D and E). This is concerning since people with poor health have relatively greater need of health literacy competencies. In
Cluster D, for instance, we found a lack of ability to engage with health care providers putting great emphasis on the provider’s initiative and support.

Both clusters also exhibit a high proportion with low education, and Cluster E is characterized by a high proportion aged above 60 years and a high proportion of men. These are all factors previously associated with low health literacy (4,5,26,29) and may indicate a need for less complex information and more individualized services in these groups.

Clusters with above average health indicators (Cluster A and B) exhibited high mean scores in all nine HLQ scales. However, in spite of having the most advantageous health literacy profile especially regarding social and healthcare provider support for health (HLQ scale 4 and 1) and the ability to manage health (HLQ scale 3), persons in Cluster A more often had poor health indicators than persons in Cluster B. Further studies should examine if these findings are dependent of disease length and severity and represents a window for effective health literacy interventions in the earlier or milder phases of certain diseases. Some indication of the latter was found in our regression analysis, where a strong sense of support from health care providers (HLQ scale 1) was associated with major health challenges such as long-term illness and multimorbidity. In these groups, however, the benefit of such support was not reflected in the experienced level of information and knowledge (HLQ scale 2) and the individual health management (HLQ scale 3). These findings are consistent with other studies that have found general associations between health literacy and multimorbidity as well as long-term illness (5,8,30). In these studies, knowledge and self-management is not directly included as a health literacy competence, but several studies have linked functional health literacy, health knowledge and self-management skills with health outcomes (16,31–33).

Considering the older mean age and increased prevalence of single living among the subgroups with long-term illness and multimorbidity, the negative association with social support (HLQ scale 4) in our study is not surprising. It does, however, have implications for the development of health literacy sensitive interventions and services in these groups, since the importance of distributed health literacy to mitigate the consequences of low health literacy is well-established (34,35). Based on that, we would recommend systematic involvement of relatives or substitutes such as professional or voluntary companions in initiatives targeting similar populations.

**Generalizability**

Any differences between our study population and the general Danish population may affect external validity. As a possible consequence of the convenience sampling, e.g. in
health facilities, and the possible differences in likelihood of participation between specific groups, our study population is characterized by a higher prevalence of females, elderly people, people who live with someone and people with poor health indicators, but with a comparable educational level to the general Danish population (table 3.1) (36,37). No statistics are available regarding the mother tongue of the general Danish population; however, approximately 14% are immigrants or descendants of immigrants (37). Any comparison of our results with similar studies in other countries with comparable health systems and socioeconomic status, should consider these differences. HLQ based surveys in populations with specific health characteristics generally support the validity of our associative results (38,39), and confirm some of the socio-demographic characteristics we found among people with health literacy challenges (6,38,39).
REFERENCES


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25. WHO European Action Network on Health Literacy for Prevention and Control of NCDs


Chapter 4: Health literacy in people with cardiac conditions
CARDIOVASCULAR DISEASE AND PREVENTION IN DENMARK AND BEYOND

Being a leading cause of morbidity and mortality at a global level, CVD constitutes one of the biggest health threats of our time (1). Although age-adjusted cardiovascular mortality rate is declining (2), the ageing populations in many European countries along with the rising prevalence of associated conditions such as obesity (3) and diabetes (4) are adding substantially to the disease burden. In Denmark approximately 450,000 people live with a cardiac condition corresponding to just above 8% of the total population (5), and CVD is the second leading cause of death after cancer (6).

Preventive actions in the form of cardiovascular risk reduction has great potential in reducing CVD prevalence (7,8), and after disease onset, CR programmes focusing on improving health behaviours and disease awareness have proven effective in reducing healthcare service use and improving quality of life (9). However, participation and adherence to rehabilitation is a big challenge in many countries at both individual and population levels (10,11).

As a major health condition, CVDs play an extensive role in the unequal distribution of health and well-being evident in many countries including Denmark (12,13). Studies have found associations between low educational attainment and the prevalence of cardiovascular risk factors (14) as well as several cardiovascular diagnoses (15), and the evidence of a socio-economic gradient in the uptake of cardio-protective behaviours including CR attendance is quite unequivocal (13,16–18). It is in the light of these associations that the Heart Skills Study is based mainly on people with cardiac disease (studies II-IV), particularly in the context of CR (studies III-IV).

Care of cardiovascular diseases in Denmark

All residents in Denmark have access to the public healthcare system, and most services are provided free of charge (19). Care of people with cardiac disease is guided by regional programmes describing the overall multidisciplinary and cross-sectoral efforts in hospitals, municipalities, and general practices (20). People presenting with symptoms of cardiac disease can, depending on the circumstances, be either hospitalized for specialized treatment acutely using the emergency services or be referred to outpatient care from the general practitioner assigned to each citizen (19).

After disease onset and in relation to CR, the regional programmes refer to three phases:
- Phase I, in-hospital rehabilitation in the early stages after acute disease onset or planned surgical treatment. Specialized cardiologists manage the pharmacological treatment.
- Phase II, early post discharge programmes delivered as outpatient services at hospitals or in municipal units. Specialized cardiologists often manage the pharmacological treatment.
- Phase III, long-term maintenance programmes of less-intense supervision. Pharmacological treatment is in most cases managed by general practitioners.

Phase I ends with the patients discharge from a hospital. In most cases, the patient is by then ready to commence physical training and should be referred to phase II rehabilitation. Phase II rehabilitation generally offers supervised exercise-training, patient education, and, when relevant, smoking cessation support or dietary, sexual, or energy management counselling. Most phase II programmes are of approximately 12 weeks’ duration. In phase III, most patients are expected to manage their condition and health behaviours on their own supported by their general practitioner and in some instances also in less supervised municipal programmes (20).

HEALTH LITERACY IN PEOPLE WITH CARDIOVASCULAR DISEASE

The literature on health literacy in relation to CVD is very diverse and should consequently be assessed and compared with appropriate caution. The term CVD covers a broad range of different diagnoses. In the studies referred in this chapter, the most frequent diagnoses examined are chronic heart failure and hypertension. The health literacy tools used in these studies are very diverse and most often examine only functional health literacy. By far, the most frequently used tools (cf. table 1.1, chapter 1) is the shortened version of TOFHLA followed by SBSQ developed by Chew et al. and REALM, while only very few studies use health literacy measures based on broader health literacy definitions, such as the HLS-EU-Q or the HLQ. Attempts to analyze each diagnostic group or methodology separately are outside the scope of this thesis.

The available evidence suggests that certain ethnicities and minority group affiliations (21–24), single living (22), low educational attainment (21–23,25), unemployment (22,23), and the presence of comorbidities (23,26) are all predictors of limited health literacy in CVD populations. The literature also reports that high age is associated with limited health literacy (21–23,25), but a review concerning people with heart failure by Cajita et al. (2016) finds, that this association may in reality be a consequence of diminishing cognitive function rather than age in itself (21). As is the case in other
Health literacy in people with cardiac conditions

populations (cf. chapter 2), the evidence on the association between gender and health literacy is inconclusive in people with different cardiac conditions (22,23,25,27).

Looking at health outcomes, studies in people with CVD suggest associations between limited health literacy and many diverse health outcomes. Low HRQoL seems to be closely associated with limited health literacy (28–35), although some studies report insignificant results (32,34,35). Differences in populations and health literacy measures could account for some of this diversity. Evidence on the associations of limited health literacy with health behaviours is scarce but confirms the findings in other population (cf. chapter 2) regarding overall health behaviour (36,37) and physical activity (32,38). Many other studies in CVD populations indicate positive association between health literacy and inadequate medication adherence (39), poor blood pressure control (i.e. disease control) (40,41), inappropriate service use (30,42–48), and high mortality (37,43,46–50), although the evidence in relation to some of these outcomes is inconclusive (36,49,51,52).

Since the vast majority of the referred studies are cross-sectional in design, there is little evidence regarding the directionalities of the associations. However, many studies, most of which are based on populations diagnosed with heart failure, confirm the positive associations between health literacy and a number of possible intermediary outcomes or modifiers such as disease specific knowledge (21,52–54), self-efficacy (33,34), self-care (32,33,54–57), as well as participation and decision-making (58–61). Unfortunately, only few studies report on the mediating effects, and the results are contradictory (32,33,37).

All in all, across the available literature on health literacy in people with CVD, there seems to be evidence of some of the same associations that have been identified in other diagnostic groups and general populations (cf. chapter 2), but the measures used are generally narrow, and in the case of health behaviour, evidence is still very limited and often does not report on specific health behaviours.

RATIONALITY AND METHODOLOGY IN STUDY II

In study II (chapter 5) (62,63), we examine the associations between health literacy and self-reported HRQoL (termed ‘health status’ in the study) as well as the association between health literacy and health behaviours (i.e. physical activity, dietary habits, smoking habits, alcohol intake, and Body Mass Index) in a large population of individuals with self-reported CVD.
We do this under the hypothesis that limited health literacy is associated with adverse health behaviours and poor HRQoL (cf. preface).

The study adds to the evidence on health literacy in CVD populations and thus supports our rationale to further study and develop health literacy responsiveness in cardiac health care in the Heart Skills Study. Below the study population and methodologies are described and will be further discussed in chapter 9. For details on design and measures, please refer to the publication (cf. chapter 5) (62).

The “How Are You?” Survey and study population

Study II is based on data from the ‘How Are You?’ Survey (HAYS) in 2013. HAYS is a regional health survey carried out in Central Denmark Region to describe status and trends in health and morbidity in the population. The survey was conducted in 2006, 2010, 2013, and 2017. For the 2013 survey, approximately 54,000 individuals above the age of 16 and living in Central Denmark Region were invited to participate (64). The sample was drawn randomly from the Danish Civil Registration System covering each of the 19 municipalities in the region. Two separate questionnaires were used. One for individuals between the age of 16 and 24 and one for individuals aged 25 and above. In study II, we only considered data from respondents aged 25 or above (65).

In the 2013 HAYS, the sample was invited by postal letter and provided a link for online responses as well as a paper questionnaire. Reminders to non-responders were distributed three times.

Response rate in the total survey was 61%, but lower in the youngest and oldest age groups and among people with a non-Danish background. Gender also affected the response rate. In the younger age groups, it was highest among females, while the opposite was true in the older age groups (65).

In the 2013 HAYS, a weight based on register data on respondents as well as non-respondents was used in statistical analyses to adjust for the differences in response rate based on age, gender, and some socio-economic variables as well as selection probability in each municipality (65). The construction of the weight was done by the central authority on Danish statistics (Statistics Denmark) and was delivered with the dataset in study II.

The survey included a large battery of questions regarding socioeconomic conditions, health behaviours, morbidity, and HRQoL. Whenever possible the questions were based on validated and tested tools. Respondents reported on current or previous diagnosis of 18 long-term conditions. In study II, we defined our population of 3,116
individuals from the total survey population as respondents reporting current or former diagnosis of acute myocardial infarction, angina pectoris, or stroke. Individuals reporting previous diagnoses were included as CVD is considered a chronic condition based on the fact that any cardiovascular event in the past places the individual at an increased lifetime risk of recurrence.

**Design, measures, and methodologies in study II**

**Design.** In study II, we used a cross-sectional design based on the simultaneous reporting of independent and dependent variables in the HAYS in 2013.

**Measures.** The independent variable, health literacy, was measured using two scales from the HLQ, namely scale 6 ‘Ability to actively engage with healthcare providers’ and scale 9 ‘Understanding health information well enough to know what to do’.

Dependent variables included five different health behaviours and HRQoL. The health behaviours were physical activity, dietary habits, smoking habits, alcohol consumption, and, as a proxy for long-term health behaviour, Body Mass Index. All measures of health behaviour were categorized based on official national recommendations or measurement standards (cf. chapter 5).

HRQoL was measured using the 12-item Short Form Health Survey version 2 (four-week recall) (SF-12), which is a validated shortened version of the 36-Item Short Form Health Survey (SF-36) (66). SF-12 measures eight health concepts, namely physical functioning, role limitations due to physical problems, bodily pain, general health, vitality, social functioning, role limitations due to emotional problems and mental health. Of these, the first four are included in the calculation of a physical component summary score (PCS) and the last four in a mental component summary score (MCS). The PCS and MCS range from 0 to 100 with high scores indicating good HRQoL. The data are transformed to norm-based scoring matching a mean of 50 and a standard deviation of 10 in the general population of the United States (67).

The associations between health literacy and a range of demographic and socio-economic factors are described in chapter 2. Many of these factors are also likely to be associated with HRQoL and health behaviours. For example, the Whitehall study II (1985-88) has shown an association between socio-economic status measured by grade of employment and health behaviour as well as self-rated health (68). We therefore included age, gender, ethnicity, cohabitation, and educational attainment as potential confounders in the analyses.
Statistical analyses. A model of the statistical analysis of the study is outlined in figure 4.1. For each health literacy scale separately, logistic and linear regression analyses were used to examine the associations (cf. chapter 5 for details).
Figure 4.1. Model of the statistical analyses in study II

Independent variables:
- Health literacy:
  - Ability to engage actively with healthcare providers
  - Understanding health information well enough to know what to do

Potential confounders:
- Age
- Gender
- Ethnicity
- Cohabitation
- Educational attainment

Dependent variables:
- HRQoL:
  - Physical component summary score (PCS)
  - Mental component summary score (MCS)
- Health behaviours:
  - Physical activity
  - Dietary habits
  - Smoking habits
  - Alcohol consumption
  - Body mass index (BMI)
HEALTH LITERACY AND CARDIAC REHABILITATION

Very little evidence is available regarding health literacy in connection with CR. In a qualitative study, McKenna et al. (2018) find, that CR has the potential to develop participant’s functional, interactive, and critical health literacy independent of initial health literacy level (69). This potential is supported in two small studies on telerehabilitation (70,71).

In relation to CR attendance, Dankner et al. (2015) have identified lack of knowledge as a crucial determinant and also shown that a simple intervention informing eligible patients of the purpose and benefits of CR can increase participation significantly (72).

Several studies also examine associations between health literacy and intermediary outcomes of CR. Health literacy may affect adherence to the health behaviour change that CR programmes aim to bring about (36), but Mattson et al. (2015) also found that health literacy is associated with the knowledge gain obtained from CR programmes (73) and Lynggaard et al. (2017) have shown that an intervention characterized by individual interviews, peer co-educators, and situational, reflective, and inductive teaching (i.e. an intervention likely to be more health literacy sensitive than traditional structured deductive teaching) was successful in increasing CR adherence (74).

In summary, the available literature suggests that health literacy may play a role in relation in CR participation and intermediary outcomes, but the evidence is still insufficient to conclude whether these associations substantially affect long-term health outcomes of CR such as health behaviour, disease severity, or quality of life.

RATIONALE AND METHODOLOGY IN STUDY III

In study III (cf. chapter 6) (75), we examine the associations between health literacy and participation in CR as well as HRQoL in a population of people referred to a municipal CR programme. Our hypothesis was, that limited health literacy within this context is associated with low participation and poor HRQoL.

The study is based on the full HLQ and thus provides detailed information on the aspects of health literacy related to participation and HRQoL in people referred to CR. Since the study is carried out in the same setting as our intervention development (cf. chapters 7 and 8), it represents part of the local data collection directly informing this process.
Below the study methodologies are described and will be further discussed in chapter 9. For details on design and measures, please refer to the publication (cf. chapter 6) (75).

The Heart Skills survey and study population

We collected data for study III through the Heart Skills Survey. The survey was carried out in Randers Municipal Rehabilitation Unit which provides free-of-charge CR programmes to: (i) Citizens with CVD excluding only individuals with unstable conditions such as acute ischaemic disease, unstable angina pectoris, or heart failure NYHA class IV, the majority being referred in connection to discharge from one of the local hospitals; and (ii) citizens in severe risk of developing a CVD based on adverse risk factors. These are often referred from a local general practitioner.

Individuals referred to CR in the unit in the year of 2017 (N = 222) were eligible to the Heart Skills Survey. Apart from three individuals that were completely unable to respond due to mental or physical weaknesses, all were invited. In all, 178 individuals responded to the survey, corresponding to a response rate of 80.2%.

Data collection began 7 March 2017, and from that date the vast majority of the respondents were invited within 3 days from referral in connection with the mandatory telephone call from the unit inviting that particular individual to attend a start-up session in the unit and learn more about the CR programme. In May 2017, it was decided to also invite individuals referred to the unit between 1 January 2017 and 6 March 2017. However, for study III, we excluded these individuals (n = 29) since they were contacted with a lag-time of 2-4 months. Thus, depending on their CR participation, their response was likely to be affected by the (lack of) impact from the CR programme.

If at invitation oral consent was given, the Heart Skills Survey was then distributed by means of e-mail, postal letter, or as a telephone or face-to-face interview depending on the participant’s preferences and support needs. We did a thorough follow-up on non-responders to ensure as high a response rate as possible and to minimize the time interval from invitation to response.

The survey content is described in detail in study III (cf. chapter 6), and the questionnaire is included in Danish in appendix II. The questionnaire was cognitively tested by four active or former CR programme attendants before the Heart Skills Survey was launched. This test led to minor linguistic changes.
Design, measures and methodologies in study III

*Design.* Study III is a cross-sectional study based on Heart Skills Survey and register data.

*Measures.* In this study we used the full HLQ (cf. chapter 1) to measure the independent variable, health literacy.

Dependent variables included sociodemographic variables (age, gender, cohabitation and educational attainment), CR participation based on self-report and HRQoL measured using the SF-12 which was described in relation to study II (cf. the section ‘Design, measures, and methodologies in study II’ above).

As in studies I and II, we included age, gender, ethnicity, cohabitation and educational attainment as potential confounders in the analyses. We also added comorbidity as a potential confounder since limited health literacy is associated with multimorbidity (76,77), which may also affect quality of life (78,79) and ability to attend CR (80,81).

*Statistical analyses.* A model of the statistical analysis of the study is outlined in figure 4.2. Logistic and linear regression analyses were used to examine the associations for each HLQ scale separately (cf. chapter 6 for details).
Figure 4.2. Model of the statistical analyses in study III

**Independent variables:**
- Feeling understood and supported by healthcare providers
- Having sufficient information to manage my health
- Actively managing my health
- Social support for health
- Appraisal of health information
- Ability to actively engage with healthcare providers
- Navigating the healthcare system
- Ability to find good health information
- Understand health information enough to know what to do

**Potential confounders:**
- Age
- Gender
- Ethnicity
- Cohabitation
- Educational attainment
- Comorbidity

**Dependent variables:**
- HRQoL:
  - Physical component summary score (PCS)
  - Mental component summary score (MCS)
- CR participation
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75. Aaby A, Friis K, Christensen B, Maindal HT. Health Literacy among People in Cardiac Rehabilitation: Associations with Participation and Health-Related Quality of Life in the


Chapter 5: Health literacy and health outcomes in cardiac conditions

Study II: Health literacy is associated with health behaviour and self-reported health: A large population-based study in individuals with cardiovascular disease.

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Bo Christensen
Gill Rowlands
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https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5680908/
Abstract

Background. Health literacy may constitute a modifiable determinant of health behaviour and affect cardiovascular disease prevention. This study investigates the associations between health literacy and health behaviour as well as health status.

Design. A cross-sectional study on a population-based sample of people with acute myocardial infarction, angina pectoris or stroke (N = 3116).

Methods. Health literacy was assessed using two dimensions from the Health Literacy Questionnaire: ‘understanding health information’ and ‘engaging with healthcare providers’. Health behaviour included physical activity, dietary habits, smoking, alcohol consumption and body mass index. Health status was examined using Short Form Health Survey 12 version 2 (four-week recall) (physical and mental components). We used regression analyses to examine the associations.

Results. ‘Understanding health information’ was inversely associated with physical inactivity (odds ratio (OR) 0.48 (0.39;0.59), unhealthy diet (OR 0.64 (0.47;0.88)), underweight (OR 0.43 (0.21;0.89)) and obesity (OR 0.79 (0.63;0.99)). ‘Engaging with healthcare providers’ was inversely associated with physical inactivity (OR 0.64 (0.53;0.77)), less than healthy diet (OR 0.79 (0.64;0.96)) and daily smoking (OR 0.81 (0.66;1.0)). An increase in ‘understanding health information’ as well as ‘engaging with healthcare providers’ was associated with an increase in both physical and mental health status.

Conclusions. The findings suggest that aspects of health literacy are associated with health status and health behaviour in cardiovascular patients and should be considered in interventions regarding cardiovascular disease prevention.
Introduction

Successful cardiovascular disease prevention requires a high level of individual self-care competences (1). Health literacy encompasses some of the skills required, such as the understanding of health information and active interaction with healthcare professionals. Health literacy is open to change through building skills or improving health services and may constitute a significant, modifiable determinant of self-care and health behaviour (2,3).

Health literacy can be defined as people’s knowledge, motivation and competences to access, understand, appraise and apply health information in order to make judgements and take decisions in every-day life concerning health (4).

Low levels of health literacy have been associated with social determinants such as low educational level, low income, ethnic minority status and living alone (5–7). It has been hypothesized at a theoretical level, that health literacy is a dynamic outcome of socio-demographic as well as individual and environmental factors (8,9), manifesting itself in the interaction between individuals and the demands of complex healthcare systems (4).

A large Danish survey investigated dimensions of health literacy and found that between 8.8% and 20.2% of the general population find tasks related to understanding health information or engaging with healthcare providers difficult (6). In another study it was shown that the proportion was significantly higher in individuals with cardiovascular disease (10), and low health literacy has also been associated with increased risk of being limited by long-term health conditions (5).

In people with cardiovascular disease low education is associated with higher prevalence of many cardiovascular risk factors (11), which may be due to lower awareness (12). At any rate, low health literacy has been related to more adverse health behaviours (13–15) and poor subjective health (5,13–18). However, all these studies were either small and/or investigated health literacy as basic skills of reading and understanding. No more comprehensive studies have explored these associations.

The aim of this study was to investigate the association between health literacy and health behaviour as well as health literacy and health status in people with cardiovascular disease.
Methods

Design, data collection and participants

This study is based on data from the Danish health and morbidity survey coined ‘How Are You? 2013’ describing health and health behaviour in the general population. The survey was conducted in Central Denmark Region, which is the residence of approximately 1.3 million people.

A random sample of 46,354 adults aged 25 years or above was drawn from the Danish Civil Registration System and they were invited to complete a comprehensive postal or web-based questionnaire. In all, 29,473 respondents (63.6%) completed the questionnaire. Of these, 3,116 individuals reported cardiovascular disease, that is, current or previous diagnosis of acute myocardial infarction, angina pectoris, or stroke, and were included in the present study.

Measures

Health literacy. The Health Literacy Questionnaire (HLQ) is a comprehensive instrument measuring nine dimensions of health literacy. The questionnaire was developed using a grounded psychometric approach and has been shown to have strong measurement properties in diverse settings (19–22). The translation and cultural adaption from English into Danish has followed standardized procedures (23).

Due to limited space in the lengthy survey only two of the nine subscales were included in the survey, namely ‘Understanding health information well enough to know what to do’ and ‘Ability to actively engage with healthcare providers’. Each of the two subscales consists of five questions. Each response is indicated on a four-point scale: very difficult (1), difficult (2), easy (3), very easy (4). Scale scores were calculated as the mean score of the number of items answered in that particular subscale. If more than two items in a scale were unanswered, the scale score for that individual was regarded missing.

Health status. Health status was measured using the Short Form Health Survey 12 version 2 (four-week recall) (SF-12). The two summary measures – physical component summary (PCS) and mental component summary (MCS) – were each calculated and adjusted using norm-based methods developed with the general US population as reference, with a mean of 50 units and standard deviation of 10 units (24).

Health behaviour. Four different aspects of reported health behaviour were included (physical activity, dietary habits, smoking, and alcohol consumption). Body mass index (BMI) was added as a proxy for long-term health behaviour.
Physical activity was measured as number of days per week with at least 30 min of physical activity and categorized as ‘very active’ (5–7 days), ‘active’ (2–4 days) and ‘inactive’ (0–1 days). Danish Health Authorities recommend 30 min of physical activity per day (25).

The Diet Quality Score was used to classify dietary habits (26). The score is a 25-item validated questionnaire, developed in a Danish setting to evaluate diet in relation to cardiovascular risk. In line with the recommended scoring dietary habits were categorized as ‘unhealthy’ (1–3 points), ‘average’ (4–6 points) or ‘healthy’ (7–9 points).

Smoking was categorized as ‘daily smoker’, ‘occasional smoker’ (less than daily), ‘former smoker’ and ‘never smoked’.

Respondents were asked how many alcoholic drinks they drank on average per week, and high-risk alcohol consumption was considered weekly consumption above Danish Health Authority recommendations of 14/21 drinks for females/males, respectively (27).

BMI (weight/(height)^2) was calculated using self-reported weight (kg) and height (m) and classified as ‘underweight’ (BMI<18.5), ‘normal’ (BMI 18.5–24.9), ‘overweight’ (BMI 25–29.9) and ‘obese’ (BMI≥30).

Socio-demographic factors. Socio-demographic factors included gender, age, educational level, cohabitation status and ethnic background. Information on gender, age and ethnic background was collected from the Danish National Civil Registry. Ethnic background was defined as Danish if the respondent or at least one parent had Danish citizenship.

Educational level and cohabitation status were self-reported. Years of education was categorized as ‘low’ (1–10 years), ‘medium’ (11–14 years), ‘high’ (>15 years). Cohabitation was defined as respondents living with another adult.

Statistical analysis

To account for selection probabilities and response rates data were weighted prior to any research access using a model-based calibration approach based on information from Statistics Denmark on gender, age, municipality of residence and a number of social variables to represent the population of Central Denmark Region.

Each of the two HLQ subscales’ association with distinct socio-demographic factors has been established (6,20,28) and we hypothesize that they cover distinct aspects of health literacy important for successful self-care of cardiovascular disease. Cronbach’s
alpha was found high in both scales, $\alpha = 0.86$ and $\alpha = 0.90$ respectively, indicating high internal reliability.

The associations between the two HLQ subscales and health behaviours were analysed using logistic regression. High physical activity, healthy diet, never smoked, low-risk alcohol consumption and BMI within normal range were used as reference categories. For each health behaviour dummy variables were created including only respondents within a specific category and the reference category. Regression analyses were performed separately for each dummy variable. Odds ratios were adjusted for gender, age, ethnic background, educational level and cohabitation status.

The association between each of the two HLQ sub-scales and health status was examined using linear regression on the summary scores for PCS and MCS. The analyses were adjusted for gender, age, ethnic background, educational level and cohabitation status.

Level of significance was set at $p<0.05$. All statistical analysis was performed using STATA version 14.

**Ethics and approvals**

Information about aim, voluntary participation and confidentiality was provided with the questionnaire. Voluntary completion of questionnaires constituted consent. The study was performed in accordance with the Helsinki Declaration. According to Danish law no specific ethic evaluation is required in survey studies such as this. The study has been approved by the Danish Data Protection Agency (ref. no. 2015-57-0002).

**Results**

**General characteristics.** Table 5.1 shows the socio-demographic characteristics, the two health literacy measures, health status, and health behaviours of this population. The mean age in the study sample was 64.3 years and a majority (56.2%) were male. Approximately two-fifths of the population (38.2%) lived alone, and two-fifths (37.3%) had low educational level.

Regarding health literacy, the mean scale score of ‘Understanding health information well enough to know what to do’ was 2.92, while the mean scale score of ‘Ability to actively engage with healthcare providers’ was 2.97.
Poor health behaviour was reflected in 28.0% of the study population reporting physical inactivity, 15.3% reporting unhealthy diet, 22.3% being daily smokers, 7.6% reporting high-risk alcohol consumption and 21.4% being obese (BMI≥30).

SF-12 physical domains were generally scored below mental domains and the population had mean PCS of 42.5 and MCS of 48.0. The effect sizes using Cohen’s d on the standardized mean of 50 equal 0.75 (0.71;0.79) and 0.20 (0.16;0.24) respectively.

Health literacy and health behaviour. Associations between health literacy and health behaviour are presented in Table 5.2. In the adjusted analyses, we found that a one-unit increase in mean scale score of ‘Understand health information well enough to know what to do’ decreased the odds of being physically inactive (odds ratio (OR) 0.48 (0.39;0.59)), moderately physically active (OR 0.69 (0.57;0.85)), eating an unhealthy diet (OR 0.64 (0.47;0.88)), being underweight (OR 0.43 (0.21;0.89)) and being obese (OR 0.79 (0.63;0.99)).

Similarly, in the adjusted analyses we found that a one-unit increase in mean scale score of ‘ability to actively engage with healthcare providers’ decreased the odds of being physically inactive (OR 0.64 (0.53;0.77)), eating a less than healthy diet (OR 0.79 (0.64;0.96)) and being a daily smoker (OR 0.81 (0.66–1.0)). No association was found between health literacy competences and high-risk alcohol consumption.
### Table 5.1. Participant characteristics among responders reporting a cardiovascular disease.

<table>
<thead>
<tr>
<th>Socio-demographic factors</th>
<th>N</th>
<th>%</th>
<th>95% CI</th>
<th>Mean ± SD</th>
</tr>
</thead>
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<tr>
<td><strong>Gender</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>1306</td>
<td>43.8</td>
<td>41.8-45.9</td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>1781</td>
<td>56.2</td>
<td>54.1-58.2</td>
<td></td>
</tr>
<tr>
<td><strong>Age (years)</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>25-44</td>
<td>224</td>
<td>10.8</td>
<td>9.4-12.4</td>
<td></td>
</tr>
<tr>
<td>45-64</td>
<td>1037</td>
<td>34.5</td>
<td>32.6-36.5</td>
<td></td>
</tr>
<tr>
<td>65-84</td>
<td>1657</td>
<td>47.5</td>
<td>45.5-49.6</td>
<td></td>
</tr>
<tr>
<td>≥85</td>
<td>198</td>
<td>7.1</td>
<td>6.1-8.3</td>
<td></td>
</tr>
<tr>
<td><strong>Educational attainment</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>High</td>
<td>464</td>
<td>15.1</td>
<td>13.7-16.7</td>
<td></td>
</tr>
<tr>
<td>Medium</td>
<td>1421</td>
<td>47.6</td>
<td>45.5-49.7</td>
<td></td>
</tr>
<tr>
<td>Low</td>
<td>1048</td>
<td>37.3</td>
<td>35.2-39.4</td>
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<td><strong>Cohabitation</strong></td>
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<td></td>
</tr>
<tr>
<td>Cohabitating</td>
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<td>61.8</td>
<td>59.6-63.9</td>
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</tr>
<tr>
<td>Live alone</td>
<td>913</td>
<td>38.2</td>
<td>36.1-40.4</td>
<td></td>
</tr>
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<td><strong>Ethnic background</strong></td>
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<td>Danish</td>
<td>2996</td>
<td>93.4</td>
<td>92.0-94.6</td>
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</tr>
<tr>
<td>Non-Danish</td>
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<td>6.6</td>
<td>5.4-8.0</td>
<td></td>
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<td><strong>Health literacy measures</strong></td>
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<td></td>
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<tr>
<td>Understanding health information well enough to know what to do</td>
<td>2805</td>
<td>2.92</td>
<td>0.62</td>
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<tr>
<td>Ability to actively engage with healthcare providers</td>
<td>2812</td>
<td>2.97</td>
<td>0.64</td>
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<td><strong>Health behaviours</strong></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Physical activity</td>
<td>2998</td>
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<td></td>
<td></td>
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<tr>
<td>High activity</td>
<td>1269</td>
<td>40.6</td>
<td>38.5-42.7</td>
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</tr>
<tr>
<td>Moderate activity</td>
<td>943</td>
<td>31.4</td>
<td>29.5-33.4</td>
<td></td>
</tr>
<tr>
<td>Low activity</td>
<td>786</td>
<td>28.0</td>
<td>26.1-30.0</td>
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<tr>
<td>Dietary quality score</td>
<td>2846</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Healthy</td>
<td>531</td>
<td>17.6</td>
<td>16.0-19.3</td>
<td></td>
</tr>
<tr>
<td>Average</td>
<td>1911</td>
<td>67.1</td>
<td>65.1-69.1</td>
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<tr>
<td>Unhealthy</td>
<td>404</td>
<td>15.3</td>
<td>13.8-17.0</td>
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<tr>
<td>Smoking habits</td>
<td>2995</td>
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### The Heart Skills Study

<table>
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<th>Status</th>
<th>Count</th>
<th>Mean</th>
<th>CI 95%</th>
</tr>
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<tbody>
<tr>
<td>Never smoked</td>
<td>950</td>
<td>33.0</td>
<td>31.0-35.0</td>
</tr>
<tr>
<td>Former smoker</td>
<td>1343</td>
<td>42.3</td>
<td>40.2-44.3</td>
</tr>
<tr>
<td>Occasional smoker</td>
<td>63</td>
<td>2.5</td>
<td>1.8-3.3</td>
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<tr>
<td>Daily smoker</td>
<td>639</td>
<td>22.3</td>
<td>20.6-24.2</td>
</tr>
<tr>
<td>Alcohol</td>
<td>2809</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Non-high risk consumption</td>
<td>2582</td>
<td>92.4</td>
<td>91.1-93.4</td>
</tr>
<tr>
<td>High risk consumption</td>
<td>227</td>
<td>7.6</td>
<td>6.6-8.9</td>
</tr>
<tr>
<td>Body mass index</td>
<td>3019</td>
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<td></td>
</tr>
<tr>
<td>Underweight</td>
<td>49</td>
<td>1.8</td>
<td>1.3-2.5</td>
</tr>
<tr>
<td>Normal weight</td>
<td>1154</td>
<td>39.7</td>
<td>37.6-41.8</td>
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<tr>
<td>Overweight</td>
<td>1188</td>
<td>37.1</td>
<td>35.1-39.1</td>
</tr>
<tr>
<td>Obese</td>
<td>628</td>
<td>21.4</td>
<td>19.7-23.2</td>
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</table>

**Subjective health status**

<table>
<thead>
<tr>
<th>Summary</th>
<th>Count</th>
<th>Mean</th>
<th>CI 95%</th>
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<tr>
<td>Physical component summary</td>
<td>2532</td>
<td>42.5</td>
<td>11.8</td>
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<tr>
<td>Mental component summary</td>
<td>2532</td>
<td>48.0</td>
<td>11.6</td>
</tr>
</tbody>
</table>

CI: confidence interval; SD: standard deviation; SF-12: Short Form Health Survey 12 version 2 (four-week recall). *All percentages and means are weighted based on register data to represent the population of Central Denmark Region, 2013.*
Table 5.2. Associations between health behaviour and Health Literacy Questionnaire subscales

<table>
<thead>
<tr>
<th></th>
<th>Physical activity</th>
<th>Dietary quality score</th>
<th>Smoking habits</th>
<th>Alcohol consumption</th>
<th>Body mass index</th>
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<tr>
<td></td>
<td>Low</td>
<td>Moderate</td>
<td>High</td>
<td>Unhealthy</td>
<td>Average</td>
</tr>
<tr>
<td></td>
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<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Understanding health information well enough to know what to do</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Crude OR</td>
<td>0.45*</td>
<td>0.72*</td>
<td>1</td>
<td>0.54*</td>
<td>0.79*</td>
</tr>
<tr>
<td>95% CI</td>
<td>0.37:0.54</td>
<td>0.60:0.87</td>
<td>0.41:0.71</td>
<td>0.64:0.98</td>
<td>0.70:1.07</td>
</tr>
<tr>
<td>Adjusted OR</td>
<td>0.48*</td>
<td>0.69*</td>
<td>1</td>
<td>0.54*</td>
<td>0.81*</td>
</tr>
<tr>
<td>95% CI</td>
<td>0.39:0.59</td>
<td>0.57:0.85</td>
<td>0.47:0.88</td>
<td>0.65:1.03</td>
<td>0.65:1.04</td>
</tr>
<tr>
<td>Ability to actively engage with healthcare providers</td>
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<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Crude OR</td>
<td>0.81*</td>
<td>0.83*</td>
<td>1</td>
<td>0.79</td>
<td>0.83*</td>
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<tr>
<td>95% CI</td>
<td>0.51:0.72</td>
<td>0.70:0.99</td>
<td>0.61:1.02</td>
<td>0.65:1.01</td>
<td>0.67:0.99</td>
</tr>
<tr>
<td>Adjusted OR</td>
<td>0.64*</td>
<td>0.84*</td>
<td>1</td>
<td>0.77</td>
<td>0.79*</td>
</tr>
<tr>
<td>95% CI</td>
<td>0.53:0.77</td>
<td>0.70:1.00</td>
<td>0.55:1.02</td>
<td>0.64:0.96</td>
<td>0.66:1.0</td>
</tr>
</tbody>
</table>

*OR adjusted for gender, age, ethnic background, educational attainment and cohabitation.
OR: odds ratio; CI: confidence interval; *P<0.05.
Health literacy and Health status. Table 5.3 shows the association between SF-12 summary scale scores and health literacy. After adjusting for gender, age, ethnic background, educational level and cohabitation status a one-unit increase in ‘Understanding health information well enough to know what to do’ was positively associated with an average increase of 4.59 (3.60;5.59) and 4.38 (3.27;5.50) for PCS and MCS respectively. The corresponding results for ‘Ability to actively engage with healthcare providers’ were average increases per HLQ-unit of 4.35 (3.43;5.28) and 5.03 (3.97;6.10) for PCS and MCS respectively.

The association between the two HLQ subscales and PCS were significantly stronger than corresponding associations in the total survey population, while this is not the case for MCS (data not shown).

Table 5.3. Associations between SF-12 summary scale scores and HLQ subscales

<table>
<thead>
<tr>
<th></th>
<th>Understanding health information well enough to know what to do</th>
<th>Ability to actively engage with healthcare providers</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Crude  β  95% CI  Adjusted a  β  95% CI  Objective  β  95% CI  Adjusted a  β  95% CI</td>
<td></td>
</tr>
<tr>
<td>Physical component score</td>
<td>5.60*  4.65;6.55  4.59*  3.60;5.59  4.81*  3.88;5.73  4.35*  3.43;5.28</td>
<td></td>
</tr>
<tr>
<td>Mental component score</td>
<td>4.99*  3.92;6.05  4.38*  3.27;5.50  5.63*  4.63;6.62  5.03*  3.97;6.09</td>
<td></td>
</tr>
</tbody>
</table>

*aadjusted for gender, age, ethnic background, educational attainment and cohabitation. *p<0.05
SF-12: Short Form Health Survey 12 version 2 (four-week recall); HLQ: Health Literacy Questionnaire; b: beta coefficient; CI: confidence interval.
Discussion

In a large population of individuals with self-reported cardiovascular disease, we found significant associations between two aspects of health literacy and increased physical activity, healthier diet and higher self-reported health status. Also, for the ability to understand health information we found significant associations with better weight control, and for the ability to actively engage with healthcare providers we found significant associations with abstinence from smoking.

Strengths and limitations

To our knowledge, this is to date the largest and most comprehensive study examining the relationship between health literacy and health behaviour as well as health status in individuals with cardiovascular disease. The large sample size has allowed strong analyses even after controlling for multiple potential confounders.

Health literacy is a dynamic quality depending on a number of contextual, individual and situational factors (4,9). The demands for health literacy competences depend on the complexity of an individual’s condition and the health services provided, but the condition may also change the individual and social resources available and thus the ability to use such competences effectively. The cross-sectional nature of this study precludes any causal conclusions. Further research with longitudinal or qualitative designs may provide a better understanding of these issues.

The survey had a high response rate (63.3%) and the population weights used on the survey data prior to our analyses compensate to some extent for selection bias based on selection probabilities and socio-demographic as well as geographic differences in response rates.

However, low health literacy may decrease the motivation and ability to fill out the survey, as would other personal and health-related characteristics. Response rate in the eldest age group was low (43% in people aged>85 years) and it is likely that people with severe chronic conditions may have refrained from returning the questionnaire. As a consequence, the health literacy level in our study may have been overrated.

The survey included three self-reported cardiovascular diseases and we did not make any comparison of reported cases with patient registers. Respondents’ knowledge of their condition and the lack of options such as chronic heart failure and heart valve conditions may have excluded relevant respondents from the population, reducing the power of our results.
To limit the length of the survey we were not able to include all nine subscales of the HLQ in this study. Conclusions can therefore only be drawn on the two included domains. Studies examining detailed health literacy profiles are warranted to identify additional health literacy challenges and opportunities to mitigate the effect of such challenges among people with cardiovascular disease.

**Interpretations**

The European Health Literacy Project has examined health literacy in a general population of approximately 8,000 individuals across Europe (5). The results indicate an association between health literacy and long-term illness, which has been confirmed in a study on the survey data on which our study is also based (10). In this, cardiovascular disease has been shown to be one of the most challenging conditions in this respect.

The role of health behaviour in relation to the prognosis and quality of life in people with cardiovascular disease is well-established (29) and so is the need for improvements in secondary prevention and rehabilitation across Europe (30,31). In concordance with our results previous research in diverse populations has found associations between low health literacy and physical inactivity (5,7,32–34), unhealthy diet (7,33–35), smoking (7,35), obesity (5,7,32,36), and underweight (37). The associations are most consistent in relation to physical activity and diet, while findings regarding smoking and weight are contradictory (5,33,34,37). Studies on the associations between health literacy and alcohol consumption report either no association, weak or even negative associations (5,32,33,37).

Interestingly, we found that in the case of smoking and weight control, health literacy was only associated with very unhealthy behaviours while being insignificant in relation to more mediocre behaviours. After cardiovascular disease onset, efforts are often made by the individual and health professionals to change unhealthy behaviours, for example, through rehabilitation programmes, preventive consultations etc. Thus, people receptive to such interventions may move towards healthier lifestyles leaving a group of individuals facing additional challenges behind. Our finding may reflect the lower health literacy of this vulnerable group and this may also explain some of the inconsistent associations regarding smoking and weight in the literature.

The widely acknowledged health literacy levels – functional, interactive and critical health literacy – presented by Nutbeam (38) are emphasized differently in the HLQ subscales with ‘Understand information well enough to know what to do’ focusing on functional health literacy while ‘Ability to actively engage with healthcare providers’ accentuates interactive health literacy. To our knowledge no previous studies on individuals with cardiovascular disease have distinguished between the two levels.
Strong associations with understanding health information were found in physical activity, dietary quality and weight control. Perhaps this reflects the complex knowledge needed to understand and change these behaviours. On the other hand, smoking is a less complex behaviour, but inducing change may depend more on the motivations created by social networks and interaction with healthcare providers.

Existing literature on general populations finds a positive association between health literacy and general health status (5,17,35) as well as physical and mental health status (39–41). However, in accordance with our findings, studies performed on people with cardiovascular conditions (15,18) suggest a far stronger association between health literacy and physical health status than mental health status. Physical function after the onset of a cardiovascular disease is highly dependent on self-care behaviours. Macabasco-O’Connell et al. (13) have shown an association between inadequate health literacy and lack of disease specific self-care behaviours in patients with heart failure, but other studies have not been able to fully reproduce this result (42–44).

Generalizability

The population characteristics of this study, that is, with the ‘typical’ respondent being a man above 60 years with low educational level, are in line with that of other studies on individuals with cardiovascular disease (45,46). The population of Central Region Denmark has similar demographic, health and social composition to the Danish population in general (47), but the generalizability of our findings to populations outside Denmark depends largely on the specific local demography and context. In this study, external validity in relation to cardiovascular patients is also limited by the lack of discrimination between all relevant diagnoses and disease severity.

Conclusion

Among individuals with cardiovascular disease, the ability to understand health information and the ability to actively engage with healthcare providers were associated with important health behaviours and health status. This places health literacy as an important determinant of successful cardiovascular disease prevention and a target in future interventions on skill development, patient–provider interaction and health service improvement.

Keeping in mind the socially unequal distribution of both health literacy competences and cardiovascular disease recovery this study provides a strong argument for health literacy interventions as a means to fight inequality in health among individuals with cardiovascular disease.
REFERENCES


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32. Husson O, Mols F, Fransen MP, Van De Poll-Franse L V., Ezendam NPM. Low subjective health literacy is associated with adverse health behaviors and worse health-related quality of life among colorectal cancer survivors: Results from the profiles registry. Psychooncology. 2015;24:478–86.


Chapter 6: Health literacy in the context of cardiac rehabilitation

Study III: Health Literacy among People in Cardiac Rehabilitation: Associations with Participation and Health-Related Quality of Life in the Heart Skills Study in Denmark

Anna Aaby
Karina Friis
Bo Christensen
Helle Terkildsen Maindal

https://www.mdpi.com/1660-4601/17/2/443/htm
Abstract

Health literacy (HL) is a dynamic determinant of health and a promising target of health equity interventions in noncommunicable disease prevention. Among people referred to a cardiac rehabilitation program, we examined the associations between (1) HL and participation in cardiac rehabilitation and (2) HL and health-related quality of life (HRQoL). Using a cross-sectional design, we invited 193 people referred to cardiac rehabilitation in Randers Municipal Rehabilitation Unit, Denmark, to respond to a questionnaire in 2017. Of these, 150 people responded (77.7%). HL was measured using the nine scales of the Health Literacy Questionnaire (HLQ), while HRQoL was measured using the Short Form Health Survey 12 (version 2) (SF-12). The mean age of respondents was 67.0 years; 71.3% of the sample were men. Nonrespondents had significantly lower educational attainment and more often lived alone than respondents. Using multiple regression analyses, we found no significant associations between HL and participation in cardiac rehabilitation. There were significant positive associations between several aspects of HL and physical and mental HRQoL. HL could be a factor of interest in initiatives aimed at improving participation and outcomes of cardiac rehabilitation.
Introduction

Cardiac rehabilitation has proven effective in improving quality of life and preventing adverse events after cardiac disease onset (1). However, participation rates are low in many European countries (2). Studies have shown that participation and adherence is largely dependent on demographic and social circumstances such as age, gender, cohabitation status, educational attainment, work situation, and income, as well as practicalities such as distance to rehabilitation facilities (3). From the perspective of a rehabilitation service unit, few of these factors are easily modified or targeted. Thus, identification of more dynamic intermediary determinants is crucial to encourage increased participation in cardiac rehabilitation and respond to the needs of those who do not attend (2,4).

Health literacy is defined as “the combination of personal competencies and situational resources needed for people to access, understand, appraise and use information and services to make decisions about health” (5). Thus, health literacy encompasses a broad spectrum of cognitive and social skills enabling an individual’s navigation, motivation, and action competence in relation to health promotion, prevention, and care (6). Moreover, health literacy is a dynamic quality formed and executed through people’s interactions with the surrounding environment, including healthcare organizations and preventive services (7).

Health literacy has been identified as a mediator between social health determinants and health outcomes (8–11). In relation to cardiac conditions, low health literacy has been associated with higher prevalence (12), poorer cardio-protective health behaviours (13,14), less disease knowledge and poorer self-management (15,16), higher hospital readmission rates (16–18), and higher mortality (17,18). In addition, low health literacy has been associated with low health-related quality of life (HRQoL) (13,16,19–21), particularly in relation to the physical components of HLQoL (19,20). Improved HRQoL is an important and well-supported outcome of cardiac rehabilitation programs (1). The effect is consistent across many types of rehabilitation programs (1), suggesting that other factors than specific program elements could play a role. However, to the best of our knowledge, no studies have examined the association between health literacy and HRQoL in the context of cardiac rehabilitation.

Few studies have evaluated the impact of health literacy in a cardiac rehabilitation context. Dankner et al. found that lack of knowledge regarding cardiac rehabilitation was the most common reason for nonparticipation in cardiac rehabilitation (22). Mattson et al. found that health literacy was associated with increased knowledge gain from cardiac patient education during a rehabilitation program (23). A few intervention
studies have also successfully addressed health literacy in their intervention design or measured it as an outcome (24,25). In all these studies, as in most studies on health literacy in people with cardiac conditions, individual health literacy was measured using a single value or category (26–29). These tools do not account for the diversity of health literacy assets and challenges within populations and thus suffer from an inability to be easily translated into appropriate responses at the individual and organizational level.

Among people referred to a municipal cardiac rehabilitation program, and using a broad measure of health literacy, the aim of this study was to

- Examine the associations between nine aspects of health literacy and participation in cardiac rehabilitation.
- Examine the associations between nine aspects of health literacy and physical and mental HRQoL.

A subsidiary aim was to examine the association between socio-demographic variables (age, gender, cohabitation status, and educational attainment) and participation in rehabilitation as well as HRQoL and compare these results with the analyses on health literacy.

**Methods**

*Design and setting*

This cross-sectional study was part of the Heart Skills study aimed at developing a co-designed intervention responding to the health literacy needs of people referred to Randers Municipal Rehabilitation Unit, Denmark. We collected survey data from 193 people referred to the cardiac rehabilitation program in the unit. Randers Municipal Rehabilitation Unit offers free-of-charge nationally recommended cardiac rehabilitation programs (30) to citizens with a cardiac condition or severely adverse cardiac risk factors in Randers Municipality. Most of these are referred to a start-up session in the unit as part of their discharge from hospitals or later in their disease course from their general practitioner. They are then contacted by the unit, and if accepted, a session is scheduled. Nonparticipants may either decline the start-up session or chose not to attend further services after the information provided at the start-up session.

The municipality has approximately 98,000 inhabitants. The program includes a twelve-week biweekly exercise training program and eight patient education sessions, as well as optional elements including smoking cessation support and dietary, sexual, or energy management counselling.
Data collection

All people referred to the cardiac rehabilitation program in Randers Municipality between 7 March 2017 and 31 December 2017 were eligible for the study. Verbal consent to participate in the survey was obtained shortly after referral as part of a telephone invitation to the cardiac rehabilitation program. The survey was then distributed to consenting individuals according to the participant’s favoured mode of communication: by e-mail, by postal letter, by telephone interview, or on a paper questionnaire or tablet at the rehabilitation unit with support from a healthcare provider. After predetermined time intervals depending on the distribution method, nonresponders were reminded to complete the survey. After another predetermined time interval, remaining nonresponders were contacted by phone to confirm their consent and preferred survey format. Figure 6.1 shows the selection procedure.

The survey included questions on health literacy, HRQoL, health behaviour and the disease course leading up to the referral. Prior to data collection, two people referred to the rehabilitation program and two people, who had completed the rehabilitation program tested the questionnaire in a small pilot. The test led to only minor linguistic changes.

Figure 6.1. The recruitment of survey respondents for the Heart Skills Survey in Randers Municipal Rehabilitation Unit, 2017.
Health literacy was measured using the comprehensively validated 44-item Health Literacy Questionnaire (HLQ) (31–33). The HLQ consists of nine scales that independently measure different aspects of health literacy (table 6.1). The HLQ was translated into Danish following standardized forward and backward procedures. The Danish language validation study showed a robust nine-dimension confirmatory factor model (34).

In scales 1–5, respondents use a four-point scale: “Strongly disagree”, “disagree”, “agree”, and “strongly agree”. In scales 6–9, respondents use a five-point scale: “Cannot do”, “very difficult”, “quite difficult”, “quite easy”, and “very easy”. Mean scales scores are calculated and reported with standard deviations. If responses to more than two items in a scale were missing for a particular respondent, the scale score for that respondent was reported missing.

Over the past decades, the concept of health literacy has developed from a narrow term closely related to literacy and numeracy into a multifaceted concept developed and understood in relation to an individual’s context and the surrounding health system and community (5). The HLQ measures health literacy from this broad understanding. Several attempts to further subcategorize aspects of health literacy are available in the literature (31,35,36). Inspired by these studies and to support the interpretation of our results, we have attempted to categorize the nine HLQ scales into three categories: cognitive capacities, executive capacities, and social capacities (table 6.1).

**Table 6.1. The nine HLQ scales characterized by capacity.**

<table>
<thead>
<tr>
<th>HLQ Scale</th>
<th>Category</th>
</tr>
</thead>
<tbody>
<tr>
<td>2. Having sufficient information to manage my health (four questions)</td>
<td>Cognitive capacities</td>
</tr>
<tr>
<td>5. Appraisal of health information (five questions)</td>
<td></td>
</tr>
<tr>
<td>9. Understand health information enough to know what to do (five questions)</td>
<td></td>
</tr>
<tr>
<td>8. Ability to find good health information (five questions)</td>
<td>Executive capacities</td>
</tr>
<tr>
<td>3. Actively managing my health (five questions)</td>
<td></td>
</tr>
<tr>
<td>6. Ability to actively engage with healthcare providers (five questions)</td>
<td></td>
</tr>
<tr>
<td>7. Navigating the healthcare system (six questions)</td>
<td></td>
</tr>
<tr>
<td>1. Feeling understood and supported by healthcare providers (four questions)</td>
<td>Social capacities</td>
</tr>
<tr>
<td>4. Social support for health (five questions)</td>
<td></td>
</tr>
</tbody>
</table>
Health and rehabilitation measures

Participation in rehabilitation and HRQoL were used as dependent variables. Respondents reported on their current or intended participation in the rehabilitation program. Only current participation was labelled as “participation in rehabilitation” in the analyses.

HRQoL was measured using the validated Short Form Health Survey 12 (version 2) (four-week recall) (SF-12), which examines self-experienced health within eight domains of physical (four domains) and mental (four domains) health. Norm-based physical (PCS) and mental (MCS) component summary scores were calculated using the standardized procedures based on the general U.S. population (37).

Data on comorbidity was used as a covariate in the adjusted analyses. This was obtained from the Danish National Patient Registry (LPR) (38) and included all International Classification of Diseases 10th Revision (ICD10) codes obtained during hospitalizations or outpatient visits between 1994 and 2017. Data was reported as a weighted Charlson index score, which is based on 17 diagnostic categories (39,40). Although the index contains several cardiovascular conditions, we included all categories to allow for comorbidity based on multiple cardiovascular diagnoses. We included data from the year of referral (2017), as the hospitalization most respondents had experienced in relation to their cardiac event would increase the likelihood of any relevant diagnoses being recorded for that individual. For analyses, data were dichotomized as a weighted Charlson index score of ≤1 or >1.

Socio-demographic measures

Age, gender, cohabitation, and educational attainment were used as independent variables and covariates in the adjusted analyses. Country of origin was only used for adjusted analyses, as the vast majority of survey participants were from Denmark. All data were obtained from registers at the central authority on Danish statistics (Statistics Denmark). Cohabitation, educational attainment, and country of origin were dichotomized. Any type of habitation that encompassed adults living together was termed cohabitation. In the case of educational attainment, we dichotomized 11 years of schooling or below versus above 11 years of schooling. Those individuals who were born or registered outside Denmark, or whose parents were born or registered outside Denmark, were classified as having a non-Danish country of origin. If one parent was Danish, the country of origin was based on the mother’s birthplace or registration.
**Statistical methods**

Descriptive information was reported using appropriate summary measures on the total population as well as to compare responders and nonresponders.

Multiple logistic regression was used to analyse associations between the independent variables (age, gender, cohabitation status, educational attainment, and the nine HLQ scales) and cardiac rehabilitation participation. We used nonparticipation as the reference category, and reported our results as odds ratios (95% CI). Multiple linear regression was used to analyse the associations between the same set of independent variables and HRQoL for physical and mental component summary scores separately. The results were reported as β coefficients (95% CI). All regression analyses were adjusted for age, gender, country of origin, cohabitation status, educational attainment, and comorbidity, excluding the independent variable under examination in relevant cases.

The level of significance was set at p < 0.05. All statistical analyses were performed using STATA version 15.1 (Metrika Consulting, Stockholm, Sweden).

**Ethics and approvals**

According to Danish law, no specific ethics evaluation was required for this survey study. The study was approved by the Danish Data Protection Agency (2015-57-0002 (62908, 141)). The study was performed in accordance with General Data Protection Regulation (GDPR) and the Helsinki Declaration. Information about the study aim, voluntary participation, and confidentiality was provided with the questionnaire. All participants gave their verbal consent to take part before the questionnaire was distributed.

**Results**

In total, 150 people (77.7%) returned the questionnaire and were included in the analysis (figure 6.1). In the few cases where the responses were obtained by telephone interview or with support in the Rehabilitation Unit, the interview was performed within 1–2 weeks after referral. The median response time among e-mail responders was 5 days (n = 110, 14 missing), and IQR was 18 days. Among mail responders, the median response time was 33 days (n = 25, 12 missing) and IQR was 32 days.

Table 6.2 summarizes characteristics of the total population as well as data stratified by survey participation.
The majority of the study population were men (68.9%), with a mean age of 67.0 years. Approximately one-third lived alone (29.3%), while 34.6% had low educational attainment. Health literacy mean scores ranged from 2.67 (scale 5) to 3.70 (scale 6). The survey participants were more highly educated than nonparticipants (70.1% versus 45.7%), and though only close to significant, less often lived alone (26.0% versus 42.9%). Just below one-fifth (19.2%) of the survey participants did not attend the offered rehabilitation program. As may be expected in a group of people with a long-term condition, both physical and mental HRQoL summary scores were well below the general population mean of 50 points (40.0 and 46.2 points, respectively).

Table 6.2. Population characteristics by survey participation in the Heart Skills Survey in Randers Municipal Rehabilitation Unit (2017).

<table>
<thead>
<tr>
<th></th>
<th>Total Population (n=193)</th>
<th>Survey Respondents (n=150)</th>
<th>Survey Non-Respondents (n=43)</th>
<th>p-Value</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Socio-Demographic Characteristics</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mean age (SD)</td>
<td>67.0 (12.1)</td>
<td>67.0 (11.8)</td>
<td>66.8 (13.4)</td>
<td>0.92</td>
</tr>
<tr>
<td>Gender</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male (%)</td>
<td>133 (68.9)</td>
<td>107 (71.3)</td>
<td>26 (60.5)</td>
<td></td>
</tr>
<tr>
<td>Female (%)</td>
<td>60 (31.1)</td>
<td>43 (28.7)</td>
<td>17 (39.5)</td>
<td>0.17</td>
</tr>
<tr>
<td>Country of origin</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Danish origin</td>
<td>273 (96.1)</td>
<td>N/A</td>
<td>N/A</td>
<td></td>
</tr>
<tr>
<td>Non-Danish origin</td>
<td>7 (3.9)</td>
<td>N/A</td>
<td>N/A</td>
<td></td>
</tr>
<tr>
<td>Cohabitation</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Lives w someone (%)</td>
<td>128 (70.7)</td>
<td>108 (74.0)</td>
<td>20 (57.1)</td>
<td></td>
</tr>
<tr>
<td>Lives alone (%)</td>
<td>53 (29.3)</td>
<td>38 (26.0)</td>
<td>15 (42.9)</td>
<td>0.05</td>
</tr>
<tr>
<td>Educational attainment</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>&gt;11 years (%)</td>
<td>117 (65.4)</td>
<td>101 (70.1)</td>
<td>16 (45.7)</td>
<td>&lt;0.05</td>
</tr>
<tr>
<td>≤11 years (%)</td>
<td>62 (34.6)</td>
<td>43 (29.9)</td>
<td>29 (54.3)</td>
<td></td>
</tr>
<tr>
<td><strong>Health-Related Characteristics</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Participation in rehabilitation (%)</td>
<td>N/A</td>
<td>118 (80.8)</td>
<td>N/A</td>
<td></td>
</tr>
<tr>
<td>Mean physical HRQoL (PCS) (SD)</td>
<td>N/A</td>
<td>40.0 (10.7)</td>
<td>N/A</td>
<td></td>
</tr>
<tr>
<td>Mean mental HRQoL (MCS) (SD)</td>
<td>N/A</td>
<td>46.2 (11.1)</td>
<td>N/A</td>
<td></td>
</tr>
<tr>
<td>Mean weighted Charlson Index (SD)</td>
<td>1.58 (1.4)</td>
<td>1.61 (1.4)</td>
<td>1.49 (1.2)</td>
<td>0.64</td>
</tr>
<tr>
<td><strong>Health Literacy Characteristics</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. Having sufficient information to manage my health</td>
<td>N/A</td>
<td>3.00 (0.52)</td>
<td>N/A</td>
<td></td>
</tr>
<tr>
<td>5. Appraisal of health information</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Scale</td>
<td>Mean (SD) N/A</td>
<td>N/A</td>
<td>2.67 (0.50) N/A</td>
<td></td>
</tr>
<tr>
<td>----------------------------------------------------------------------</td>
<td>---------------</td>
<td>-----</td>
<td>-----------------</td>
<td></td>
</tr>
<tr>
<td>9. Understand health information enough to know what to do</td>
<td>Mean (SD)</td>
<td>N/A</td>
<td>3.61 (0.65) N/A</td>
<td></td>
</tr>
<tr>
<td>8. Ability to find good health information</td>
<td>Mean (SD)</td>
<td>N/A</td>
<td>3.56 (0.70) N/A</td>
<td></td>
</tr>
<tr>
<td>3. Actively managing my health</td>
<td>Mean (SD)</td>
<td>N/A</td>
<td>2.92 (0.48) N/A</td>
<td></td>
</tr>
<tr>
<td>6. Ability to actively engage with healthcare providers</td>
<td>Mean (SD)</td>
<td>N/A</td>
<td>3.70 (0.66) N/A</td>
<td></td>
</tr>
<tr>
<td>7. Navigating the healthcare system</td>
<td>Mean (SD)</td>
<td>N/A</td>
<td>3.38 (0.72) N/A</td>
<td></td>
</tr>
<tr>
<td>1. Feeling understood and supported by healthcare providers</td>
<td>Mean (SD)</td>
<td>N/A</td>
<td>2.99 (0.57) N/A</td>
<td></td>
</tr>
<tr>
<td>4. Social support for health</td>
<td>Mean (SD)</td>
<td>N/A</td>
<td>3.10 (0.52) N/A</td>
<td></td>
</tr>
</tbody>
</table>

SD: Standard deviation; significance level \( p > 0.05 \). HLQoL: Health-Related Quality of Life. PCS: physical component summery. MCS: mental component summary.

Table 6.3 shows the results of the unadjusted and adjusted logistic regression analyses on the four socio-demographic measures and each mean HLQ scale score in relation to rehabilitation participation.

None of the socio-demographic measures was significantly associated with the odds of participating in rehabilitation. Similarly, a one-unit increase in any of the nine mean HLQ scale scores was not significantly associated with the odds of participation in rehabilitation. There was a non-significant trend in eight of the nine scales that higher health literacy levels increased the odds of participation in rehabilitation.

Table 6.4 shows the unadjusted and adjusted linear regression analyses on the four sociodemographic measures and each mean HLQ scale score in relation to physical and mental HRQoL.

In the adjusted analyses, none of the four socio-demographic measures showed significant associations with either PCS or MCS. By contrast, a one-unit increase in mean HLQ was positively associated with higher PCS for scales 6 and 7, with \( \beta \) coefficients of 3.53 (0.88;6.18) and 2.79 (0.12;5.46), respectively. A one-unit increase in mean HLQ was also positively associated with higher mental MCS across five scales (scales 4, 6, 7, 8, and 9), with \( \beta \) coefficients of 6.61 (3.53;9.68), 4.63 (1.63;7.64), 7.10 (4.36;9.83), 4.83 (2.00;7.66), and 9.64 (6.09;13.18) respectively.
Table 6.3. Associations between socio-demographic and health literacy measures and rehabilitation participation in the Heart Skills Survey in Randers Municipal Rehabilitation Unit (2017).

<table>
<thead>
<tr>
<th>Participation in Rehabilitation</th>
<th>Socio-demographic characteristics</th>
<th>Crude OR (95% CI)</th>
<th>Adjusted* OR (95% CI)</th>
<th>Health literacy characteristics</th>
<th>Crude OR (95% CI)</th>
<th>Adjusted** OR (95% CI)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age (per year)</td>
<td>0.99 (0.95;1.02)</td>
<td>1.00 (0.96;1.04)</td>
<td></td>
<td>2. Having sufficient information to manage my health</td>
<td>1.23 (0.53;2.83)</td>
<td>1.39 (0.55;3.53)</td>
</tr>
<tr>
<td>Gender (ref. woman)</td>
<td>1.74 (0.74;4.11)</td>
<td>1.48 (0.57;3.82)</td>
<td></td>
<td>5. Appraisal of health information</td>
<td>1.50 (0.61;3.71)</td>
<td>1.49 (0.56;4.01)</td>
</tr>
<tr>
<td>Cohabitation (ref. lives alone)</td>
<td>2.35 (0.97;5.69)</td>
<td>2.32 (0.90;6.01)</td>
<td></td>
<td>9. Understand health information enough to know what to do</td>
<td>1.19 (0.61;2.33)</td>
<td>1.47 (0.69;3.12)</td>
</tr>
<tr>
<td>Educational attainment (ref. ≤11 years)</td>
<td>0.78 (0.30;2.01)</td>
<td>0.62 (0.23;1.69)</td>
<td></td>
<td>8. Ability to find good health information</td>
<td>1.29 (0.70;2.38)</td>
<td>1.57 (0.77;3.21)</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>3. Actively managing my health</td>
<td>1.67 (0.68;4.14)</td>
<td>1.72 (0.64;4.58)</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>6. Ability to actively engage with healthcare providers</td>
<td>1.33 (0.71;2.51)</td>
<td>1.36 (0.69;2.66)</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>7. Navigating the healthcare system</td>
<td>1.24 (0.66;2.33)</td>
<td>1.51 (0.74;3.08)</td>
</tr>
<tr>
<td>1. Feeling understood and supported by healthcare providers</td>
<td>1.89 (0.85;4.18)</td>
<td>1.74 (0.74;4.07)</td>
<td></td>
<td>4. Social support for health</td>
<td>0.90 (0.40;2.06)</td>
<td>0.97 (0.41;2.31)</td>
</tr>
</tbody>
</table>

OR: odds ratio; CI: confidence interval; significance level p > 0.05.* Adjusted for age, gender, country of origin, cohabitation, educational attainment, and comorbidity, excluding the independent variable in question. ** Adjusted for age, gender, country of origin, cohabitation, educational attainment, and comorbidity.
Table 6.4. Associations between socio-demographic and health literacy measures and health-related quality of life.

<table>
<thead>
<tr>
<th></th>
<th>Physical health status (PCS)</th>
<th>Mental health status (MCS)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Crude (95% CI)</td>
<td>Adjusted (95% CI)</td>
</tr>
<tr>
<td>Age (years)</td>
<td>-0.13 (-0.29;0.03)</td>
<td>-0.02 (-0.18;0.14)</td>
</tr>
<tr>
<td>Gender (ref women)</td>
<td></td>
<td>2.54 (-1.45;6.54)</td>
</tr>
<tr>
<td>Cohabitation (ref single living)</td>
<td>3.99 (-0.09;8.08)</td>
<td>2.68 (-1.53;6.89)</td>
</tr>
<tr>
<td>Educational attainment (ref ≤11 years)</td>
<td>2.47 (-0.48;6.43)</td>
<td>1.61 (-2.26;5.48)</td>
</tr>
<tr>
<td>Health literacy characteristics</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. Having information</td>
<td>3.12 (-0.36;6.59)</td>
<td>2.56 (-0.93;6.05)</td>
</tr>
<tr>
<td>5. Appraisal of health information</td>
<td>1.93 (-1.63;5.49)</td>
<td>1.59 (-1.93;5.10)</td>
</tr>
<tr>
<td>9. Understanding health information</td>
<td>3.17 (0.34;6.00)</td>
<td>2.81 (-0.14;5.76)</td>
</tr>
<tr>
<td>8. Finding health information</td>
<td>2.51 (-0.07;5.10)</td>
<td>1.59 (-1.22;4.41)</td>
</tr>
<tr>
<td>3. Actively managing health</td>
<td>2.79 (-0.98;6.55)</td>
<td>3.04 (-0.63;6.71)</td>
</tr>
<tr>
<td>6. Active engagement</td>
<td>3.90 (1.25;6.55)</td>
<td>3.53 (0.88;6.18)</td>
</tr>
<tr>
<td>7. Navigating the health system</td>
<td>3.34 (0.88;5.80)</td>
<td>2.79 (0.12;5.46)</td>
</tr>
<tr>
<td>1. Healthcare provider support</td>
<td>0.70 (-2.40;3.81)</td>
<td>0.42 (-2.66;3.50)</td>
</tr>
<tr>
<td>4. Social support for health</td>
<td>1.92 (-1.59;5.42)</td>
<td>1.13 (-2.43;4.70)</td>
</tr>
</tbody>
</table>

CI: confidence interval; significance level p < 0.05. * Adjusted for age, gender, ethnicity, cohabitation, educational attainment, and comorbidity, excluding the independent variable in question. ** Adjusted for age, gender, ethnicity, cohabitation, educational attainment, and comorbidity.
Discussion

In a population of people referred to a municipal cardiac rehabilitation program, we found no association between health literacy and participation in rehabilitation. We showed that several aspects of health literacy were positively associated with physical and mental components of HRQoL. Finally, we showed that age, gender, cohabitation, and educational attainment were not associated with participation in rehabilitation or with physical and mental components of HRQoL.

Interpretations

To a large extent, our population resembles other populations in cardiac rehabilitation, with a large proportion of men and a relatively high mean age (1). Compared with a similar study in a general Danish population (41), the HLQ scores of our population are low for scales 5 through 9, while the mean score for scale 3 (actively managing my health) was somewhat high in comparison. In summary, the population generally has low “cognitive capacities”, while the level of “executive capacities” is more mixed (cf. table 6.1).

Very few studies have been conducted on health literacy in relation to rehabilitation. In contrast to our findings, Dankner et al. show that some cognitive capacities related to health literacy may play a significant role in rehabilitation participation (22). In eight of nine HLQ scales, our results trended towards positive associations between health literacy and participation. The non-significance may simply have been a consequence of the small sample size. However, since the majority of the population was referred by a clinician (general practitioner or physician at hospital), a possible association between health literacy and participation may also have been clouded by the tendency to simply do as prescribed. We do not have any data providing evidence of the subsequent adherence to the rehabilitation program or the resulting health behaviour changes, but it is possible that participants with low health literacy adhere less from the services offered. Thus, a recent Danish randomized controlled trial testing a patient education intervention with several health-literacy-sensitive features in cardiac rehabilitation has also shown promising results regarding rehabilitation adherence (24). To inform health-literacy-sensitive initiatives in cardiac rehabilitation, future research using longitudinal designs in larger populations should further explore the possible associations between health literacy and participation and adherence to cardiac rehabilitation.

Our results on the positive association between health literacy and physical HRQoL (PCS) most likely reflect the complex reality of many people with extensive physical health problems, where the demands placed on their health literacy may be multiple.
These findings are consistent with several other studies in people with cardiac disease (13,19,42). Strong associations were found in relation to actively engaging with healthcare providers and navigating the healthcare system (scales 6 and 7), that is, “executive capacities”, which may reflect the many players and services that are often involved in the care of people with physical health challenges. An earlier study in people with cardiovascular disease also found associations between the more “cognitive capacities” of understanding health information (scale 9) and PCS (13). However, in our study, this association did not reach statistical significance. Thus, even though most cardiac rehabilitation programs focus on educating patients about disease and risk, the learning needs that people with low PCS present with may also be associated with their ability to act upon this knowledge and use the health system in an appropriate way (36,41).

In line with our results, literature on general populations confirms strong associations between health literacy and mental HRQoL (MCS) (9,43). Studies based on populations with cardiac disease are less conclusive (13,19). However, none of these studies include very comprehensive health literacy measures. Our results thus add evidence to the nature of this probable association.

We found a very strong association between the “social capacity” of having social support (scale 4) and MCS. This was perhaps to be expected, as social networks and mental well-being are closely related (44). However, the finding is important to consider in relation to health literacy interventions, as research has shown that relations and social networks are important in mitigating the consequences of low health literacy (45,46). As with PCS, we also found strong associations between MCS and the “executive capacities” of actively engaging with healthcare providers and navigating the healthcare system (scales 6 and 7) and with the ability to find good health information (scale 8). Furthermore, MCS was associated with the “cognitive capacity” of understanding health information well enough to know what to do (scale 9). It is not possible to infer causality in these associations, but we conjecture that there may be a vicious cycle between the different aspects of low health literacy, where they mutually reinforce each other. If so, all three types of capacities should be targeted simultaneously if successful improvements are to be achieved (36).

Reviews of international literature have shown that socio-demographic characteristics are strong predictors of low participation in rehabilitation (3) but are not necessarily predictors of rehabilitation outcomes such as quality of life (47). The evidence in this area is still insufficient (1). Surprisingly, in our study we found that socio-demographic characteristics were not strongly associated with participation in rehabilitation or physical and mental components of HRQoL. To some extent, these results may reflect
our relatively small homogenous sample and our single-site setting. In any case, these factors are difficult to act upon within the constraints of a rehabilitation service. Thus, other indicators of vulnerability may be more useful in this context.

Based on our results, actions to improve individual health literacy or respond to individual health literacy needs through organizational change or individualized service delivery may offer a promising opportunity to improve the impact of cardiac rehabilitation. Our data indicate that broad measures of health literacy provide a comprehensive picture of the challenges faced by people referred to cardiac rehabilitation. These measures could potentially inform the development of more targeted services such as individualized care plans. Attempts to use HLQ scales to inform intervention development have been reported in different settings (48–50). Future research should focus on evaluating the use and effect of these and other tools and interventions in this field.

**Strengths and limitations**

To the best of our knowledge, this is the first study to explore multiple dimensions of health literacy among people referred to cardiac rehabilitation. The use of the nine-scale HLQ is a strength of the study as it provides comprehensive evidence of the specific challenges in this population.

Low health literacy probably increased the likelihood of nonresponse to our survey, since responding to questionnaires is in itself a health literacy challenge. We sought to counter this issue by offering support when filling out the questionnaire and reminding nonresponders to reply. Our high questionnaire response rate (77.7%) is an indication of some success in this regard. However, a statistically significant difference was identified regarding educational attainment in the group of responders compared to nonresponders. If education is interpreted as a proxy for health literacy, this may indicate that the problem may not have been fully eliminated. Other studies confirm the role of educational attainment in health awareness and beliefs (51,52).

The lack of statistical strength due to the low number of people included in the study ($n = 150$) and the even smaller number reporting on their nonparticipation in the rehabilitation program ($n = 28$) is likely to have affected our results regarding health literacy and participation in rehabilitation. It is also likely that a relatively large share of the nonresponders in the survey were also nonparticipants in parts or the entire rehabilitation program. However, we have no data to support this assumption.

All our data are cross-sectional and do not allow causal inference. Health literacy is a dynamic capacity, and we did not have the opportunity to adjust for the time interval...
between the distribution of the questionnaire and the response. Thus, in some cases, responders may have concluded parts of the rehabilitation program before responding to the questionnaire, potentially skewing their health literacy levels compared with quick responders. In the case of rehabilitation participation, this may have increased the health literacy difference between participants and nonparticipants.

Conclusions

Using a broad health literacy measure covering nine aspects of health literacy across “cognitive”, “executive”, and “social capacities”, we provide a comprehensive analysis of some the challenges faced by people referred to cardiac rehabilitation. Our results indicate that health literacy may not be associated to participation in cardiac rehabilitation programs, while it is associated to some aspects of physical and mental HRQoL. Responding to peoples with diverse health literacy needs could be a potential target of future interventions targeting participation and outcomes in cardiac rehabilitation. We encourage further research to investigate the role of health literacy in cardiac rehabilitation. Results can be used to develop and pilot interventions using local information on health literacy and health literacy responsiveness.
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Chapter 7: Responding to health literacy challenges
Although the evidence regarding the role of health literacy as a determinant of health and healthcare service use is extensive (cf. chapters 2 and 4), less is known about the potential to influence these associations through interventions that improve individual health literacy capabilities or through initiatives in a social, cultural, or political context that affect the response to people’s diverse health literacy strengths and limitations.

Up until now, most published research on health literacy interventions has targeted individual health literacy. Several reviews are available summarizing the evidence concerning specific populations and outcomes. They recommend different intervention strategies such as specific communication techniques (1,2), certain design features of information materials (3,4), and patient empowering initiatives (1,3,4), or they suggest different intervention settings (5) and intervention intensities (3,5). Other reviews identify gaps of evidence in specific populations (6,7).

Many of the referred interventions only target the functional level of health literacy, and some reviews comment specifically on the paucity of interventions at interactive and critical health literacy levels (8–10), which may require more skill-directed initiatives focusing on the development of new capabilities rather than the acquisition of specific knowledge or management of specific health-related tasks (10).

Furthermore, the majority of the reported intervention studies have been conducted in the United States, and their findings may not be generalizable, e.g., to a Danish healthcare context (3,5,8). The few reviews focusing specifically on European studies are generally unable to identify specific effective intervention strategies (8,11). However, two WHO Health Evidence Network synthesis reports concerned with the prevalence and evaluation of health literacy policies acknowledge the broad range of components and domains addressed across health literacy initiatives in Europe (12,13), and a large review of evidence on health literacy in the European Union (HEALIT4EU, 2015) does point to two promising practices, namely: (i) interventions tailored to the needs of patients or groups with inadequate health literacy emphasizing patient or citizen involvement in the process, and (ii) interventions targeting critical and/or interactive skills and competencies (11). Both practices are very much in line with the strategies applied in study IV (chapter 8).

In relation to people with CVD, intervention studies are still sporadic and too diverse to draw conclusions on effectiveness within specific diagnostic groups (14,15). However, in small populations characterized by different cardiovascular conditions promising interventions have been reported in relation to, e.g., design of information material...
(16–18), medication management and adherence (19–21), and self-care (22,23). Also, more complex interventions involving both practice and patient level initiatives have yielded positive results (24,25). For example, the intervention study on CR adherence by Lynggaard et al. (2017) referred to in chapter 4 (cf. the section ‘health literacy and cardiac rehabilitation’) (25).

**Organizational responses to people’s diverse health literacy**

As evident from the above, most intervention studies are carried out in clinical settings and aim at improving health outcomes in populations with defined health challenges. There is a paucity of strategies targeting health literacy through health promotion at community or population levels (10,26,27). However, in consequence of a rising political focus on health literacy and the growing body of international, national, and local policies and strategies concerning health literacy, more and more attention has been given to health literacy interventions in settings that focus on the lifelong development of health literacy capabilities (10,28,29) and the reduction of contextual demands and complexities under which individual health literacy capabilities are developed and applied (28,30). Organizations involved in health promotion, prevention, and care is one such setting.

Several studies are available discussing theoretical approaches to identify and respond to gaps in health literacy responsiveness of organisations. Paasche-Orlow et al. (2006) suggest three overarching principles, namely:

1. **Productive client-provider interactions enhanced through comprehensible communication practices, provider capacity building, and the development of health communication technologies;**

2. **Improved organization of healthcare based on patient-centred principles, simple access and utilization, as well as improved quality development concerning vulnerable populations;**

3. **Embracing an ecological perspective on vulnerability by acknowledging the numerous personal and contextual factors influencing health and enhancing trustworthy public communication on health** (31).

Furthermore, Willis et al. (2014) report on strategies to improve the organizational capacity for providing health literacy responsive services at political, organizational, and collaborative levels. They suggest that building upon fixed policies or guidelines, organizations may further improve the impact of health literacy initiatives by using bottom-up approaches and distributed leadership to enhance local fit and induce a
Responding to health literacy challenges

local culture of learning and responding. Such an approach could furthermore
transcend the individual organization and include partnerships and cross-sectoral
collaborations (32).

At a more practical level, a spectrum of tools and guidelines to assess organizational
health literacy responsiveness are available (30) and have proven effective in raising
awareness of organizational challenges relating to health literacy in healthcare
organizations (33). The Agency for Healthcare Research and Quality (United States) has
even commissioned the development of *the Health Literacy Universal Precautions
Toolkit* to inspire and support the development of health literacy sensitive practices
(34), and there is some evidence that selected tools have been applied with success
(35–39). However, the complex reality of most health organizations including a range of
external demands and targets, the local organization, leadership and bureaucracy, as
well as the available technology and workforce capacity constitute potential barriers
affecting the local fit and long-term sustainability of such initiatives (36). Thus, there is
a lack of approaches to improve health literacy responsiveness in a more
comprehensive and flexible manor across organizations or their subunits (30,33).

In study IV, we use local knowledge and participatory approaches to enhance the
integration of a health literate thinking as well as the organizational health literacy
responsiveness in CR services which are otherwise designed according to national and
regional guidelines. We test a health literacy intervention development methodology –
the OPtimising HEalth LiterAcy and Access (Ophelia) approach – focusing not on specific
improvement initiatives or tools, but rather on organizational impact in terms of
changing values, organizational strategies, and day-to-day practices.

**RATIONALE AND METHODOLOGY IN STUDY IV**

The explorative study IV (chapter 8) (40) examines the application of an extended
version of the Ophelia approach (cf. sections below) in a Danish municipal CR unit.
Accordingly, we hypothesize that organizational changes aimed at improving
organizational health literacy responsiveness in a municipal cardiac rehabilitation unit
can be developed and integrated using a systematic intervention development
methodology based on local needs assessments, co-design methodologies, and
pragmatic intervention testing (cf. preface).

The study builds on the results of studies I-III (cf. chapters 3, 5, and 6) and is further
based on local knowledge and needs assessments. It provides evidence on the
organizational impact of using the Ophelia methodology to develop organizational health literacy responsiveness.

Below, the study setting and methodologies are described and will be further discussed in chapter 9. For further details on the approaches used, please refer to the publication (cf. chapter 8) (40).

**Randers Municipal Rehabilitation Unit**

Denmark has 98 municipalities divided among five administrative regions. Randers Municipal Rehabilitation Unit, where study IV was carried out, is situated in Randers Municipality in Central Denmark Region and has approximately 98,000 inhabitants. Compared with the regional average, Randers Municipality has a less favourable socio-geographic profile based on the income, work situation, and educational attainment of inhabitants in municipal subareas (41). Also, the prevalence of low health literacy based on HLQ scale 9 (Understanding health information well enough to know what to do) is significantly higher in Randers Municipality than the Regional average (41).

Randers Municipal Rehabilitation Unit is housed in Randers Health Centre together with other regional, municipal, and private health services including a pharmacy, prenatal and child healthcare services, a dental care clinic, and several specialized health clinics. Randers Municipal Rehabilitation Unit offers free-of-charge rehabilitation programmes covering major chronic conditions and post-hospitalization rehabilitation. The majority of rehabilitation attendees are referred from local hospitals or general practitioners.

The staff is divided into eight teams, one of which is concerned with CR. Most healthcare professionals in the unit are physiotherapists, but there are also nurses, occupational therapists, and dietitians. On the management level, there is a manager in charge of organizational development, one in charge of professional development, and a unit leader. The last named refers to the health director of the municipality.

The CR services in Randers Municipal Rehabilitation Unit is based on national (42) and regional recommendations (43) and includes phase 2 and phase 3 rehabilitation (cf. chapter 4), although the former constitute the vast majority. The CR programme is described in further detail in study III (cf. chapter 6).

**The Ophelia approach in the Heart Skills Study**

In study IV (cf. chapter 8), we applied the Ophelia approach in the CR team of Randers Municipal Rehabilitation Unit. The Ophelia approach aims to strengthen health systems through the enhancement of the health literacy of individuals and/or the improvement
of health literacy responsiveness of organizations. The Ophelia approach was developed and tested in Victoria, Australia, in 2014-16 (44,45). A step-by-step manual (46) as well as additional tools and templates (47,48) are available to guide and support users of the approach. The methodology also makes up the foundation of the WHO information sheets ‘Health literacy toolkit for low- and middle-income countries’. Around the world several applications of the Ophelia approach are under way (49,50), though few are yet reported scientifically (45,51,52).

Basically, the Ophelia approach consists of three phases (figure 7.1): (i) A needs assessment based on the measurement of health literacy in a relevant population using the HLQ or the ISHA-Q (cf. table 1.1, chapter 1) with the purpose of identifying local health literacy strengths and needs, (ii) a co-design process involving all relevant stakeholders in designing and planning local health literacy interventions, and (iii) an implementation and evaluation process refining the planned interventions using continuous quality improvement methodologies (46). Each phase involves a series of steps thoroughly described in study IV (chapter 8).

Figure 7.1. The three phases of the Ophelia approach (adapted* from Beauchamp et al. (2017) (45))

![Phase 1: Needs assessment](Identifying local health literacy strengths, needs and issues)

![Phase 2: Co-design](Stakeholders deciding and planning interventions responding to local needs)

![Phase 3: Implementation and evaluation](of interventions using continuous quality improvement cycles)

*The figure text is reduced compared to the original.

Needs assessments in the Heart Skills Study (phase 1)

The Heart Skills Survey previously described in chapter 4 (cf. the section ‘Rationale and methodology in study III’) was the basis of the user health literacy needs assessment in study IV. All respondents referred between 1 January and 31 December 2017 and reporting on all HLQ scales were included in the analysis (N = 162). The processing included the descriptive cluster analysis technique also applied in study I (cf. chapters 2
and 3), yielding seven distinct clusters. To facilitate the understanding and reflection of the identified health literacy challenges, three vignettes (user narratives) corresponding to the three most challenged clusters were developed and used in the co-design process.

Although the Ophelia Approach aims at improving both individual health literacy as well as health literacy responsiveness (45), the recommended needs assessment is based upon the identification of health literacy needs and strengths using individual health literacy measures only. In study IV, we wished to focus specifically on the health literacy responsiveness of Randers Municipal Rehabilitation Unit CR services and therefore decided to add an assessment – namely the Organizational Health Literacy Responsiveness (Org-HLR) process (53) – identifying organizational strengths and needs in relation to health literacy. Thereby, we obtained an overview of the baseline health literacy responsiveness and a good indication of the organizational challenges we needed to address. We also had the opportunity to introduce a health literate thinking in Randers Municipal Rehabilitation Unit, which was useful considering the general ignorance of the concept of health literacy in the Danish healthcare system including Randers Municipal Rehabilitation Unit.

The Org-HLR process was developed in an Australian setting by Trezona et al. (53). The process aims to support organizations to assess and improve their health literacy responsiveness. It consists of three consecutive activities each supported by a tool and carried out as workshops within the organization. Table 7.1 outlines the process and tools involved. The result is a health literacy responsiveness action plan enabling the involved organization to plan, implement, and follow up on health literacy responsiveness improvements over time.
Table 7.1. The Org-HLR process and supportive tools based on Trezona et al. (2018) (53)

<table>
<thead>
<tr>
<th>Activity</th>
<th>Content</th>
<th>Supportive tool</th>
</tr>
</thead>
<tbody>
<tr>
<td>Reflection activity</td>
<td>A 1- to 2-hour workshop presenting the concepts of health literacy and health literacy responsiveness and encouraging discussion and reflection on their local application</td>
<td>A reflection tool consisting of five open-ended questions</td>
</tr>
<tr>
<td>Self-assessment activity</td>
<td>A 4-hour workshop in which participants self-assess their organizational health literacy responsiveness</td>
<td>A self-assessment tool based upon the six internal domains of the Org-HLR framework (domain no 2-7). In all the tool includes 110 statements to consider. Existing good practices and improvement ideas are identified.</td>
</tr>
<tr>
<td>Prioritization activity</td>
<td>A 3-hour workshop in which improvement ideas identified at the self-assessment workshop are discussed and prioritized</td>
<td>A prioritization tool allows participants to discuss each improvement idea based on its importance, its urgency, and the resources acquired to carry it out.</td>
</tr>
</tbody>
</table>

The Org-HLR self-assessment tool plays a central role in the methodology and theoretically builds upon the Org-HLR framework, which describes the characteristics of organizational health literacy responsiveness across seven domains. The domains were developed using concept mapping methodologies among health and social service professionals (54). Figure 7.2 illustrates the framework.
Our application of the Org-HLR process is described in a brief report (55) and only briefly in study IV (cf. chapter 8). The process was carried out in four of the eight teams in Randers Municipal Rehabilitation Unit including the CR team. The methodology does not dictate the number or composition of participants, but we chose to include staff in all three phases, while leaders were only included in the reflection and prioritization activities, leaving the self-assessment to be carried out from a staff perspective.

Co-design and continuous quality improvement in the Heart Skills Study (phase 2-3).

The co-design process of the Heart Skills Study adheres closely to the Ophelia manual (46) and included intervention idea generation, prioritization of intervention ideas, detailed intervention planning, and adjustment of interventions according to test results. As an add-on to the first testing of the Ophelia approach in nine healthcare setting in Victoria, Australia, we included CR users throughout the process. The users
participated along with staff and leaders in the co-design workshops. Furthermore, two CR user representatives were included in the project management team facilitating, structuring, and analyzing the Ophelia application. Together with the CR team and unit leaders, these two also served as informants in the qualitative organizational impact analysis (cf. chapter 8).

The Ophelia approach builds its intervention implementation and evaluation on quality improvement collaborative methodologies (56,57), refining and optimizing the interventions through collaboration and feedback across participating sites (44). However, the Heart Skills Study was conducted in only one setting. Consequently, we were not able to apply this methodology fully. We did adhere to the suggested local iterative quality improvement test cycles – that is the Plan-Do-Study-Act (PDSA). This methodology was first introduced by Langley et al. (1992) (58) and has been widely spread through the Institute for Health Care Improvement (IHI) (59). The technique dictates planning (P), initial small-scale tests of improvements (D), and simple data collections (S) followed by refinement of the improvement (A) before renewed testing, e.g. on a slightly larger scale. This approach allows initiatives to develop slowly in the local context, ensuring optimal local fit and minimal intrusion before accepted as being advantageous. During the Heart Skills study period, two PDSA cycles were carried out, and interventions were adjusted according to the findings at co-design workshops in Randers Municipal Rehabilitation Unit (cf. chapter 8 for further details).


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Chapter 8: Improving health literacy responsiveness in cardiac rehabilitation

Study IV: Improving Organizational Health Literacy Responsiveness in Cardiac Rehabilitation Using a Co-Design Methodology: Results from the Heart Skills Study

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https://www.mdpi.com/1660-4601/17/3/1015/htm
Abstract

For health services, improving organizational health literacy responsiveness is a promising approach to enhance health and counter health inequity. A number of frameworks and tools are available to help organizations boost their health literacy responsiveness. These include the Ophelia (OPtimising HEalth Literacy and Access) approach centred on local needs assessments, co-design methodologies, and pragmatic intervention testing. Within a municipal cardiac rehabilitation (CR) setting, the Heart Skills Study aimed to: (1) Develop and test an organizational health literacy intervention using an extended version of the Ophelia approach, and (2) evaluate the organizational impact of the application of the Ophelia approach. We found the approach successful in producing feasible organizational quality improvement interventions that responded to local health literacy needs such as enhanced social support and individualized care. Furthermore, applying the Ophelia approach had a substantial organizational impact. The co-design process in the unit helped develop and integrate a new and holistic understanding of CR user needs and vulnerabilities based on health literacy. It also generated motivation and ownership among CR users, staff, and leaders, paving the way for sustainable future implementation. The findings can be used to inform the development and evaluation of sustainable co-designed health literacy initiatives in other settings.
Introduction

Responding to population health literacy needs is a promising approach to counter inequity in health and healthcare delivery (1). Health literacy is “the combination of personal competencies and situational resources needed for people to access, understand, appraise and use information and services to make decisions about health. It includes the capacity to communicate, assert and act upon these decisions.” (2).

The application of health literacy capabilities cannot be separated from the demand and complexity of the context in which they are used, e.g., the health system (3). Organizational health literacy responsiveness refers to “the way in which services, organizations and systems make health information and resources available and accessible to people according to health literacy strengths and limitations” (2). Frameworks and tools to develop or evaluate organizational health literacy responsiveness have emerged over the past decades (4), paving the way for the integration of the concept into intervention development methodologies. Farmanova et al. (2018) provide a summary of the different tools available to tackle health literacy barriers and to facilitate the promotion of health literacy at the organizational level (4). Despite recent progress, there is little robust evidence of the effectiveness of initiatives to improve organizational health literacy responsiveness (5). A rapid realist review by Willis et al. (2014) suggests that actions across governmental, organizational, and partnership level can boost organizational capacity to address health literacy (6). These include strategies that build organizational commitment, create ownership and involvement, promote a culture of ongoing organizational experimentation and learning, build community support, and strengthen teams through shared responsibilities (6).

Featuring all of these strategies, the Ophelia (OPtimising HEalth Literacy and Access) approach is a methodology available to help improve individual and organizational health literacy responsiveness. It was inspired by a set of well-established intervention development methodologies (7). Intervention Mapping (IM) is a stepwise process originally designed to identify, develop, implement, and evaluate health education programs (8). The Ophelia approach has a similar structure, but seeks, in particular, local fit by combining the individual needs assessment with local knowledge on organization and context, and by recommending continuous low-scale quality improvement cycles (9) before large-scale implementation. It also prescribes an intervention development inspired by realist methodologies’ focusing on contexts, mechanisms, and outcomes (10). The Ophelia approach has been tested in a number of settings and is an effective and flexible guide to help identify health literacy challenges.
and develop and implement locally appropriate solutions (11–13). However, to the best of our knowledge, the Ophelia approach has not previously been applied in cardiac rehabilitation (CR).

People with cardiac conditions are subject to high demands on their self-care abilities, including their health literacy capabilities. They undergo complex treatment regimens that usually require extensive health behaviour modifications (14). A large Danish study has shown that people with cardiac conditions have significantly lower health literacy than the general population (15). Among people with cardiac conditions, low health literacy is associated with adverse health behaviours (16,17) and poor quality of life (17–19). CR programs are designed to sustain or improve self-care, health behaviour, and quality of life, but participation and adherence is dependent on social health determinants such as education, cohabitation, and income (20). Health literacy is associated with all of these determinants (21) and may be a modifying factor in relation to their impact on health outcomes (22,23). Organizational initiatives responding to health literacy needs may be a suitable approach to improve the equitable impact of CR services (24,25).

With the ultimate goal of improving organizational health literacy responsiveness in a municipal CR setting, the Heart Skills Study aimed to: (i) develop and test an organizational health literacy intervention using an extended version of the Ophelia approach, and (ii) evaluate the organizational impact of the application of the Ophelia approach.

Materials and methods

The Ophelia Approach

The Ophelia approach is a systematic intervention development and testing methodology and entails a series of steps (figure 8.1) (7,26). To allow flexibility and creativity in local settings while maintaining the central values of the Ophelia approach, a set of core principles guides its application (table 8.1) (11).

In the following section, we present how the seven steps of the Ophelia approach were applied in the Heart Skills Study and subsequently how we carried out our examination of organizational impact of the process.
Figure 8.1. The Ophelia approach in seven steps (adapted from Batterham et al. (7)*).

- **Step 1. Aim, scope, and set-up.** Identify project aim and scope to guide the following data collection.

- **Step 2. Needs assessment.** Identify health literacy needs and contextual assets and barriers.

- **Step 3. Idea generation.** Allow local stakeholders to interpret local needs and generate improvement ideas through co-design workshops.

- **Step 4. Program logic model.** In the project management team select interventions to test and develop program logic model and define specific goals.

- **Step 5. Plan intervention details.** Together with stakeholders plan intervention details and thier testing and evaluation.

- **Step 6. Pilot testing.** Pilot the interventions using repeated improvement cycles.

- **Step 7. Implementation.** Interventions showing potential to improve health literacy and/or health outcomes, plan full scale implementation and intervention trial.

* The steps were adapted in accordance with the steps described in the Ophelia manual (26), e.g., adding step 1 to the original methodology.
Table 8.1. Eight Ophelia principles to guide the development and implementation of interventions (adapted from Beauchamp et al. (11)*).

<table>
<thead>
<tr>
<th>Principle</th>
<th>Explanation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Outcomes focused</td>
<td>Improve health and reduce health inequities, e.g., by meeting project aims and intervention objectives, and implementing logic models</td>
</tr>
<tr>
<td>Equity driven</td>
<td>All activities at all stages prioritize disadvantaged groups and those experiencing inequity in access and outcomes, e.g., by identifying and acting upon the needs of disadvantaged groups.</td>
</tr>
<tr>
<td>Co-design approach</td>
<td>In all activities at all stages, relevant stakeholders engage collaboratively to design solutions.</td>
</tr>
<tr>
<td>Needs-diagnostic approach</td>
<td>Participatory assessment of local needs using local data, e.g. using multidimensional health literacy tools.</td>
</tr>
<tr>
<td>Driven by local wisdom</td>
<td>Intervention development and implementation is grounded in local experience and expertise.</td>
</tr>
<tr>
<td>Responsiveness</td>
<td>Organizational response to health literacy diversity and other unique needs in the target population takes account of individuals, contexts, cultures and time</td>
</tr>
<tr>
<td>Systematically applied</td>
<td>A multilevel approach in which resources, interventions, research and. Policy are organized to optimize health literacy, e.g., by improving client’s skills, enabling clinicians, changing organizational processes or engaging with external agencies.</td>
</tr>
<tr>
<td>Sustainable**</td>
<td>Optimal health literacy practice becomes normal practice and policy, e.g., when small interventions at one level build up over time to achieve organizational priorities and objectives.</td>
</tr>
</tbody>
</table>

*Details and examples were added to the original version. **In the original publication of the principles ‘sustainable’ was listed before ‘systematically applied’. We changed the order to support the logic of our reporting, ending with long-term sustainability.
Application of the Ophelia Approach

Aim, Scope, and Setup (Step 1). The Heart Skills Study was carried out between January 2017 and November 2019. It was set in Randers Municipal Rehabilitation Unit in Randers Municipality, Denmark, an area with approximately 98,000 inhabitants. The Unit is situated in a community health centre along with several other health services and clinics. The unit offers rehabilitation programs covering major chronic conditions or post-hospitalization rehabilitation as part of the Danish free-of-charge public health insurance system. The Heart Skills Study was carried out by the CR team, which consisted of a nurse, three physiotherapists, an occupational therapist, and a dietician.

The study focus, scope, and overall aim were developed by leaders in the rehabilitation unit and the research team prior to the co-design process. A project management team, consisting of a development physiotherapist, two user representatives, and a researcher (A.A.), facilitated the Heart Skills Study co-design process.

Needs Assessment (Step 2). We completed two distinct local needs assessment analyses: a user health literacy assessment and an organizational health literacy responsiveness analysis. The latter was included as an add-on to the original Ophelia approach.

For the user health literacy assessment, we carried out a cross-sectional survey among all 222 people referred to CR in Randers Municipal Rehabilitation Unit in 2017. The survey is described in detail elsewhere (27). Adhering to the Ophelia approach (26), we based our survey on the Health Literacy Questionnaire (HLQ). The HLQ consisted of 44 items divided into nine scales each covering one of the following aspects of health literacy: (1) Feeling understood and supported by healthcare providers, (2) having sufficient information to manage health, (3) actively managing my health, (4) social support for health, (5) active appraisal of health information, (6) ability to actively engage with healthcare providers, (7) navigating the healthcare system, (8) ability to find good health information, and (9) understanding health information well enough to know what to do. The HLQ was thoroughly validated (28,29) and was translated into Danish using standardized procedures (30).

We analysed the survey data using hierarchical cluster analysis. This provided further details on different health literacy profiles within the population than is available in the original survey study (27). The cluster analysis was based on all nine HLQ scale scores using Square Euclidian Distance as the distance measure and Ward’s linkage as the clustering method (31). Since the HLQ scales use two different response ranges (1–4 and 1–5), all scores were converted to z-scores when reported to allow direct comparison between scales. Based on the clusters, we drafted short vignettes...
(narratives) representing the typical health literacy profiles. Eight short semi-structured telephone interviews with representatives from the three most challenged clusters were conducted to provide examples of life conditions and health literacy challenges. This information was then anonymized, processed, and combined in the final vignettes (7,11). The vignettes were developed before the data were converted to z-scores. Individuals interviewed were not relocated to other clusters after conversion.

We based our organizational health literacy responsiveness analysis on the Organizational Health Literacy Responsiveness Self-assessment Tool and Process (Org-HLR) (32,33), which was carried out across the rehabilitation unit (not only the CR team). The Org-HLR comprised three consecutive workshops and associated tools: (1) a two-hour reflection workshop in which staff and leaders from the rehabilitation unit familiarized themselves with the concept of health literacy and applied it to their local context, (2) a four-hour self-evaluation workshop in which staff evaluated their organization’s health literacy responsiveness and came up with improvement ideas, and (3) a three-hour prioritization workshop in which staff representatives (N = 4) and leaders (N = 3) prioritized their ideas in order to inform a future action plan to improve their organizational health literacy responsiveness. Our methodology and analysis are reported in detail elsewhere (34).

Idea Generation, Program Logic Model, and Intervention Details (Steps 3–5). In order to generate ideas derived from the needs assessment, we continued the process conducting three separate idea-generating workshops for staff from the cardiac team, leaders from the rehabilitation unit, and users of the CR service. Users were recruited by convenience and interest by the CR nurse among those enrolled in the CR program, while all staff and leaders available at the time participated. In each workshop, the vignettes were presented and participants were asked to consider how each of the people described could be supported at an individual and organizational level. After the workshop, we categorized each of the emerging ideas under one of the following themes: Program referral and start-up, program activities, patient education and information, relations with healthcare providers, social support, external collaborators, program completion, and any other ideas.

As part of the co-design process, a crude prioritization of ideas for interventions was subsequently made by the project management team. Guided by the overall aim of the Heart Skills Study (step 1), we first developed specific intervention objectives. From the workshop ideas and the Org-HLR results we then choose preliminary intervention elements. Based on these and a systematic literature assessment of CR interventions, researcher A.A. developed a preliminary program logic model for two novel interventions. During the subsequent planning workshop, the program logic model was
presented simultaneously to staff, leaders, and users to be discussed and allow changes and adjustments. At the same workshop, the intervention elements were refined and developed in further detail. Participants in the planning workshop included all users, staff, and leaders, who participated in one of the idea-generating workshops and were willing to continue their participation.

**Testing and Implementation (Steps 6 and 7).** The Ophelia approach recommends the use of quality improvement cycles to test and adjust interventions. In spring 2019, each intervention element was tested in small scale in the rehabilitation unit or with relevant collaborators. We kept each test separate to be able to study the effect of the elements independently. Our results were discussed among staff, leaders, users, and collaborators at a follow-up workshop and relevant adjustments were made. Participants in the follow-up workshop included all users, staff, and leaders, who participated in one of the idea-generating workshops and were willing to continue their participation. The full and adjusted intervention was then tested in a second improvement cycle during a two-month study period in autumn 2019.

**Evaluating the Organizational Impact of the Intervention**

We evaluated the organizational impact of the application of the Ophelia approach based on the eight Ophelia principles (table 8.1) (11). This allowed us to link the evaluation directly to the aims and values underlying the Ophelia approach.

We conducted a focus group discussion with the staff on the cardiac team that had been most involved in the Heart Skills Study \(n = 3\) as well as semi-structured individual interviews with leaders above day-to-day managerial level in the rehabilitation unit \(n = 2\) and both user representatives on the project management team \(n = 2\). In the following text the seven participating individuals are termed “participants”. To ensure validity, the interviews were conducted (C.B.S. and K.R.), transcribed verbatim (C.B.S.), and analysed (C.B.S.) by researchers who did not facilitate the co-design process (A.A.). The interview guides were based on the eight Ophelia principles and are available in the supplementary material.

The organizational impact analysis was based on a deductive closed coding (i.e., preselected codes) (35). The codes corresponded to the eight Ophelia principles. Each interview was coded separately, then data was merged to examine similarities and differences across participant type (staff, leaders, and users), and, finally, we synthesized and summarized the findings and highlighted major points using participant quotes.
Approvals and Ethical Considerations

The Heart Skills Study adhered to the General Data Protection Regulation (GDPR), the Helsinki Declaration, and national consent guidelines. The study was approved by the Danish Data Protection Agency (2015-57-0002 (62908, 141)).

All survey respondents in the user health literacy assessment were informed about the aims of the study and gave verbal consent before the questionnaire was distributed. Their voluntary completion and return of the survey questionnaires constituted implied consent.

In the organizational impact analysis, written informed consent was obtained from all participants. Because of the small number of participants and their active roles in the Heart Skills Study, complete anonymity could not be provided. This was accepted by all participants.

Results

Application of the Ophelia Approach

Figure 8.2 provides an overview of the different steps we undertook to develop and test our intervention using the Ophelia approach.

Figure 8.2. Application of the extended Ophelia approach to develop a health literacy responsiveness intervention in Randers Municipal Rehabilitation Unit 2017–2019.

Aim, Scope, and Setup (Step 1). Following a few rounds of iteration, leaders in the rehabilitation unit and the research team decided that the specific aim of the intervention development should focus specifically on vulnerable groups. The aim was phrased ‘to develop a specific intervention taking off from the concept of health literacy and aiming to improve the quality of CR services offered to vulnerable individuals or groups.’
Needs Assessment (Step 2). The first part of the needs assessment was the user health literacy assessment. There were 178/222 (80.2%) people referred to CR in 2017 who responded to the survey. Of these, 162 respondents provided enough information for their data to be included in the cluster analysis. Table 8.2 outlines the results. We chose a seven-cluster solution based on variance within clusters and diversity between clusters. One of the clusters which appeared already in very low cluster solutions was very small. Due to data protection, we merged this cluster with its closest fit (clusters 1 and 2 in table 8.2).

Each cluster had its own socio-demographic composition. For example, mean age was highest in cluster 4 (71.87 years), and there was a larger likelihood of being female (46.7%), living alone (46.7%), and having ≤11 years of schooling (38.5%) in cluster 7 (representing lowest overall health literacy) compared to other clusters. Clusters 1 and 2 (representing highest overall health literacy) had the highest percentage of male gender (75.86%) and the lowest percentage having ≤11 years of schooling (17.2%).

In general, there was a tendency towards more adverse health outcomes in the clusters with the most health literacy challenges. For example, cluster 7 had the highest percentage not participating in rehabilitation (33.3%), the highest percentage of smokers (46.7%), and the lowest mean physical health-related quality of life score (36.6 units). Cluster 6 had the lowest mean mental health-related quality of life score (36.9 units), though this was also low in clusters 4 (42.3 units) and 7 (43.5 units).

The second part of the needs assessment was the organizational health literacy responsiveness analysis. The results are described in detail in a separate publication (34). The process served as a local capacity development activity, which improved the general knowledge and understanding of health literacy. As a result of the process, the rehabilitation unit developed a local action plan consisting of 11 initiatives across both strategic, managerial, and practice levels in the unit. Of these, some were integrated in the subsequent Ophelia intervention development concerning CR and others were implemented alongside it and across the unit as a whole. An example was the introduction of the “Conversational Health Literacy Assessment Tool” (37,38), to identify health literacy strength and weaknesses in start-up sessions, which was integrated in the intervention package 2. Another example was the use of health literacy as a formal local quality indicator in the unit, which was not part of the tested intervention, but served to support the integration of a health literate thinking in the unit.
Table 8.2. Socio-demographic, health, and health literacy characteristics by cluster (n = 162) in the Heart Skills Study survey (2017).

<table>
<thead>
<tr>
<th>Cluster</th>
<th>1 &amp; 2*</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>All</th>
</tr>
</thead>
<tbody>
<tr>
<td>n in cluster</td>
<td>29</td>
<td>64</td>
<td>10</td>
<td>18</td>
<td>26</td>
<td>15</td>
<td>162</td>
</tr>
<tr>
<td>% of total population</td>
<td>17.90</td>
<td>39.51</td>
<td>6.17</td>
<td>11.11</td>
<td>16.05</td>
<td>9.26</td>
<td>100.00</td>
</tr>
</tbody>
</table>

**Socio-demographic characteristics**

<table>
<thead>
<tr>
<th></th>
<th>Cluster 1 &amp; 2*</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>All</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mean age (years) (SD)</td>
<td>67.86 (10.03)</td>
<td>65.95 (11.53)</td>
<td>71.87 (10.66)</td>
<td>68.88 (10.72)</td>
<td>66.26 (11.03)</td>
<td>63.53 (13.89)</td>
<td>66.78 (0.91)</td>
</tr>
<tr>
<td>Male gender (%)</td>
<td>22 (75.86)</td>
<td>46 (71.88)</td>
<td>10 (100.00)</td>
<td>N/A</td>
<td>17 (65.38)</td>
<td>8 (53.33)</td>
<td>N/A</td>
</tr>
<tr>
<td>Living alone (%)</td>
<td>N/A</td>
<td>17 (27.87)</td>
<td>N/A</td>
<td>5 (27.78)</td>
<td>5 (20.00)</td>
<td>7 (46.67)</td>
<td>42 (26.58)</td>
</tr>
<tr>
<td>≤11 years of schooling (%)</td>
<td>5 (17.24)</td>
<td>10 (17.86)</td>
<td>N/A</td>
<td>N/A</td>
<td>5 (20.00)</td>
<td>5 (38.46)</td>
<td>30 (20.83)</td>
</tr>
</tbody>
</table>

**Health characteristics**

<table>
<thead>
<tr>
<th></th>
<th>Cluster 1 &amp; 2*</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>All</th>
</tr>
</thead>
<tbody>
<tr>
<td>Not participating in rehabilitation (%)</td>
<td>N/A</td>
<td>10 (15.87)</td>
<td>0 (0.00)</td>
<td>5 (27.78)</td>
<td>N/A</td>
<td>5 (33.33)</td>
<td>24 (14.91)</td>
</tr>
<tr>
<td>Smoker (%)</td>
<td>6 (20.69)</td>
<td>19 (30.65)</td>
<td>N/A</td>
<td>N/A</td>
<td>6 (23.08)</td>
<td>7 (46.67)</td>
<td>44 (27.50)</td>
</tr>
<tr>
<td>Mean HRQoL (physical component summary) (SD)</td>
<td>44.00 (10.38)</td>
<td>40.40 (11.03)</td>
<td>41.80 (11.50)</td>
<td>41.95 (9.52)</td>
<td>37.93 (10.45)</td>
<td>36.59 (9.99)</td>
<td>40.49 (0.86)</td>
</tr>
<tr>
<td>Mean HRQoL (mental component summary) (SD)</td>
<td>51.81 (9.10)</td>
<td>48.82 (9.92)</td>
<td>42.27 (13.30)</td>
<td>48.91 (9.39)</td>
<td>38.87 (10.26)</td>
<td>43.50 (10.26)</td>
<td>46.76 (0.89)</td>
</tr>
</tbody>
</table>

**Health literacy (mean Scale Scores)**

<table>
<thead>
<tr>
<th></th>
<th>Cluster 1 &amp; 2*</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>All</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Healthcare provider support (SD)</td>
<td>3.73 (0.49)</td>
<td>2.92 (0.42)</td>
<td>3.33 (0.35)</td>
<td>3.19 (0.39)</td>
<td>2.52 (0.39)</td>
<td>2.67 (0.43)</td>
<td>3.03 (0.57)</td>
</tr>
<tr>
<td>2. Having sufficient information</td>
<td>3.61</td>
<td>3.12</td>
<td>3.20</td>
<td>2.88</td>
<td>2.56</td>
<td>2.42</td>
<td>3.03</td>
</tr>
</tbody>
</table>
3. Actively managing health
(SD) (0.38) (0.25) (0.15) (0.33) (0.25) (0.38) (0.47)
3. Actively managing health
(SD) 3.52 3.01 3.02 2.39 2.87 2.25 2.94
4. Social support for health
(SD) (0.52) (0.35) (0.41) (0.46) (0.57) (0.43) (0.53)
4. Social support for health
(SD) 3.66 3.10 3.52 2.99 2.75 2.89 3.14
5. Appraisal of health information
(SD) (0.42) (0.31) (0.30) (0.45) (0.34) (0.32) (0.52)
5. Appraisal of health information
(SD) 3.28 2.76 3.16 2.12 2.57 2.05 2.71
6. Active engagement w. healthcare providers
(SD) (0.54) (0.35) (0.45) (0.38) (0.46) (0.61) (0.65)
6. Active engagement w. healthcare providers
(SD) 4.38 3.88 3.32 3.98 2.96 3.16 3.73
7. Navigating the health system
(SD) (0.60) (0.46) (0.41) (0.43) (0.50) (0.57) (0.73)
7. Navigating the health system
(SD) 3.99 3.64 2.88 3.58 2.64 2.41 3.37
8. Finding health information
(SD) (0.51) (0.30) (0.34) (0.50) (0.47) (0.45) (0.68)
8. Finding health information
(SD) 4.14 3.88 3.06 3.60 3.06 2.34 3.57
9. Understanding health information
(SD) (0.53) (0.30) (0.31) (0.47) (0.42) (0.71) (0.63)
9. Understanding health information
(SD) 4.05 3.90 3.00 3.86 3.25 2.60 3.64

SD, standard deviation; HLQ, Health Literacy Questionnaire; HRQoL, health-related quality of life, measured using the Short Form Health Survey 12 (SF-12) and its component scores (36); N/A, not available due to data protection regulations; * clusters 1 and 2 were merged post-analysis due to data protection considerations.

Idea Generation (Step 3). Based on clusters 5 through 7, three vignettes were developed. These were used to present the survey results in an easily understandable way and to inspire the participants in the three co-design workshops (users n = 6, staff n = 5, leaders n = 3). Collectively, the workshops generated 47 unique ideas on how to improve health literacy responsiveness of the unit. For example, participants suggested comprehensive individual needs assessments in each start-up session (theme referral and start-up) and a stronger call for support from relatives (theme social support).
Program Logic Model (Step 4). The project management team defined specific intervention objectives for three phases of the CR program: (1) Referral and start-up, (2) program delivery, and (3) program termination. Guided by these, the draft program logic model was developed by researcher (A.A.) and the project management team. Due to the limited time and resources available, we chose to focus mainly on the referral and start-up phases of the CR program. Table 8.3 (left column) provides an overview of the intervention objectives for this part of the CR program.

Table 8.3. Intervention objectives related to the initial phases of the cardiac rehabilitation (CR) program and results of the second quality improvement cycle.

<table>
<thead>
<tr>
<th>Intervention Objective</th>
<th>Test Result</th>
</tr>
</thead>
<tbody>
<tr>
<td>In the test period the number of referred people declining CR are reduced by 25% compared to survey data from 2017</td>
<td>Of 33 participants in start-up sessions in the test period 2 (6.1%) declined further rehabilitation. In the 2017 survey 25/174 (14.4%) reported non-participation—it is not known how many of these attended start-up sessions.</td>
</tr>
<tr>
<td>Before the test period, resources and support to encourage relatives and friends to participate in the rehabilitation program is developed</td>
<td>A written information leaflet was produced based on consultations with users and their relatives. Also, verbal invitation of relatives and friends has been introduced in the initial telephonic contact was with people referred to the unit.</td>
</tr>
<tr>
<td>In the test period 50% of people attending their CR start-up session bring a relative, friend or lay counsellor</td>
<td>Out of 33 referrals, 18 (54.5%) brought a relative or friend to the start-up session.</td>
</tr>
<tr>
<td>Before the test period a resource to support the problem-based needs assessment and planning sessions is developed</td>
<td>To identify vulnerable CR attendants, the “Conversational Health Literacy Assessment Tool” (37,38) was introduced and implemented. A consultation guide was developed to support the problem-based needs assessment and planning sessions.</td>
</tr>
<tr>
<td>In the test period vulnerable users are successfully identified and offered a problem-based needs assessment and planning session</td>
<td>Out of 31 rehabilitation starters 4 (12.9%) were identified as vulnerable and all were offered the problem-based needs assessment and planning session.</td>
</tr>
</tbody>
</table>

CR, cardiac rehabilitation.
Planning Intervention Details (Step 5). The program logic model was adjusted and adopted at the planning workshop (users $n = 5$, staff $n = 3$, leaders $n = 3$) where further co-design resulted in the two intervention packages adopted for pilot testing (table 8.4).

Table 8.4. Intervention packages developed in the Heart Skills Study in Randers Municipal Rehabilitation Unit (2017–2019).

<table>
<thead>
<tr>
<th>Package</th>
<th>Aim</th>
<th>Content of Package</th>
</tr>
</thead>
</table>
| 1       | Improve the social support of all people referred to CR in the unit | 1. Handing out written information at the regional hospital aimed at supporting relatives or friends.  
2. Verbally invite users to bring a relative or friend to CR start-up sessions.  
3. In collaboration with a local lay counsellor association, offer a voluntary ‘substitute relative’ when a referred person has no relevant person to bring. |
| 2       | Identify and respond to the needs of vulnerable people referred to the rehabilitation program | 1. Identify vulnerability based on a negative assessment of health literacy using the “Conversational Health Literacy Assessment Tool” (38), identification of mental challenges using the “Hospital Anxiety and Depression Scale” (39) or ‘at risk of non-adherence’ to the rehabilitation program.  
2. Offer an extra problem-based needs identification and program planning session to the vulnerable group. This involves discussion of their general situation and challenges, leading to an individualized care plan. |

CR cardiac rehabilitation.
Pilot Testing (Step 6). A few materials were developed prior to intervention piloting. Staff guides for all interventions were developed by a researcher (A.A.) based on workshop input and feedback from the cardiac team. Also, for intervention package 1.1 a pamphlet was developed based on workshop input and a focus group discussion with three relatives of CR attendees.

Results from the initial quality improvement cycle (data not shown) were presented and discussed at the follow-up workshop (users $n = 3$, staff $n = 5$, leaders $n = 3$, lay counsellor $n = 1$). Adjustments were made, e.g., improved distribution of written information to relatives and changes in the timing of offering lay counsellors.

In the second quality improvement cycle, all elements of both packages were tested simultaneously. The results in relation to the intervention objectives are reported in table 8.3.

Implementation (Step 7). The Heart Skills Study was not designed to report on long-term and full-scale implementation. However, the intention to maintain the current intervention activities and develop them further is evident from the organizational impact analysis as reported below.

Organizational Impact of the Heart Skills Study

Overall, our application of the Ophelia approach had a substantial organizational impact affecting both organizational values, service development strategies, and day-to-day practices. In the following, we report on our results by Ophelia principle (cf. table 8.1).

Outcomes Focused. All participants reported that the Heart Skills Study had already or has the potential to enhance service quality in the unit. According to user representatives and a leader, the process might not directly increase skills training or improve clinical measurements but, rather, there have been improvements in organizational quality, thus supporting participation and adherence to CR services.

The staff perceived that some CR users profited from the new initiatives. They have also personally enhanced their understanding about the health literacy needs of their users. Now, staff perceived themselves as being more persistent when they invited users to the program and that they differentiated their services to a larger extent:

“...If we want to act and help people in a good way, we have to differentiate, which we also did before, but now it is just much, much more clear and we have less “standard-package”...Sure, I think it has increased the quality.” (Staff)
Equity Driven. All participants acknowledged that the identification of vulnerability based on health literacy has been a core improvement resulting from the Heart Skills Study. A leader put it thus:
“Well, you can say, that it is almost the DNA in this project...” (Leader).

According to the leaders, working with health literacy has increased recognition of vulnerable users and their diverse abilities to profit from health services. However, both a leader and a user representative emphasize that health literate CR users may also have unforeseen challenges that need to be met.

The staff commented on the lack of vulnerable users involved in the co-design process, e.g., the workshops. They reflected that this type of user does not often have the resources or energy to participate. This may have affected the initiatives that were developed:
“Because I think, that we would have attained something completely different, if it was this type of users, we had involved from the beginning, right?...I just think it had been something different. But we just can’t really do that.” (Staff)

Co-Design Approach. All participants were very positive about the participatory methodologies of the Heart Skills Study. They valued the inclusion of many different perspectives, through which they have become wiser and developed a greater understanding of each other.

The leaders particularly appreciated the involvement of users, who they feel had given weight to the decision-making. They described their own role as mainly relating to the allocation of resources. However, the staff really appreciated the managerial backing, which meant they could invest time and resources in the study.

The staff felt that they had the opportunity to influence the design of the developed initiatives while also being receptive to the other partners involved. The co-design process has become part of their day-to-day practice:
“You see, it does not just go on in the organization where you develop a service, but co-creation also happens between the user and me. You help him move on or you find out how you can move on together, but I am also supported to understand...the next patient better in the future.” (Staff)

To the staff and the user representatives, in particular, the co-design approach supported a sense of community and ownership of the study. This was emphasized by the use of words such as “our project” and “the band” (i.e., the project management team). Both the user representatives and staff reflected on the importance of ownership. They described how the peripheral involvement of the hospital was not
enough to create engagement. As a result, the hospital did not distribute the information pamphlet (intervention package 1.1, table 8.4) as consistently as intended. Thus, staff recommend that future cross-sectoral processes should involve co-creation with all stakeholders at an early stage.

**Needs-Diagnostic Approach.** The user representatives acknowledged that the Heart Skills Study had identified some of the challenges of vulnerable users. According to one leader, the unit now works systematically with health literacy as an integrated part of practice, which has improved the staff’s ability to identify user needs. This observation was confirmed by the staff, who reflected that the concept has helped them understand users from a more holistic perspective and discover needs and vulnerabilities that may previously not have been detected:

“There are also some who surprised us, right? Where at first I would not have thought, that there might have been something. But then given the answers they gave (there was something, red.), which I would not necessarily have discovered otherwise.” (Staff)

**Driven by Local Wisdom.** According to both leaders and staff, the Heart Skills Study has built on local knowledge through the involvement of relevant stakeholders, including users, at different levels in the organization. Both user representatives felt that they had been able to contribute with their own experiences and that this played a substantial role in the study.

According to the staff and leaders, the study was in line with a general user-centred approach in the municipality. Hence, it was not a new concept to work with differentiated care. However, according to one leader, the health literacy thinking adds a useful holistic and systematic approach to their work:

“... because one thing is the somatic disease itself, but another is...how it is experienced by the citizen. So you might be able to sort of build on, that you learn that those two things are connected...” (Leader)

**Responsiveness.** Both leaders and staff confirmed that a procedure to identify users’ needs based on health literacy has been integrated into day-to-day practice. The Heart Skills Study has increased the understanding of what the organization should do to meet these needs. Health literacy could also be used to help guide financial prioritization in the unit. As one leader stated, however, if all users’ health literacy needs should be met, it would require a greater degree of differentiation than the present financial constraints allow.

The staff had several requests in relation to the development of more individualized services in the unit in the future. They stated that smaller exercise teams would be beneficial as it would allow them to respond better to users with low health literacy.
Furthermore, they articulated a need for tools to manage the new user-provider interactions introduced through the Heart Skills Study. Sometimes they identified challenges which they did not have the opportunity to solve. They consequently felt incapable and unsure if they had done their job well enough:

“...I would like to have had some personal tools to conduct conversations even more professionally... how do I leave them and feel that I have done well enough...That is, to communicate and be in control of the chaotic conversation it can sometimes be.” (Staff)

Systematically Applied. Beyond the new intervention packages, the Heart Skills Study has produced changes at several levels in the unit. According to a leader, health literacy and differentiated care have become key strategic priorities for the unit. This new focus has influenced the staff, who feel that differentiation has become a more legitimate topic and that the concept of health literacy has provided a professional argument for further differentiation. One leader emphasized the two aspects of the study that she would bring forward in particular:

“...the material content of the health literate way of thinking, but then I would also be interested in the methodological parts, that is the process, the design, if we could learn something from that. At any rate I am interested in how the staff, for one, become an integrated part of the process, and then how you could consider user involvement, which is already something we are discussing.” (Leader)

Sustainable. All participants acknowledged the value of the Heart Skills Study and supported its continued implementation and development. The staff reported that the simultaneous organizational changes support the long-term sustainability of the initiatives.

According to one leader, health literacy is now a theme in the professional development strategy of the municipal health administration beyond the rehabilitation unit. Health literacy awareness has been promoted to the whole health centre and the staff involved in the Heart Skills Study have transferred their experience to other teams and divisions. This was confirmed by staff who experienced the Heart Skills Study as a more involving process, than other similar improvement processes:

“Because sometimes it is dictated from above what we have to do, right? But this is a project, which has spread very much up and down and sideways...” (Staff)

The leaders reported that health literacy is likely to be a continued focus in the unit as it is aligned with general strategies on inequity in health in the municipality. If so, municipal health policies may support the long-term sustainability of the Heart Skills Study:
“...and when I have confidence in this, it is because I think, that it connects to our politics on inequality in health, which is not just something we have been thinking about in this municipality. It is, after all, a general problem in the whole healthcare system.” (Leader)

Finally, the participants believed that other municipalities could benefit from the Heart Skills Study, for example, in helping health professionals and relatives achieve a greater understanding of vulnerable citizens. However, a leader emphasized that the results of the study could not be directly transferred to another context, as it would be in conflict with the study methodology, i.e., the participatory approach.

Discussion

In this study, we reported on a well-applied co-designed intervention development process responding to local health literacy needs in a municipal CR unit. We produced feasible interventions targeting vulnerable users and facilitated their initial implementation. We also found that the intervention development process had substantial organizational impact by leading to the integration of the concept of health literacy, a familiarity with the use of participatory methodologies, and an improved focus on differentiated healthcare practices in the CR unit.

Below we discuss central themes related to the development of health literacy interventions in general as well as our specific methodology. We also comment on the strengths and limitations of our study.

Systematic Development and Evaluation of Health Literacy Interventions

In the past, most health literacy interventions targeted individual health literacy and very often only the functional level of obtaining and understanding health information (40). This study contributes to counter the paucity of interventions targeting health literacy at the organizational level (4,5). Health literacy interventions based on the Ophelia approach have successfully been carried out in primary care (11) and hospital settings (12). More projects using the approach are in progress (41,42). However, to the best of our knowledge, the Ophelia approach was not previously applied in CR, where low health literacy is a particular problem (27). Only one other study reported briefly on the application of the eight Ophelia principles, but did not systematically evaluate the organizational impact (11).

Needs Assessments at User and Organizational Levels

By basing our user health literacy assessment on the nine-dimensional HLQ, we provided valuable insight into the health literacy strengths and weaknesses of a population referred to the CR services in much greater detail than most other health
literacy measures would have allowed (43). Using the cluster analysis, we were able to draw multidimensional profiles across the population providing a detailed picture of the challenges faced by specific subpopulations. The vignettes helped us share this data in an accessible way among staff, leaders, and users. Our organizational impact analysis confirmed that a new and more holistic understanding of user needs and vulnerabilities based on health literacy had been developed and integrated in the unit during the Heart Skills Study.

Our add-on to the Ophelia approach, i.e., organizational health literacy responsiveness analysis, served several purposes. Health literacy is not a commonly integrated concept in the Danish healthcare system. We, therefore, used the Org-HLR process to familiarize local providers with the concept. At the same time, the organizational inadequacies identified in the Org-HLR process served to place health literacy on the local agenda, securing managerial backing for the intervention development. According to the staff, this was crucial in allowing them to invest time and resources in the process. Both these purposes were supported by our particular choice of methodology (as opposed to other available frameworks for organizational health literacy assessment). The participatory process on which the Org-HLR is based allowed both staff and managers time to reflect on and integrate health literacy in their thinking, and the concrete output (i.e., the agreed action plan) ensured clear authorization for a sustained focus on health literacy in the future. In summary, this added feature to the Ophelia approach may be effective in building organizational commitment and promoting a culture of ongoing organizational learning, especially in settings not familiar with health literacy. Willis et al. (2014) argued that this may be a central mechanism to ensure organizational impact in successful health literacy initiatives (6).

**Idea Generation, Co-Designing, and Testing the Intervention**

Using co-design throughout the intervention development process is a central feature of the Ophelia approach as a means to increase applicability and penetration. However, in the original protocol (7) and Ophelia manual (26) the participatory elements were not ascribed to any particular methodology. Participatory health research may involve different participatory methodologies within the spectra of action research (44,45). Many of these are structured similarly to the iterative co-design process of the Ophelia approach (44). Our results indicate the usefulness of the participatory methodology in integrating different perspectives and creating ownership (6). Similar results were achieved in other Ophelia projects (11).

For co-design processes, a sample size of 6–12 participants for each activity is recommended (44), which we adhered to in most workshops. However, as we recruited participants for the workshops based on convenience and interest, the sample may not
have been representative of the actual user population in the unit. This may have affected the resultant interventions.

Leask et al. (2019) provided a set of recommendations regarding co-creation in public health interventions, including evaluation of such interventions (44). They recommended evaluating the co-creation process both in terms of validity and co-creator satisfaction along with evaluating the effectiveness of the intervention itself. In this study, validity was evaluated continuously through the iterative process and feedback loops during the intervention development and co-creator satisfaction and ownership was thoroughly evaluated in the organizational impact analysis. From our test cycles, we know that the intervention to a large extent met our predefined objectives. In our organizational impact analysis, we also observed some promising indications about future maintenance, development, and dissemination of the initiatives. The literature on health literacy in relation to CR is scarce but suggests a possible association between health literacy and participation (46), as well as adherence (24) and learning outcomes (25). Thus, our results call for a future larger scale effectiveness trial of the intervention.

**Strengths and Limitations**

The combined methodologies used to describe the application of the Ophelia approach and the evaluation of the organizational impact is a major strength of this study and provides new knowledge on the potential of the Ophelia approach.

Another strength is the study setup involving staff and user representatives in all steps of the process including the overall coordination. This approach is likely to have increased local ownership and enhance the potential for long-term sustainability (47).

The structured intervention development was based on validated health literacy measures and methodologies described in the Ophelia manual (26). This ensured that the process is reproducible. Our user and organizational needs assessment was more comprehensive than the original Ophelia recommendations. This proved particularly valuable in a setting that was not familiar with the concept of health literacy.

The intervention was tested with very small sample sizes, providing insight into feasibility and possible outcomes, but we have not been able to assess the effect on rehabilitation outcomes or long-term sustainability. A large-scale trial would provide more information regarding intervention effect and sustainability.

Each part of the intervention development process also had limitations, which will not be discussed in detail here. Limitations of the needs assessments are reported elsewhere (27,34). The user health literacy assessment produced seven clusters of
which only three were described in the vignettes. This may have affected the discussions in the co-design workshops and limited the number of identified intervention ideas.

In terms of data collection for the organizational impact analysis, we chose to conduct individual interviews for the leaders and user representatives as they were not part of day-to-day practice in the unit. We used these two different approaches to acknowledge the participants’ different qualifications in sharing their experiences, as staff members contrary to leader and user representatives experienced the entire development, testing, and implementation process through their daily practice of the CR Team. However, the staff group still held very different positions within the team. The moderator (C.B.S.) sought to minimize the inherent risk of one participant voice dominating the others (48) by continuously encouraging and directly appealing to all participants to contribute (48).

Our closed coding procedure in the data analysis had clear advantages in relation to evaluating the application of the Ophelia approach, but at the same time such a strategy precludes unexpected findings outside the predefined areas of interest (35). Other evaluation frameworks might have led to different results. In future scaled-up intervention evaluations it would also be relevant to include clinical measures such as rehabilitation outcomes and in a longer perspective cardiovascular risk and disease outcomes.

In summary, our findings support the use of the Ophelia approach in developing initiatives to improve health literacy responsiveness. Using the approach not only produced feasible interventions, but our results also indicate that the organizational values, strategies, and practices were affected by the process in a way that is likely to support long-term sustainability. Furthermore, all CR staffs and relevant leaders were involved, which is likely to have further increased local ownership. Thus, we recommend the use of the Ophelia approach in future intervention studies aimed at improving health literacy responsiveness, and encourage research evaluating its application in larger settings.

Conclusions

In a municipal CR unit, the Heart Skills Study improved organizational health literacy responsiveness by developing a feasible intervention using an extended version of the Ophelia approach. Applying the Ophelia approach also had a substantial organizational impact in the unit, improving its health literacy responsiveness further by developing and integrating a new and more holistic understanding of user needs and vulnerabilities.
based on health literacy and by creating a familiarity with the use of participatory methodologies and improving focus on differentiated healthcare practices.

Our findings can be used to inform the development and evaluation of sustainable co-designed organizational health literacy responsiveness initiatives in other settings.

Supplementary material

Supplementary material to this publication is available in appendix III and includes:
Interview guide used in staff focus group (English translation), interview guide used in individual interviews with leaders (English translation), and interview guide used in individual interviews with user representatives (English translation).
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Chapter 9: Discussion
Over the past decades, the Danish healthcare system has developed rapidly. The demographic challenges, e.g. an ageing population, has caused a relocation of many less specialized services to the primary care sector (1,2). This, along with the rising burden of long-term illnesses characterised by their dependency on individual health behaviours and self-care (3), has increased the demands placed on users and the complexity of information, services, and options they are expected to navigate. Furthermore, strict political regulations to optimize overall health care quality have increased the amount of clinical standards, guidelines and quality indicators (1). Although such initiatives is potentially a big improvement in overall care, it does potentially limit the organisational capacity and opportunity to deliver flexible and individualised services to vulnerable subpopulations.

The Heart Skills Study addresses some of these challenges from a health literacy perspective (cf. the hypotheses stated in the preface). In the Heart Skills Study, we examined the patterns of health literacy capacities and limitations observed in people with long-term conditions and CVD in particular. We demonstrated methodologies that may prove useful in improving the organizational health literacy responsiveness of the healthcare system and counter inequalities based on differences in ability to find, understand, and use health information and health services.

In this chapter, we first summarize the main findings of the Heart Skills Study before discussing methodological strengths and limitations including selection bias, information bias, and study designs. We then proceed to interpret our results across the four studies, and end the chapter with a discussion of the study implications in the light of a larger research agenda as well as from a practical and political point of view.

**MAIN FINDINGS OF THE HEART SKILLS STUDY**

In the Heart Skills Study, we have consistently interpreted health literacy as a complex phenomenon consisting of a range of dynamic individual capabilities. As a result of changing life conditions or health situations, these capabilities change over time, and are at any given time executed in the interaction with the individual’s general or specific environment (chapter 1).

We have found that from a clinical perspective, a large quantity of mainly epidemiological research confirms the association between health literacy and a number of health determinants and health outcomes (chapter 2). However, in the Heart Skills Study we have not only perceived limited health literacy as a risk factor of ill health and well-being, but also accentuated health literacy capabilities as assets.
developed throughout the life course, empowering the individual to take action on his or her health or health concerns within his or her community. In the final parts of the Heart Skills Study, health literacy is used as an instrument to improve health and well-being supported and enhanced by professionals and organizations working in CR.

In study I (chapter 3) we provided a detailed description of the health literacy strengths and limitations of a Danish population (N = 490) sampled by convenience from a range of settings. In agreement with the literature on the association between health literacy and disease prevalence (chapter 2), the emerging health literacy profiles confirmed that poor health is common in people with below average health literacy. The regression analyses revealed that low scores of actively managing my health (HLQ scale 3) and social support for health (HLQ scale 4), as well as high scores of feeling understood and supported by healthcare providers (HLQ scale 1) was associated with having a long-term condition or multimorbidity.

The literature on health literacy and CVD is diverse in terms of the addressed diagnostic groups and the health literacy measures applied (chapter 4). Across these differences, a number of studies demonstrate associations between health literacy and a range of different health outcomes including overall health behaviour and more specifically physical activity as well as HRQoL.

In study II (chapter 5), we investigated health literacy in relation to health behaviour and HRQoL in people with self-reported current or former acute myocardial infarction, angina pectoris or stroke (N = 3,116). We found statistically significant associations between ability to engage actively with healthcare providers (HLQ scale 6) and physical activity, healthy diet, and abstinence from daily smoking. We also found statistically significant associations between understanding health information well enough to know what to do (HLQ scale 9) and physical activity, healthy diet, and weight within normal ranges. Both scales were also significantly associated with physical and mental HRQoL.

Very little research is available in relation to health literacy and CR (chapter 4). In study III (chapter 6), we examined the association between health literacy and CR participation as well as HRQoL in people referred to a municipal CR programme (N = 150). We found no significant associations between health literacy and participation, although a positive trend was reported in eight of nine HLQ scales (save social support for health, HLQ scale 4). On the contrary, ability to engage active with healthcare providers (HLQ scale 6) and navigating the healthcare system (HLQ scale 7) were positively associated with physical HRQoL as well as mental HRQoL, while in addition social support for health (HLQ scale 4), ability to find good health information (HLQ
scale 8), and understanding health information well enough to know what to do (scale 9) were positively associated with mental HRQoL.

The evidence on effective health literacy initiatives is less comprehensive than the epidemiological literature on the associations between health literacy and health determinants and outcomes (chapter 7). However, the interest in developing interventions at a supra-individual level in organizations and communities is rising. Across the available literature more interventions based on a broad understanding of health literacy; interventions tailored to vulnerable user needs; interventions based on stakeholder involvement; and interventions aiming to build professional and organizational capacities to meet user needs, are encouraged.

These strategies were all in some form part of the co-design process and the resulting interventions developed and tested in study IV (chapter 8) in which an extended version of the Ophelia approach was applied.

Overall, we succeeded in developing and piloting an intervention aimed at improving organizational health literacy responsiveness through enhanced inclusion of user’s relatives and relations (enhancing social support for health) (package 1) and through problem-based needs assessment and individualized care planning for vulnerable users (package 2). We also showed that the development process itself had substantial organizational impact. This included a deepened local understanding of vulnerability, user needs, and user involvement, as well as an integration of a health literate thinking. Overall, the process enhanced local ownership and engagement in the transformation towards becoming a more health literacy responsive organization.

The above findings generally confirm the hypotheses of the Heart Skills Study (cf. preface) with the following modifications: (i) Some but not all examined aspects of health literacy were associated with long-term illness and multimorbidity in study I, (ii) health literacy was not measured using the full HLQ in study II making conclusions on the entire health literacy concept impossible, (iii) aspects of health literacy were associated with some but not all examined health behaviours in study II, (iv) health literacy was not significantly associated with CR participation in study III, and (v) we do not know the long-term sustainability of our positive results in study IV.
In this section methodological considerations of studies I-IV will be discussed. First selection bias, information bias and study designs of the three epidemiological studies (studies I-III) are addressed, followed by reflections on the methodologies used in the intervention study (study IV). Finally, we comment on the external validity of all four studies.

Selection bias in studies I-III

Selection bias are ‘distortions that result from procedures used to select subjects, and from factors that influence study participation’ (4) and may thus occur if the study sample is not representative of the target population. The target populations and samples in studies I-III are very different, and the studies are therefore not equally vulnerable to selection bias.

In study I, the intended target population (cf. the study aims) was the general Danish population. However, compared to this, the samples has a surplus of women (60%), is slightly older (31% against 26% that are above 60 years of age), and includes less people living alone (19% against 25%) (6). Furthermore, participants were recruited by convenience primarily in health settings. Therefore an overrepresentation of people suffering from poor health is likely. Hence, the regional rate of poor self-rated health status is approximately 15% (5), which is significantly less than the 45% found in study I. Based on the association between general health status and health literacy (cf. chapter 2), the recruitment procedure is likely to have introduced an underestimation of the health literacy level in the target population. This affects the composition of the health literacy profiles, but not necessarily the reported association between limited health literacy and long-term illness/multimorbidity.

Study II was based on HAYS data and represented a subgroup reporting CVD from a large sample of the general population in Central Denmark Region. As described in chapters 4, the HAYS population was weighted to account for differences in selection probability and to correct for differences in response rate (7). In this way, a lot was done to ensure that the HAYS population in terms of socio-demography represents the general population of the region.

The target population of study III was people referred to CR in Randers Municipal Rehabilitation Unit. Interestingly, among the eligible individuals only 3.9% had non-Danish origin against approximately 9.1% in Randers Municipality in general (8). This distortion may reflect resistances towards rehabilitation services within a culturally
very diverse group, but it could also be a result of problematic referral systems not supporting people with a non-Danish background effectively enough. We encourage further local investigations on this issue.

In all, 22.3% of the eligible population for study III did not participate in the Heart Skills Survey. The study compared sociodemographic characteristics of participants and non-participants and concluded that non-participants were less educated (P<0.05). Although low educational attainment and limited health literacy are not the same thing, they are closely associated (cf. chapter 2). The finding may therefore reflect a general risk of selection bias in health literacy studies including studies I-III, where people with limited health literacy are reluctant to participate or simply cannot fill out the questionnaire, causing health literacy levels to be overrated.

In the Heart Skills Survey, we tried to minimize the problem by offering support from a healthcare provider when responding to the questionnaire. However, very few chose this option. Using mandatory face-to-face interviews such as those conducted in study I, would probably have been a better (although resource-intensive) approach, provided that such interaction did not provoke inflated responses, e.g. due to shame. Hence, in study I the percentage having completed only primary and lower secondary school was comparable to that of the total Danish population (19% against 18%) (6). Based on studies confirming the association between health literacy and health outcomes (chapters 2 and 4) it is likely that a better inclusion of people with very limited health literacy in study III could have strengthened the reported associations.

Information bias and the validity of measures in studies I-III

Information bias occurs ‘whenever there are errors in the measurement of subjects’ (4), i.e. if the collected information does not describe the true characteristics of the target population because of imprecise measurement or interpretation.

Since there isn’t a general agreement on the extent of the concept of health literacy and consequently a large number of instruments are available to measure it (9), the precision of health literacy measurement is not determinable. Studies comparing some of the available tools have shown that their estimates are not directly comparable (10–12).

In the case of the Heart Skills Study, we chose to adhere to the HLQ across all studies. The HLQ refrains from reducing health literacy to a single score or level but provides insights into a range of health literacy aspects (13). This limits the comparability with research not using the HLQ. However, the HLQ supports our interpretation of health
literacy as a target of professional, organizational, and systemic support (cf. Paasche-Orlow’s model figure 1.2, chapter 1), and as an individual asset enabling the individual to take charge over his or her health (cf. Nutbeam’s health literacy levels, chapter 1).

Due to the limited space reserved for health literacy in the long HAYS survey, study II only included HLQ scales 6 and 9 and thus did not measure health literacy ‘in full’. Therefore, in relation to the study hypothesis, only a partial confirmation of the associations between health literacy and the outcomes was possible. The choice of the two scales in particular was made by the team behind the HAYS in collaboration with the developers of the HLQ (5). It was based on their applicability in a large population survey and the assumption that they represent diverse and central preconditions for participation in healthcare processes (14). In support of this, they do represent the functional and communicate levels in Nutbeam’s classification (15) (cf. chapter 1, table 1.2), and a study based on the total HAYS population aged 25 years or above has established the distinct sociodemographic features of the two scales (14).

In studies I–III, we generally relied on the accuracy of self-reported information on health, health behaviour, and to some extent socio-demography. In study I and study II, we identified individuals eligible for inclusion in the study populations and subpopulations based on self-report. The involved questions included major but not all long-term diseases/CVDs, and some level of underreport is likely. Depending on the health literacy of precluded individuals, this could have affected the reported associations in either direction.

In terms of outcomes, self-assessed health status or HRQoL based on SF-12 was included in all three studies. Both measures are strongly associated with other health and CVD outcomes including mortality, and thus reasonably reliable proxies (16–18). We do not believe them to have caused any significant bias. On the contrary, depending on context and personal factors survey respondents tend to understate unhealthy or socially undesired behaviours due to recall bias and/or social desirability bias (19,20). This may have affected study II in particular, where dependent outcomes included physical activity, dietary habits, smoking habits, alcohol consumption, and Body Mass Index. However, we have no reason to believe that such a bias would be dependent on health literacy capabilities, and also the problem was minimised by the use of a self-administered survey consisting of validated tools or measures based official national recommendations.
Study designs in studies I-III

The cross-sectional nature of studies I-III does not provide any information on the causal pathways between health literacy and the included dependent variables, and, as evident from chapters 2 and 4, future research based on longitudinal data is highly warranted in most fields of health literacy research including studies on people with CVD.

In study III, the cross-sectional design and timing of the data collection gave rise to some concern. Since a CR programme in consequence of its educative elements is likely to increase health literacy levels of the participants, and since we were not able to ensure that all survey responses were collected shortly after CR referral, the associations between health literacy and the dependent outcomes may have been exaggerated (cf. chapter 6 for details). Again, using mandatory face-to-face interviews at first contact after referral could have prevented these limitations.

Study I and study III were both characterized by small sample sizes and we did not do any prior calculations regarding optimal sample size. In study I the sample was originally collected for a validation study and in study III we based our sample size on the population needed to perform the cluster analysis as part of the Ophelia approach (the researchers behind the Ophelia recommend ≥100 individuals). The small samples may have led to the faulty rejection of parts of our hypotheses. For example, regarding the association between health literacy and participation in CR in study III, eight of the nine insignificant estimates showed a positive association in adjusted analysis. We thus recommend future similar studies to base sample sizes on power calculations.

Regarding covariates, the still limited evidence on causal relations between health literacy and possible predictors and outcomes as well as the diversity of health literacy definitions and measures affect the possibility of identifying relevant confounders. In spite of this limitation, we have still tried to base our choices on the available literature (chapters 2 and 4). Thus, all regression analyses were adjusted for age, gender, ethnicity or mother tongue, cohabitation, and educational attainment. Furthermore, study III was adjusted for comorbidity. There is always a risk of residual confounding, but the sample sizes of study I and study III limited the options for meaningful analysis if many confounders were to be included. In study II, it could have been interesting to assess the impact of including a health measure such as general health status or comorbidity as a possible confounder.
Methodological considerations in study IV

Study IV was based on methodologies very different from studies I-III and is therefore discussed separately in this section addressing each phase of the Ophelia approach (cf. figure 7.1, chapter 7).

Needs assessment (phase 1).
The user health literacy needs assessment was carried out based on the Heart Skills Survey. The survey was discussed above and in chapter 4 and will not be further discussed here.

The Org-HLR was an add-on to the original Ophelia approach, providing a baseline knowledge on the organizational strengths and weaknesses with regard to health literacy responsiveness. As a consequence of the Org-HLR process, the staff and leaders of Randers Municipal Rehabilitation Unit were also familiarized with the concept of health literacy and health literacy responsiveness before the Ophelia workshops took place (21). Based on study IV, we believe the Org-HLR positively affected the impact of the Ophelia approach in Randers Municipal Rehabilitation Unit. However, because the application of the Ophelia approach was intertwined with the results of the Org-HLR process, any future comparisons between the Heart Skills Study and other Ophelia-based studies should take this into account.

Co-design (phase 2).
To induce organizational changes in a long-term perspective, participatory research must add value to the process and its outcomes through meaningful collaboration between researchers and stakeholders and careful integration of the research within the organizational infrastructure (22–24). The methodological procedures to achieve this in the Ophelia approach (25,26) share many similarities with other co-design frameworks in health (23,27). Study IV supported their appropriateness in improving local fit, implementation, and sustainability.

In the original Ophelia protocol, end users were only involved as respondents in the needs assessment (25,28). As opposed to this, in the Heart Skills Study we involved CR users at all stages of the process as well as in the project management team. Research confirms the usefulness of involving end users in intervention development and health care research (23,24,29). However, doing so places high demands on the nature of involvement in order to ensure that co-designers are representative for the target population, motivated to engage in the process, and assigned meaningful roles empowering them to participate (23). In the Heart Skills Study, users participating in co-design activities were recruited from ongoing or newly ended CR programmes and based on the participant’s active volunteering. It is likely that some of the most
vulnerable users tended to refrain from the offer, and important insights into their views and needs may have been lost. In future similar processes, it may be useful to assess basic characteristics of the involved users, and if possible, carry out a more purposeful selection of representative participants (23,24), although participation must still remain voluntary and should also be propelled by interest and engagement.

**Implementation and evaluation (phase 3).**
The iterative intervention testing and adaption in the Ophelia approach is in accordance with many participatory techniques (23,27,30). In the Ophelia approach, the process is based on PDSA cycles. The evidence on the effectiveness of this approach is not conclusive and may depend largely on the quality of its application (31–34). In the Heart Skills Study, two PDSA cycles were carried out, but we did not collect data on their effect in terms of clinical measures such as CR or CVD outcomes. This could be the focus of interesting future research.

An important part of evaluating co-designed interventions is to assess the quality of the process in itself. This is to ensure that the participatory methodologies were applied as intended (23,30). Also, the process may in itself disrupt the common behaviours in the organization and induce changes that support the implementation and effect of the intervention (23,35). The organisational impact assessment in study IV was an attempt to perform such an evaluation, although our approach did have some limitations.

Firstly, we did the assessment based on qualitative data collected from user representatives in the project management team as well as leaders and staff in Randers Municipal Rehabilitation Unit. Users involved in the co-design workshops and the Heart Skills Survey were not part of the data collection, which may have precluded important reflections.

Secondly, staff and user representatives directly involved in the Heart Skills Study were co-researchers. As such, their own perspectives and assumptions including their close relationship with the main researcher may have affected their contributions as participants in the organizational impact assessment (36,37). This was to some extent countered by using interviewers not otherwise involved in the Heart Skills Study.

Lastly, we chose a deductive approach using predefined codes in the data analysis. Applying the eight Ophelia principles as evaluation criterions allowed us to conduct an evaluation closely linked to the aims of the study and the guiding values and participatory strategies of the underlying the Ophelia approach (38). However, at the same time such a strategy may preclude unexpected findings outside the predefined areas of interest (39).
External validity

External validity (or generalizability) of research results is ‘the validity of the inferences as they pertain to people outside the [source] population’ (40). Below we comment on the generalisability of the Heart Skills Study to other settings. However in general, since health systems, health education, and the availability and quality of health information differ significantly between countries generalization to non-Danish settings should be done cautiously.

Regarding study I, we have already argued that the population did not fully resemble the general Danish population. Since the majority of the sample was recruited in Danish primary care health settings, the results may be generalizable to such contexts. Further reflections on generalizability are stated in the study (cf. chapter 3).

The 3,116 individuals included in study II constitutes only approximately 0.7% of the 450,000 Danes living with CVD (41). In addition, only people reporting current or former acute myocardial infarction, angina pectoris, or stroke were included. From other studies we know that health literacy is not equally related to all long-term conditions, but the associations between health literacy, health behaviours and HRQoL have been observed in other diagnostic groups (cf. chapters 2 and 4). We therefore have confidence that the results of study II are generalizable to other populations suffering from CVD and many other long-term conditions, although the extent of such associations is likely to depend on, e.g., disease severity, the significance of health behaviours, and the provided support for self-care in particular contexts.

Study III concerns individuals referred to municipal CR programmes in Randers Municipality. The extent to which our findings are generalizable to other CR contexts depends on their referral practices and coverage. Even within Denmark, phase 2 CR is not always conducted in municipal programmes comparable to the one studied, and outside Denmark, services and referral procedures may differ even more. Any generalization should take such differences into account.

The thoroughly integrated participatory elements of the Ophelia approach applied in study IV impacts possible intervention dissemination outside Randers Municipal Rehabilitation Unit. Traditionally, fidelity (i.e. the extent to which an intervention is implemented and delivered as prescribed) is perceived as conflicting any local adaption (i.e. tailoring of interventions to local contexts), as it may induce the programme to drift away from its intended purposes (42). In the Heart Skills Study, the intervention development process itself was an important part of the effective means to induce organizational change. Consequently, any up-scaling outside Randers Municipal
Rehabilitation Unit would require similar local participatory processes, which would result in adaptations of the intervention and its underlying concepts.

In recent years, the discourse on fidelity and adaption has moved in the direction of enabling the two concepts to coexist (35,42,43). Thus, Moore et al. (2019) suggest focusing on ‘fidelity of function (rather than form)’ when testing feasibility across settings (35), and Leask et al. (2019) describe different approaches to scaling-up of interventions developed using participatory methodologies including local adaptions, building on the experiences from other settings (23). Any future activities inspired by the Heart Skills Study should explore how best to balance fidelity and adaption in settings with more or less resemblance to Randers Municipal Rehabilitation Unit.

FURTHER REFLECTIONS ON THE FINDINGS

In each of the four studies embedded in this thesis we discuss the concrete results in relation to the relevant literature. However, the consistent use of the HLQ allows us to look for patterns across the studies and reflect on the findings substantiating our intervention development. This is the focus in this section. To support our interpretation, we use our own classification of the HLQ scales according to cognitive, executive and social health literacy capacities introduced in study III (chapter 6, table 6.1).

Findings in relation to cognitive and executive health literacy capacities

The improvement of cardiovascular risk factors plays a central role in prevention and care in individuals diagnosed with CVD, and is therefore dominant in most CR programmes (44,45). Large reviews on the impact of CR confirm its positive effect on HRQoL (45). Therefore, any positive associations between health literacy and CVD risk reduction as well as HRQoL may support the development of health literacy initiatives in CR settings.

In the Heart Skills Study, study II and study III provided information on health literacy in relation to preventive behaviour and HRQoL in individuals with CVD. Both cognitive and executive health literacy capacities were associated with desirable outcomes suggesting that health literacy initiatives might best be designed with elements aimed at improving or responding to both types of capacities. This is in accordance with literature suggesting the use of a comprehensive understanding of health literacy in relation to interventions (46,47) as well as a recent study by Rademakers et al. (2018) based on a Dutch population with chronic conditions. This study confirms the
importance of both cognitive and non-cognitive (resembling executive capacities) aspects of health literacy (48), and find both to be related to a range of outcomes potentially relevant in CR settings including healthcare use, user experience, and self-management.

In relation to our intervention development (study IV), these findings substantiate and support the initiatives included in intervention package 2, which focused on additional healthcare provider attention and support to the most vulnerable CR attendants identified by their health literacy capacities and mental health situation (cf. chapter 8, table 8.4). The purpose was among this group to mitigate the effect of diverse health literacy limitations. A review by Taggart et al. (2012) identifies primary care interventions effectively improving health literacy in relation to chronic disease behavioural risk factors and finds some effect of brief individual counselling not unlike the counselling provided in package 2, though not specifically targeting vulnerable populations (49).

**Findings in relation to social health literacy capacities**

In general, the role of social health literacy capacities in relation to primary and secondary disease prevention is not yet well explored. However, evidence suggests that relations and peers may play an important role in mitigating the effect of limited health literacy (50,51) – a phenomenon sometimes termed distributed health literacy – and a review by de Wit et al. (2018) on community interventions enhancing critical health literacy among older citizens identified social support as a crucial element (52).

In study I, we identified health literacy challenges associated with the presence of long-term illness/multimorbidity. We found, that one of these were low scores on social support for health (HLQ scale 4). Likewise in study III, we saw a strong association between social support for health (HLQ scale 4) and mental HRQoL in people referred to CR. Because of the cross-sectional design of our studies, we cannot confirm the directionality of the associations, however, since improving quality of life is an important CR objective (53), the results do suggest that social support could be a target of health literacy interventions in CR worth further investigation.

In study IV, these findings substantiate social support being the core of intervention package 1, and low social support (characterized using the CHAT tool) being part of the identification of vulnerability in intervention package 2 (cf. chapter 8, table 8.4). To strengthen the evidence behind similar initiatives in the future, we encourage research to map and define the concept of distributed health literacy in greater detail and explore its significance in relation to prevention of long-term conditions.
IMPLICATIONS

In the following section we reflect on the role and implications of the Heart Skills Study within a broader context of intervention development as well as other research, practice and policy agendas.

Developing interventions in complex systems

In the Heart Skills Study, we used an extended Ophelia approach as our framework for complex intervention development. Many previous frameworks and guidelines on complex intervention development draw heavily on the use of evidence from other settings as well as theoretical frameworks linking intervention elements into complex initiatives or programmes (54–56). In contrast, the Heart Skills Study intervention development process (cf. study IV) was based on the lived experiences of users, staff, and leaders in Randers Municipal Rehabilitation Unit. It addressed health literacy not primarily as a risk factor for adverse CR outcomes by attempting to identify and target specific pathways between health predictors and outcomes (figure 9.1, upper section). Rather, the study activities affected the dynamics between individual health literacy capabilities and the system in which they are utilized (i.e. Randers Municipal Rehabilitation Unit and to some extent the individuals’ family and other systems in his or her surroundings) (figure 9.1, lower section).

The emerging literature argues that complex intervention research needs to pay increased attention to contexts and the complex systems in which interventions are applied (35,57,58). For example, Hawe et al. (2009) suggest that instead of defining interventions in terms of individual components, developers should ‘think of interventions as events in systems that either leave a lasting footprint or wash out depending on how well the dynamic properties of the system are harnessed’ (57).

If Randers Municipal Rehabilitation Unit in accordance with the above is interpreted as a complex system, the effect of the Ophelia approach and the added methodologies in themselves constitute events with potentially far reaching consequences within the dynamics of the unit. This is in accordance with our findings in the qualitative analyses of study IV, which showed positive indications of successful system ‘disruptions’ leading to a deeper local understanding and integration of health literacy and local motivation for increased health literacy responsiveness. Whether these new dynamics will endure over time is yet to be determined, however, we do recommend that the Ophelia approach and similar co-design frameworks are further explored as effective tools within the complex systems agenda.
Figure 9.1. Pathways between health literacy and health outcomes in the Heart Skills Study

### Health literacy as a risk factor affecting outcomes directly or by moderation

![Diagram showing health literacy as a risk factor affecting outcomes directly or by moderation.]

### Health literacy as an individual asset interacting with complex systems

![Diagram showing health literacy as an individual asset interacting with complex systems.]

### Other implications for research

In general, the Heart Skills Study offers new evidence on health literacy among people suffering from long-term conditions and CVD in particular, and constitute strong arguments for addressing health literacy in relation to prevention and care of such conditions.

The use of the HLQ instrument throughout the Heart Skills Study provides detailed information on major health literacy challenges not identified in comparable studies on similar populations (cf. chapters 2 and 4), and we do see a large potential in increased use of broad health literacy measures in future studies informing health literacy interventions by providing elaborate information on potential target groups and focus areas.

The evidence on effective health literacy interventions is still scarce, and study IV only modestly contributes to fill this gap. However, the study does provide a strong example of how the concepts of health literacy and health literacy responsiveness can be integrated and work to enhance individualized care in a CR setting. In the future, it would be pertinent to apply and share experiences of the Ophelia approach in (i) larger settings where inclusion of all relevant staffs and stakeholders in the intervention
development process is less feasible, and (ii) settings targeting other aspects of health care such as specialised care (e.g. at hospitals), primary prevention (e.g. in pre- and postnatal care or at jobcentres), and health promotion (e.g. in community health programmes or school health initiatives). It might also be helpful to develop and test less resource-intensive methods to assess local needs, although we do think the detailed HLQ based survey provides useful data not obtained from most available alternatives. Future comparison with the other studies using the Ophelia (59) will help put our results into perspective and identify the most efficient components of the approach.

Implications for practice and policy

In the Shanghai Declaration on promoting health in the 2030 Agenda for Sustainable Development adopted in 2016, health literacy was highlighted as a pillar in health promotion and an important factor in countering health inequity (60). In recent years, both national governments (61) and several international organizations (46,62–64) have cast attention on identifying and addressing health literacy challenges of individuals and populations. In their ‘roadmap on supporting health literacy development over the life course’, WHO in Europe identifies the advancement of developing and implementing health literacy initiatives as one of five strategic directions (64). In pursuit of this goal, a WHO European ‘Action Network on Health Literacy for Prevention and Control of NCDs’ has been launched (65), and, inspired by similar global initiatives (66), seven European ‘National Health Literacy Demonstration Projects’ (NHLDPs) have been adopted so far (59). The Heart Skills Study is one of these and will thus enter into a pool of experiences and findings from similar health literacy intervention development processes meant to inform and inspire future initiatives across Europe.

The Heart Skills Study is to our knowledge the first intervention study in Denmark focusing on health literacy responsiveness. Our findings highlight the relevance of health literacy across several arenas. In particular, we emphasize the possibilities and responsibilities of health organizations in integrating a health literate thinking at all organizational levels and working to improve access to and use of information and services. We also stress the role of healthcare professionals in mitigating the effect of individual health literacy challenges through supportive communication strategies and differentiated care. Lastly, although there are no national policies on health literacy in Denmark and few national strategies in health that integrate or even mention health literacy, local health literacy inspired initiatives are emerging (67). Based on the results of the Heart Skills Study, we support the introduction of health literacy in relevant
Danish (health) policies and guidelines and any future political investments in the adoption of a health literate thinking among professionals and organizations in the Danish health care system.
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Discussion

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Chapter 10: General conclusion
The Heart Skills Study contributes to the international evidence on health literacy in individuals with chronic conditions and CVD in particular. New details on the associations between health literacy and central health outcomes are provided, due to the use of a broader health literacy measure than most available studies.

Based on our findings, we can conclude that not all aspects of the concept of health literacy are equally important in relation to the prevalence of long-term illness, adoption of healthy behaviors, and the experience of good HRQoL. Furthermore, in responding to health literacy challenges, there is often a need to consider different types of capabilities, i.e. capacities of a cognitive, executive, and social nature.

The application of a needs-driven, participatory intervention development approach (the Ophelia approach) in the Heart Skills Study is one of the first of its kind to be reported in the form of scientific communication. Our results were positive, although limited by the singular small setting in which the approach was applied and the yet-to-be-seen long-term sustainability of the resulting intervention.

The Ophelia approach in itself, with the added elements of an organizational needs assessment (Org-HLR) and the enhanced inclusion of user participation, showed promising organizational impact in relation to the integration of a health literate thinking and in improving the local motivation and facilitators of health literacy responsiveness.

While the concept of health literacy is still to a large extent unknown in relation to the Danish health system, the Heart Skills Study has shown its potential in identifying and responding to vulnerabilities in individuals with CVD and possibly other long-term conditions. In doing so, the study provides a first step in using health literacy responsiveness as a way to counter health inequalities in Denmark and mitigate the effect of limited abilities to access, understand, and use health information and health services.
Chapter 11: English summary
Background and hypotheses

As a major health condition, cardiovascular diseases play an extensive role in the unequal distribution of health and well-being evident in many countries including Denmark. Health literacy may play a role in the causal chain creating the social gradient in health.

The Heart Skills Study examines the association of health literacy and outcomes related to cardiovascular disease prevention under the following three hypotheses:

i. In a general Danish population, long-term illness and multimorbidity are associated with specific health literacy challenges.

ii. In a Danish population with self-reported cardiovascular disease, limited health literacy is associated with adverse health behaviour and poor health-related quality of life.

iii. In a Danish population of people referred to municipal cardiac rehabilitation, limited health literacy is associated with low participation and poor health-related quality of life.

In addition, the study examines the potential of a co-design intervention development process aimed at improving health literacy responsiveness under the hypothesis that:

iv. Organizational changes aimed at improving organizational health literacy responsiveness in a municipal cardiac rehabilitation unit can be developed and integrated using a systematic intervention development methodology based on local needs assessments, co-design methodologies, and pragmatic intervention testing.

Methods

The Heart Skills Study consists of four separate scientific studies.

Study I is based on survey data collected among a general population mainly in health settings for the purpose of a validation study (not included in the thesis) \((N = 490)\).

Study II is based on data from individuals reporting cardiovascular disease in a large regional health survey \((N = 3,116)\). Study III is based on survey data which we collected from people referred to cardiac rehabilitation in Randers Municipal Rehabilitation Unit in 2017 \((N = 150)\). Studies I-III are all cross-sectional in design, use the Health Literacy Questionnaire to measure health literacy, and use regression analysis to examine associations between health literacy and health outcomes.
In study IV, an extended version of the Ophelia approach to health literacy intervention development is applied to cardiac rehabilitation services in Randers Municipal Rehabilitation Unit. Local needs are assessed through user health literacy profiles and an organizational health literacy responsiveness self-assessment. Based on this, interventions are co-designed and tested by users, staff, and leaders. Organizational impact is examined through qualitative analyses among involved stakeholders.

**Results**

The Heart Skills Study is based on a broad interpretation of health literacy. By examining several aspects of the concept the study provides new detailed knowledge on health literacy among people with long-term illness and cardiovascular disease in particular.

In study I, we found significant associations between aspects of health literacy and the likelihood of having a long-term illness or multimorbidity.

In study II, we found significant associations between aspects of health literacy and several cardio-protective behaviours including physical activity, healthy dietary habits, absence of smoking, and Body Mass Index within the normal range as well as health-related quality of life among people reporting cardiovascular disease.

In study III, we found significant associations between aspects of health literacy and health-related quality of life in people referred to municipal cardiac rehabilitation. We did not find any significant associations between health literacy and participation in cardiac rehabilitation.

In study IV, we developed and piloted an intervention aimed at improving organizational health literacy responsiveness in Randers Municipal Rehabilitation Unit. We showed that the development process itself had a substantial organizational impact that deepened the local understanding of vulnerability, user needs, and user involvement, as well as integrated a health literate thinking and created local ownership and engagement in the process of becoming a more health literacy responsive organization.

**Conclusion and perspectives**

The Heart Skills Study offers new evidence on health literacy among people suffering from long-term conditions and cardiovascular disease in particular. To our knowledge, it is the first intervention study in Denmark focusing on health literacy responsiveness. While the concept of health literacy is still to a large extent unknown in relation to the
Danish health system, the Heart Skills Study has shown its potential to identify and respond to vulnerabilities in individuals with or in risk of cardiovascular disease. Furthermore, as a National Health Literacy Demonstration Project adopted by the World Health Organisation, the Heart Skills Study has entered into a pool of health literacy interventions meant to inform and inspire future initiatives across Europe.
Chapter 12: Dansk resume
Baggrund og hypoteser

Hjertekarsygdomme er hyppige og ofte alvorlige tilstande af stor betydning for den ulige fordeling af sundhed og velvære, der opleves i mange lande, herunder Danmark. Sundhedskompetence, dvs. evnen til at finde, forstå og anvende sundhedsinformation og sundhedstilbud til at tage beslutninger om sundhed, er en dynamisk faktor stærkt associeret med flere sociale sundhedsdeterminanter. Initiativer med fokus på sundhedskompetence kan måske kan bidrage til at mindske uligheden.

Studiet Hånden på Hjertet (Eng. the Heart Skills Study) undersøger sammenhængen mellem sundhedskompetence og faktorer relateret til forebyggelse af hjertekarsygdom med følgende tre hypoteser:

v. I en generel dansk befolkning er langvarig sygdom og multimorbiditet forbundet med udfordringer inden for specifikke aspekter af sundhedskompetence.
vi. I en dansk population med hjertekarsygdom er begrænset sundhedskompetence forbundet med uhensigtsmæssig sundhedsadfærd og ringe sundhedsrelateret livskvalitet.

vii. I en dansk population af personer henvist til kommunal rehabilitering efter hjertesygdom er begrænset sundhedskompetence forbundet med lav deltagelse og ringe sundhedsrelateret livskvalitet.

Hånden på Hjertet undersøger endvidere potentialet af en interventionsudviklingsproces baseret på samskabelse. Processen har til formål at øge lokal organisatorisk sundhedskompetence under hypotesen:

viii. Organisatoriske forandringer, der har til formål at forbedre organisatorisk sundhedskompetence i en kommunal rehabiliteringsenhed, kan udvikles og integreres gennem systematisk interventionsudvikling baseret på lokal behovsanalyse, samskabelse og pragmatisk afprøvning.

Metoder

Hånden på Hjertet består af fire separate videnskabelige studier.

Studie I-III er alle tværsnitsstudier. Studie I er baseret på spørgskemadataset indsamlet til et valideringsstudie (ikke inkluderet i afhandlingen) i en generel population primært rekrutteret i sundhedscentre og almen praksis ($N = 490$). Studie II er baseret på data fra personer med selvrapportert hjertekarsygdom, der indgik i en stor regional spørgskemeundersøgelse ($N = 3.116$). Studie III er baseret på spørgskemadataset

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indsamlet fra personer henvis til rehabilitering efter hjertesygdom i Randers kommunale rehabiliteringsenhed (N = 150). I alle tre studier måles sundhedskompetence ved hjælp af spørgeskemaet the Health Literacy Questionnaire (HLQ), og alle tre benytter regressionsanalyser til at undersøge sammenhænge mellem sundhedskompetence og sundhedsmål.


**Resultater**

Hånden på Hjertet tager udgangspunkt i en kompleks forståelse af sundhedskompetence og inddrager mange aspekter af begrebet. Herved bidrager projektet med ny og detaljeret viden om sundhedskompetence blandt personer med langvarig sygdom og særligt hjertekarsygdom.

I studie I fandt vi signifikante sammenhænge mellem aspekter af sundhedskompetence og sandsynligheden for at have en langvarig sygdom eller multimorbiditet.

I studie II fandt vi signifikante sammenhænge mellem aspekter af sundhedskompetence og sundhedsadfærd herunder fysisk aktivitet, kostvaner, rygevaner og Body Mass Index samt sundhedsrelateret livskvalitet blandt personer med selvrapporteret hjertekarsygdom.

I studie III fandt vi signifikante sammenhænge mellem aspekter af sundhedskompetence og sundhedsrelateret livskvalitet blandt personer henvis til kommunal rehabilitering efter hjertesygdom. Vi fandt ikke signifikante sammenhænge mellem sundhedskompetence og deltagelse i rehabilitering efter hjertesygdom.

I studie IV udviklede og pilottestede vi en intervention, der havde til formål at øge kvaliteten af tilbuddet efter hjertesygdom i Randers kommunale rehabiliteringsenhed. Vi viste, at udviklingsprocessen i sig selv havde betydelig organisatorisk effekt, idet den uddybede den lokale forståelse af sårbarhed, borgernes behov og borgerinvolvering samt integrerede en tilgang baseret på sundhedskompetence. Tilgangen skabte lokalt
ejerskab og engagement i bestræbelserne på at øge den organisatoriske sundhedskompetence i enheden.

**Konklusion og perspektiver**

_Hånden på hjertet_ har gennem epidemiologiske studier vist, at både kognitive, handlingsorienterede og sociale aspekter af sundhedskompetence har betydning for sundhed og velvære bladt mennesker med langvarig sygdom og hjertekarsygdom.

_Hånden på Hjertet_ er desuden det første interventionsstudie i Danmark med fokus på organisatorisk sundhedskompetence, og har vist begrebet relevans og anvendelse i relation til at identificere og respondere på sårbarheder blandt personer med hjertekarsygdom og potentielt andre langvarige sygdomme.

Internationalt indgår _Hånden på Hjertet_ som National Health Literacy Demonstration Project under Verdenssundhedsorganisationen (WHO) i en pulje af sundhedskompetenceindsatser, der skal informere og inspirere fremtidige initiativer i Europa.
Chapter 13: Appendices
APPENDIX I: THE HEALTH LITERACY QUESTIONNAIRE (HLQ)

Content of the questionnaire

The Health literacy Questionnaire (HLQ) is a licensed tool and it is therefore not possible to publish the full version in this thesis. However, the original publication on the development of the tool (1) does provide some information on scales and item which is reported in table A.1.

Table A.1. The contents of the Health Literacy Questionnaire

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<th>HLQ scale</th>
<th>Scale items</th>
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</thead>
</table>
| 1. Feeling understood and supported by healthcare providers | I have at least one healthcare provider who...  
I have at least one healthcare provider I can...  
I have the healthcare providers I need...  
I can rely on at least one... |
| 2. Having sufficient information to manage my health | I feel I have good information about health...  
I have enough information to help me deal...  
I am sure I have all the information I...  
I have all the information I need to... |
| 3. Actively managing my health                   | I spend quite a lot of time actively managing...  
I make plans for what I need to do to be...  
Despite other things in my life, I make time...  
I set my own goals about health and fitness  
There are things that I do regularly... |
| 4. Social Support for health                     | I can get access to several people who...  
When I feel ill, the people around me really...  
If I need help, I have plenty of people I...  
I have at least one person...  
I have strong support from... |
<table>
<thead>
<tr>
<th>5. Appraisal of health information</th>
<th>I compare health information from different sources. When I see new information about health, I... I know how to find out if the health information is... I ask healthcare providers about the quality of the information...</th>
</tr>
</thead>
<tbody>
<tr>
<td>6. Ability to actively engage with healthcare providers</td>
<td>Make sure that healthcare providers understand your health concerns. Feel able to discuss your health concerns with a... Have good discussions about your health... Discuss things with healthcare providers... Ask healthcare providers questions to get...</td>
</tr>
<tr>
<td>7. Navigating the healthcare system</td>
<td>Find the right healthcare... Get to see the healthcare providers I need to... Decide which healthcare provider you need... Make sure you find the right place to get... Find out what healthcare services you are... Work out what is the best care for you...</td>
</tr>
<tr>
<td>8. Ability to find good health information</td>
<td>Find information about health problems... Find health information from several... Get information about health so you are... Get health information in words you... Get health information by yourself...</td>
</tr>
<tr>
<td>9. Understanding health information well enough to know what to do</td>
<td>Confidently fill medical forms in the correct... Accurately follow the instructions from... Read and understand written health... Read and understand all the information on... Understand what healthcare providers are...</td>
</tr>
</tbody>
</table>
Answering and scoring of the questionnaire

In scales 1 through 5 there are four response options: ‘strongly disagree’, ‘disagree’, ‘agree’, and ‘strongly agree’. In scales 6 through 9 there are five response options: ‘cannot do’, ‘very difficult’, ‘quite difficult’, ‘quite easy’, and ‘very easy’.

The responses are converted to numerical values from 1-4 (scales 1 through 5) and 1-5 (scales 6 through 9) with 1 being ‘strongly disagree’/‘cannot do’ and 4/5 being ‘strongly agree’/‘very easy’.

The scores are used to calculate scale means and standard deviations. If more than two items in a scale are unreported for a particular respondent, that particular scale score is reported as missing for that respondent.

References

APPENDIX II: THE HEART SKILLS SURVEY QUESTIONNAIRE (DANISH)

Hånden på hjertet
En spørgeskemaundersøgelse om din sundhed og dit samarbejde med sundhedsvæsenet

Kære ______________________

Vi vil gerne stille dig nogle spørgsmål om, hvordan du finder og bruger information om sundhed og sygdom. Vi vil også gerne stille spørgsmål om, hvordan du tager dig af din sundhed og hvordan du samarbejder med læger og andre om din sundhed. Dine svar bruger vi til at undersøge, hvordan vi kan forbedre genoptøringstilbuddet efter hjertesygdom.

Spørgsmålene er udviklet sammen med borgere, der har deltaget i et genoptøringstilbud efter hjertesygdom.


Det kan være svært at overskue så mange spørgsmål lige efter en sygdomsperiode eller en operation. Du skal udfylde skemaet, når du føler du har tid og overskud til det. Du kan eventuelt udfylde lidt ad gangen. Hvis du er synes det er svært eller er i tvivl om noget, er du velkommen til at kontakte Anna Aaby, der står for undersøgelsen på tlf: 41668262 eller e-mail: aaby@ph.au.dk.

Hvis du kan vil vi gerne at du returnerer skemaet inden 14 dage i vedlagte frankerede svarkurvert.

Husk, der findes ingen rigtige eller forkerte svar!

Mange TAK fordi du vil tage dig tid til at udfylde spørgeskemaet.

Med venlig hilsen,

Læge, PhD studerende
Anna Aaby

Randers
Rehabiliteringsenhed
Hvilken dato er det?
__________________________________________

Hvad er din adresse?
(Din adresse skal bruges til at identificere din besvarelse efterfølgende)
__________________________________________
__________________________________________
__________________________________________

Sprog, uddannelse og arbejde
1. Hvad er dit modersmål?
(sæt kun ét kryds)
☐ Dansk
☐ Andet sprog end dansk, hvilket? ____________________

2. Hvilken uddannelse har du?
(sæt kun ét kryds ved dit højeste uddannelsesniveau)
☐ 7 eller færre års skolegang
☐ 8-9 års skolegang
☐ 10-11 års skolegang
☐ Studenter-, HF- eller anden gymnasiel eksamen (f.eks. HTX, HHX, EUD)
☐ Erhvervsfaglig uddannelse (f.eks. kontor- eller butiksassistent, frisør, murer, sekretær, social- og sundhedssættet, landmand)
☐ Kort videregående uddannelse, 2-3 år (f.eks. markedsøkonom, politibetjent, laborant, datamatiker, økonom, tandplejer)
☐ Mellemlangt videregående uddannelse, 3-4 år (f.eks. folkeskolelærer, socialrådgiver, sygeplejerske, diplomingeniør, pædagog)
☐ Lang videregående uddannelse, mere end 4 år (f.eks. civilingeniør, cand. mag., læge, psykolog)
☐ Anden uddannelse, hvilken? ____________________

2
3. Var du tilknyttet arbejdsmarkedet op til dit aktuelle forløb med hjertesygdom/tilstand i hjertet?
(sæt kun ét kryds)

- Ja, jeg var i arbejde
- Ja, jeg var på dagpenge
- Ja, jeg var på kontanthjælp
- Ja, andet (uddyb) ___________________________
- Nej, jeg var folkepensionist
- Nej, jeg var førtidspensionist eller invalidepensionist
- Nej, andet (uddyb) ___________________________

4. Hvis du var i arbejde op til din hjertesygdom/tilstand i hjertet: Hvor mange timer arbejdede du om ugen?
(sæt kun ét kryds)

- Ingen
- 1-9 timer
- 10-19 timer
- 20-29 timer
- 30-36 timer
- 37 timer
- Mere end 37 timer
- Ved ikke
**Information om sundhed og dit samarbejde med sundhedsprofessionelle**

Dette afsnit handler om den information du modtager om sundhed, og hvordan du bruger den.

I nogle spørgsmål bruger vi ordet *sundhedsprofessionelle*. Her med mener vi læger, sygeplejersker, fysioterapeuter, diætister og andre personer, som du møder i sundhedsvæsenet, eller som du får råd fra om sundhed.

Vi bruger også ordet *sundhedsydelser*. Her med mener vi behandling, konsultation, pleje, træning eller anden kontakt, du har med sundhedsvæsenet.

5. Angiv hvor uenig eller enig du er i nedenstående udsagn
(sæt kun ét kryds ved hvert udsagn)

<table>
<thead>
<tr>
<th>Meget uenig</th>
<th>Uenig</th>
<th>Enig</th>
<th>Meget enig</th>
</tr>
</thead>
<tbody>
<tr>
<td>Jeg føler mig godt informeret om sundhed</td>
<td>✔</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Der er mindst én sundhedsprofessionel, som kender mig godt</td>
<td>✔</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Jeg har mange, jeg kan kontakte, der forstår mig og støtter mig</td>
<td>✔</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Jeg sammenligner informationer om sundhed fra forskellige steder</td>
<td>✔</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Når jeg har det dårligt, har mine omgivelser virkelig forståelse for, hvordan jeg har det</td>
<td>✔</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Jeg bruger en hel del tid på at tage mig af mit helbred og min sundhed</td>
<td>✔</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Når jeg støder på nye informationer om sundhed, undersøger jeg, om de er rigtige</td>
<td>✔</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Der er mindst én sundhedsprofessionel, jeg kan tale med om mine helbredsproblemer</td>
<td>✔</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Jeg planlægger, hvordan jeg holder mig sund og rask</td>
<td>✔</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Opfordring</td>
<td>Meget uenig</td>
<td>Uenig</td>
<td>Enig</td>
</tr>
<tr>
<td>---------------------------------------------------------------------------</td>
<td>-------------</td>
<td>-------</td>
<td>------</td>
</tr>
<tr>
<td>Jeg har nok information til, at jeg kan tage mig af mine helbredssproblemer</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>Hvis jeg har brug for hjælp, har jeg mange mennesker, jeg kan regne med</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>Jeg sammenlignes altid informationer om sundhed fra forskellige steder, før jeg beslutter, hvad der er bedst for mig</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>Jeg tager mig tid til at leve sundt, uanset hvad der ellers sker i mit liv</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>Jeg er sikker på, at jeg har nok information til at tage mig bedst muligt af mit helbred</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>Jeg har mindst én person, der kan tage med mig til lægen</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>Jeg ved, hvordan jeg finder ud af, om den information jeg får om sundhed, er rigtig</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>Jeg har adgang til sundhedsprofessionelle, der kan hjælpe mig med at finde ud af, hvad jeg skal gøre</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>Jeg sætter mine egne mål for min sundhed</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>Jeg har stor støtte fra familie eller venner</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>Jeg spørger sundhedsprofessionelle om, hvor god den information er, jeg selv har fundet</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>Der er ting, jeg gør regelmæssigt for at blive sundere</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>Der er mindst én sundhedsprofessionel, jeg kan regne med</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>Jeg har al den information, jeg behøver for at passe på mit helbred</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
</tbody>
</table>
### 6. Angiv hvor svært eller let du finder nedenstående opgaver lige nu

(sæt kun ét kryds ved hvert udsagn)

<table>
<thead>
<tr>
<th>Kan ikke eller altid svært</th>
<th>Oftest svært</th>
<th>Nogle gange svært</th>
<th>Oftest let</th>
<th>Altid let</th>
</tr>
</thead>
<tbody>
<tr>
<td>Finde de rigtige tilbud i sundhedsvæsenet</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Sikre mig, at sundhedsprofessionelle forstår mine problemer rigtigt</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Finde information om helbredsproblemer</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Være i stand til at tale om mine helbredsproblemer med en sundhedsprofessionel</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Udfylde skemaer med sundhedsoplysninger rigtigt</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Finde information om sundhed fra flere forskellige steder</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Have gode samtaler om mit helbred med læger</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Få en tid hos de sundhedsprofessionelle, jeg har brug for</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Præcist følge de anvisninger, jeg får af sundhedsprofessionelle</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Få relevant information om sundhed, så jeg er godt opdateret</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Afgøre, hvilken type sundhedsprofessionel, jeg har brug for at opsøge</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Læse og forstå skriftlig information om sundhed</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Finde frem til det rigtige sted at få de sundhedsydelser, jeg har brug for</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Få information om sundhed i et forståeligt sprog</td>
<td>Kan ikke eller altid svært</td>
<td>Oftest svært</td>
<td>Nogle gange svært</td>
<td>Oftest let</td>
</tr>
<tr>
<td>-----------------------------------------------</td>
<td>---------------------------</td>
<td>--------------</td>
<td>-------------------</td>
<td>-----------</td>
</tr>
<tr>
<td>Blive ved med at spørge den sundhedsprofessionelle, indtil jeg har forstået det, jeg har brug for</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Finde ud af, hvilke sundhedsyldelser jeg har ret til</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Læse og forstå al information på medicinpakninger</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Selv finde informationer om sundhed</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Finde frem til, hvad der er den bedste sundhedsydelse for mig</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Stille spørgsmål til sundhedsprofessionelle for at få den information, jeg har brug for</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Forstå, hvad sundhedsprofessionelle vil have mig til at gøre</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
</tbody>
</table>
Dit helbred og dine vaner

I dette afsnit spørger vi til din sundhed.
Du skal tænke på dit helbred generelt, og ikke kun på din hjertesygdom.

7. Hvordan synes du, dit helbred er alt i alt?
(sæt kun ét kryds)

☐ Fremragende
☐ Vældig godt
☐ Godt
☐ Mindre godt
☐ Dårligt

De følgende spørgsmål handler om aktiviteter i dagligdagen.

8. Er du på grund af dit helbred begrænset i disse aktiviteter? I så fald, hvor meget?
(sæt kun ét kryds ved hvert udsagn)

<table>
<thead>
<tr>
<th></th>
<th>Ja, meget begrænset</th>
<th>Ja, lidt begrænset</th>
<th>Nej, slet ikke begrænset</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lettere aktiviteter, såsom at flytte et bord, støvsuge eller cykle</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>At gå flere etager op ad trapper</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
</tbody>
</table>

9. Hvor stor en del af tiden inden for de sidste 4 uger har du haft følgende problemer med dit arbejde eller andre daglige aktiviteter på grund af dit fysiske helbred?
(sæt kun ét kryds ved hvert udsagn)

<table>
<thead>
<tr>
<th></th>
<th>Hele tiden</th>
<th>Det meste af tiden</th>
<th>Noget af tiden</th>
<th>Lidt af tiden</th>
<th>På intet tidspunkt</th>
</tr>
</thead>
<tbody>
<tr>
<td>Jeg har nået mindre, end jeg gerne ville</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Jeg har været begrænset i hvilken slags arbejde eller andre aktiviteter, jeg har kunnet udføre</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
</tbody>
</table>

8
10. Hvor stor en del af tiden inden for de sidste 4 uger har du haft følgende problemer med dit arbejde eller andre daglige aktiviteter på grund af følelsesmæssige problemer?
(sæt kun ét kryds ved hvert udsagn)

<table>
<thead>
<tr>
<th></th>
<th>Hele tiden</th>
<th>Det meste af tiden</th>
<th>Noget af tiden</th>
<th>Lidt af tiden</th>
<th>På intet tidspunkt</th>
</tr>
</thead>
<tbody>
<tr>
<td>Jeg har nået mindre, end jeg gerne ville</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Jeg har udført mit arbejde eller andre aktiviteter mindre omhyggeligt, end jeg plejer</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

11. Inden for de sidste 4 uger, hvor meget har fysisk smerte vanskeliggjort dit daglige arbejde? Både arbejde uden for hjemmet og husarbejde.
(sæt kun ét kryds)

- Slet ikke
- Lidt
- Noget
- En hel del
- Virkelig meget

Disse spørgsmål handler om, hvordan du har haft det i de sidste 4 uger. For hvert spørgsmål, vælg venligst det svar, som bedst beskriver, hvordan du har haft det.

12. Hvor stor en del af tiden i de sidste 4 uger...
(sæt kun ét kryds ved hvert udsagn)

<table>
<thead>
<tr>
<th></th>
<th>Hele tiden</th>
<th>Det meste af tiden</th>
<th>Noget af tiden</th>
<th>Lidt af tiden</th>
<th>På intet tidspunkt</th>
</tr>
</thead>
<tbody>
<tr>
<td>har du følt dig rolig og afslappet?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>har du været fuld af energi?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>har du følt dig trist til mode?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
13. Inden for de sidste 4 uger, hvor stor en del af tiden har dit fysiske helbred eller følelsesmæssige problemer gjort det vanskeligt at se andre mennesker? F.eks. besøge venner, slægtninge osv.
(sæt kun ét kryds)

- Hele tiden
- Det meste af tiden
- Noget af tiden
- Lidt af tiden
- På intet tidspunkt

14. Ryger du?
(sæt kun ét kryds)

- Ja, hver dag
- Ja, men ikke hver dag
- Jeg er ved at stoppe eller netop holdt op i forbindelse med min nuværende sygdom
- Nej, jeg er holdt op før min nuværende sygdom
- Nej, jeg har aldrig røget

15. Hvad vejer du?
(Angiv din vægt i kilo)

______________ Kg

16. Hvor høj er du?
(Angiv din højde i centimeter)

______________ cm
Dit aktuelle sygdomsforløb

Dette afsnit handler om den indlæggelse for hjertesygdom eller tilstand i hjertet, der førte til at du nu er blevet henviset til genoptræning i rehabiliteringsenheden på Randers Sundhedscenter. Hvis du ikke har været indlagt for din hjertesygdom/tilstand i hjertet, skal du blot angive dette under hvert spørgsmål.

17. Hvilken hjertesygdom/tilstand i hjertet er baggrunden for din henvisning til genoptræning i rehabiliteringsenheden på Randers Sundhedscenter?
(sæt ét eller flere krydser)

☐ Hjertekrampe (angina pectoris, hjertesmerter)
☐ Blodprop i hjertet
☐ Efter ballonudvidelse i hjertets blodkar (PCI)
☐ Efter bypass-operation (CABG) i hjertet
☐ Efter operation af hjerteklap eller indsættelse af Kunstig hjerteklap
☐ Hjertesvigt
☐ Anden hjertesygdom/tilstand, hvilken?______________________________________________
☐ Ved ikke

18. Hvornår blev du udskrevet fra din indlæggelse for din hjertesygdom/tilstand i hjertet?
(Angiv tidspunktet så præcist som muligt med dato eller måned)
______________________________________________

Hvis du ikke har været indlagt for din hjertesygdom/tilstand i hjertet forud for din henvisning til rehabiliteringsenheden i Randers Sundhedscenter skal du markere her:
☐ Jeg har ikke været indlagt for min hjertesygdom/tilstand i hjertet
19. Hvilken af følgende udsagn passer bedst på det forløb du har været igennem ved din indlæggelse for din hjertesygdom/tilstand i hjertet?
(sæt kun ét kryds)

- Jeg har vidst et stykke tid, at jeg har en hjertesygdom, og indlæggelsen var planlagt
- Jeg har vidst et stykke tid, at jeg har en hjertesygdom, men indlæggelsen var ikke planlagt
- Jeg vidste ikke, at jeg var syg og indlæggelsen var ikke planlagt
- Jeg har ikke været indlagt
- Ingen af ovenstående udsagn passer på mit forløb

20. Blev du opereret for din hjertesygdom/tilstand i hjertet under din indlæggelse?
(sæt kun ét kryds)

- Ja
- Nej
- Ved ikke

21. Deltager du eller skal du deltage i genoptøning i rehabiliteringsenheden på Randers Sundhedscenter?
(Sæt kun ét kryds)

- Ja
- Nej
- Jeg har ikke besluttet mig endnu

Hvis du har svaret "Ja" i spørgsmål 21 skal du nu springe spørgsmål 22 over og gå videre til spørgsmål 23
22. Hvad er de vigtigste årsager til at du ikke deltager eller overvejer ikke at deltage i genoptæning i rehabiliteringsenheden på Randers Sundhedscenter?
(Sæt ét eller flere krydser)

☐ Jeg føler ikke, jeg har behov for genoptæning
☐ Jeg benytter mig af andre sundhedstilbud i stedet (f.eks. samtaler med praktiserende læge eller sygeplejerske), hvilke?
☐ Jeg benytter mig af andre træningsstilbud i stedet (f.eks. privat træning, fitnesscenter), hvilke?
☐ Jeg tror ikke på, at jeg kan opnå en forandring ved at deltage i genoptæningen
☐ Jeg har ikke mulighed for at deltage på grund af fremmøde-tidspunkterne
☐ Jeg har ikke mulighed for at deltage, fordi det tager for meget af min tid
☐ Jeg har ikke mulighed for at deltage, fordi jeg bor for langt væk
☐ Jeg har ikke mulighed for at deltage, fordi jeg har svært ved at transportere mig til Sundhedscentret
☐ Jeg har ikke mulighed for at deltage på grund af fysisk sygdom eller svækkelse
☐ Jeg har ikke mulighed for at deltage på grund af psykisk sygdom eller svækkelse
☐ Jeg har ikke lyst til at deltage, fordi jeg er utryg eller bange for at træne
☐ Jeg har ikke lyst til at deltage, fordi jeg skal træne sammen med andre
☐ Jeg har ikke lyst til at deltage af andre årsager, hvilke?
☐ Anden årsag, hvilken?

23. Hvilke faktorer er vigtige for dit valg om at deltage eller ikke deltage i genoptæningen i Rehabiliteringsenheden ved Randers Sundhedscenter?
(Du må skrive alle de ting, som har betydning for dig personligt. Det kan f.eks. være praktiske forhold, forhold der har motiveret dig eller andre forhold, der har haft betydning for din beslutning om at deltage)

________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________

13
Du har nu svaret på alle vores spørgsmål. Tusind tak for din hjælp - det betyder meget.

Må vi kontakte dig, hvis vi får brug for en uddybning af din besvarelse?
- Ja
- Nej

Hvis ja: Hvad er dit telefonnummer?
APPENDIX III: INTERVIEW GUIDES FOR STUDY IV

The organizational impact analysis in study IV was based on a focus group discussion among staff in the cardiac team of Randers Municipal Rehabilitation Unit as well as individual qualitative interviews with two leaders and two user representatives in Randers Municipal Rehabilitation Unit.

Interview guides for these activities were translated from Danish to English and included as supplementary material in the original publication (1). The English versions are in a slightly adjusted format inserted below.

Reference

**Guide for staff focus group**

**Information before the interview:**

I would like to give you some information, before we start the interview. I also need some basic information about you.

The purpose of this interview is to collect information on your experiences and reflections in connection with the process Randers Rehabilitation Unit and in particular the Heart Team have undergone since the data collection for the Heart Skills Project was started in 2017.

- A lot has happened during the project and you may have experienced this in different ways. It is important for me to say that there are no right and wrong answers; we are just curious about your perspectives as staff and participants
- Some questions during the interview may be easier to answer than others. It is perfectly okay if you need time to think during the course of the interview
- When you have worked closely together on a project it can be difficult to be critical afterwards. It is important for the value of our results that you are honest – also about things that have not been optimal and things that have not had the desired effect.

What we are going to do today is different from a usual interview where one person interviews another person. In this type of interview, a group interview, you are supposed to talk about, discuss and share experiences with each other. This means that:

- It is primarily you who talk and discuss with each other
- I am primarily interested in your perceptions, experiences and narratives – NOT just your attitudes
- All experiences are equally important. I would like to hear all of your voices
- I will ask clarifying questions during the interview or put a mild pressure on you if I can see that we are pressed for time
- I may also ask one question at a time related to specific topics
- The interview will be recorded to allow me to concentrate on listening to what you are saying instead of taking notes.

Before we start, I will ask each one of you to sign this consent form (handing out consent form). With your signature you consent to my use of your statements in future scientific dissemination. You will not be mentioned by name; however, we need to describe your role in the project and the unit and full anonymity is thus not possible. I am obliged to maintain confidentiality and it will only be a limited number of
researchers who describe and analyse the interview. These researchers are also obliged to maintain confidentiality and the information is only used to communicate results of the Heart Skills Project. First of all, information will be disseminated in scientific journals, but quotations and summary results may also be used in presentations and popular science communication.

(Obtain consent before moving on!!!)

Thank you!

Now I switch on the dictaphone.

Before we start the actual interview, I would like some basic information about you. Please, introduce yourselves and state your name, age and position as well as your role in Randers Rehabilitation Unit.

---

<table>
<thead>
<tr>
<th><strong>Research theme:</strong></th>
<th><strong>Research question:</strong></th>
<th><strong>Interview question:</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>Ophelia values</td>
<td></td>
<td></td>
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</tbody>
</table>

**Introduction**

We are going to talk about the project ‘Heart Skills’.

‘Heart Skills’ has been an ongoing project since 2017 and there are many sub processes involved; among these, the one you have participated in:

1) Collection of questionnaire data in 2017
2) Self-evaluation of the organizational health literacy of your unit in 2017 and 2018
3) Pilot testing of CHAT in 2018
4) The co-creation process on the basis of questionnaire data with citizens and leaders in 2018 and 2019
5) Pilot testing of initiatives to increase involvement of relatives and individual pathways for vulnerable citizens in 2019

We would like you to relate to the entire process you have been through in Randers Rehabilitation Unit and in particular in the heart team, since you were introduced to the concept health literacy for the first time.

Teaser question

Please, describe your experiences of the process in your own words.

How much have each of you been
Are there any experiences you attach particular importance to?

Have you thought about anything in particular which is characteristic of your experiences?

Remember there are no right and wrong answers. You can say whatever you want – this is just to warm up for our talk.

### Experience of the process

| 5 | **Driven by local wisdom.**  
Intervention development and implementation are grounded in local experience and expertise | Based our efforts on local needs, possibilities and values? Have we used the local context well enough?  
**Ability to implement (acceptable, realistic)** | When you think about the Heart Skills Project, how do you think the project has related to the local context at Randers Rehabilitation Unit? 
Does the project e.g. use the knowledge and expertise available at Randers Rehabilitation Unit and in the heart team? If yes, how? 
Does the project fit your local values and work approach? If yes, how? 
Has the project managed to use the local context e.g. in the health centre, the local community and the municipality? If yes, how? |
|---|---|---|---|
| 4 | **Needs-diagnostic approach.**  
Participatory assessment of local needs using local data | Have we identified what characterizes health literacy among citizens referred to | Try to discuss if the project ‘Heart Skills’ has been able to:  
1) Identify the needs of citizens referred to rehabilitation after heart disease?  
2) Identify the possibilities and |
<p>| | | |</p>
<table>
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</table>
| **Appendices** | **Co-design approach.**  
In all activities at all stages relevant stakeholders engage collaboratively to design solutions | **Relevance**  
Have we characterized the organizational health literacy in Randers Rehabilitation Unit (the Heart Team)  
Limitations of Randers Rehabilitation Unit and your team to meet these needs?  
Has health literacy been a good starting point for identifying these needs? Why/why not? |
| 3 | **Ownership**  
Have we included all relevant stakeholders in the process and have their participation produced ownership and better solutions? | **Heart Skills** has involved you, your leaders and a group of citizens in rehabilitation through different phases.  
Try to discuss the importance of your participation and the participation of others in the Heart Skills Project. What are the positive and negative consequences of many people being involved in the process? What are the positive and negative consequences for you personally and as health professionals?  
Are there any participants you have missed because they did not participate?  
Are there any parts of the process where you could have contributed even more? Or parts of the process where you felt your contribution was superfluous? |
| 2 | **Equity driven.** All activities at all stages prioritize | **Now we are going to talk about vulnerability and vulnerable citizens.**  
Has there been focus on the most |
### Experiences related to the effects of the process

Now we have talked a lot about the process you have been through. You are welcome to add something if you wish to elaborate on something we have missed.

We are now going to talk about the impact of the process. I do not only think about the initiatives you have tested this autumn and their results, but also on the impact the process has had for you, the team and Randers Rehabilitation Unit.

<table>
<thead>
<tr>
<th>1</th>
<th><strong>Outcome focused.</strong> Improved health and reduced health inequities</th>
<th>Has the process and the intervention improved the quality of the offer to citizens referred to Randers Rehabilitation Unit after heart disease? Has it improved the quality for the most vulnerable citizens?</th>
<th>From your perspective, has the process with the Heart Skills Project changed the quality of the offer to citizens referred after heart disease? How?</th>
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<tr>
<td></td>
<td>Responsiveness. Recognises that health literacy needs and appropriate responses vary across individuals, contexts, countries, cultures and time</td>
<td>To which extent has the process reflected the identified needs? What are the prospects of responding to health literacy at Randers Rehabilitation Unit in the future?</td>
<td>Do you think the project has prepared you for recognizing and responding to citizens’ needs in the future? If yes, how? If no, what do you miss?</td>
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<tr>
<td>7</td>
<td></td>
<td>Relevance</td>
<td></td>
</tr>
</tbody>
</table>
| 8 | Systematically applied. A multilevel approach in which resources, interventions, research and policy are organized to optimize health literacy | How has our project become relevant for other parts of the health care system? At which levels have changes happened at Randers Rehabilitation Unit: Culture and values? Strategy and process? Access? | Try to discuss how (and if) the Heart Skills Project has impacted on the following areas:  
- Your organizational culture and values? If yes, how? If no, why not?  
- The strategy and work procedures in your organization? If yes, how? If no, why not?  
- Access to your offers? If yes, how? If no, why not?  
- The way you communicate with citizens? If yes, how? If no, why not?  
- Your competencies as employees? If yes, how? If no, why not?  
- Your collaboration with other teams, external collaborators and persons or organizations in the local community? If yes, how? If no, why not? |
<table>
<thead>
<tr>
<th>Communication?</th>
<th>Employee competencies?</th>
<th>External collaborators/local community?</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Long-term sustainability</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Possibilities for dissemination and spreading</strong></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

| 6 | **Sustainable.** Is health literacy integrated in the local practice and politics – is our effort sustainable? | How can it be possible to sustain the changes as a result of the Heart Skills Project in the heart team and Randers Rehabilitation Unit in the future? Which barriers do you see? |
|  | **Long-term sustainability** | Can other organizations or other municipalities in Denmark learn anything from the Heart Skills Project? |
|  | **Possibilities for dissemination and spreading** |  |

**Round-off**

I have no further questions but if you have anything else to say about the Heart Skills Project, please come forward.

*(time for this)*

Before you leave, I would like to thank you for your help. We are grateful for all your perspectives and thoughts and they are very important for our possibility to evaluate the Heart Skills Project to benefit the rehabilitation unit and others.

If you regret your participation, you can withdraw your consent at any time. If your do, we delete all information about you and the interview you have participated in.
If you have doubts or questions after today, you are welcome to contact us. Contact information is available in the information material handed out in the beginning of the interview.

Thank you again.

Now I turn off the dictaphone.
Interview guide for leaders

Information before the interview:

I would like to give you some information, before we start the interview. I also need some basic information about you.

The purpose of this interview is to collect information on your experiences and reflections in connection with the process Randers Rehabilitation Unit and in particular the Heart Team have undergone since the data collection for the Heart Skills Project was started in 2017.

- A lot has happened during the project and people may have experienced this in different ways. It is important for me to say that there are no right and wrong answers; we are just curious about your perspectives as leader
- Some questions during the interview may be easier to answer than others. It is perfectly okay if you need time to think during the course of the interview
- When you have worked closely together on a project it can be difficult to be critical afterwards. It is important for the value of our results that you are honest – also about things that have not been optimal and things that have not had the desired effect.

Before we start, I ask you to sign this consent form (handing out consent form). With your signature you consent to my use of your statements in future scientific dissemination. You will not be mentioned by name; however, we need to describe your role in the project and the unit and full anonymity is thus not possible. I am obliged to maintain confidentiality and it will only be a limited number of researchers who describe and analyse the interview. These researchers are also obliged to maintain confidentiality and the information is only used to communicate results of the Heart Skills Project. First of all, information will be disseminated in scientific journals, but quotations and summary results may also be used in presentations and popular science communication.

(Obtain consent before moving on!!!)

Thank you!

Now I switch on the dictaphone.

Before we start the actual interview, I would like some basic information about you. Please, introduce yourselves and state your name, age as well as your role in Randers Rehabilitation Unit.
Research theme:
Ophelia principle

Research question:

Interview question:

Introduction

We are going to talk about the project **Heart Skills**.

Heart Skills has been an ongoing project since 2017 and there are many sub processes involved; among these, you have participated in:

- 6) Collection of questionnaire data in 2017
- 7) Self-evaluation of the organizational health literacy in 2017 and 2018
- 8) Pilot testing of CHAT in 2018
- 9) The co-creation process on the basis of questionnaire data with citizens and leaders in 2018 and 2019
- 10) Pilot testing of initiatives to increase involvement of relatives and individual pathways for vulnerable citizens in 2019

We would like you to relate to the entire process you have been through in Randers Rehabilitation Unit and in particular the heart team, since you were introduced to the concept of health literacy for the first time.

Teaser question

Please, try to describe your experiences of the process of the Heart Skills Project in your own words

How much have you been involved?

Are there any experiences you attach particular importance to?

Or have you thought about anything in particular which is characteristic of your experiences?

Remember there are no right or
Experience of the process

<table>
<thead>
<tr>
<th></th>
<th><strong>Driven by local wisdom.</strong> Intervention development and implementation is grounded in local experience and expertise</th>
<th>Based our efforts on local needs, possibilities and values? Have we used the local context well enough? <strong>Ability to implement (acceptable, realistic)</strong></th>
<th>When you think about the Heart Skills Project, how do you think the project has related to the local context and Randers Rehabilitation Unit? Does the project e.g. use the knowledge and expertise available at Randers Rehabilitation Unit and in the heart team? If yes, how? Does the project fit your local values and work approach? If yes, how? Has the project managed to use the local context – e.g. in the health centre, the local community and the municipality? If yes, how?</th>
</tr>
</thead>
<tbody>
<tr>
<td>5</td>
<td><strong>Needs-diagnostic approach.</strong> Participatory assessment of local needs using local data</td>
<td>Have we identified what characterizes health literacy among citizens referred to rehabilitation in Randers? Have we</td>
<td>In the Heart Skills Project, you have taken your starting point in the concept <em>health literacy</em> and spent a lot of energy on finding out which needs citizens referred to rehabilitation after heart disease have. Moreover, to find out which possibilities and limitations Randers Rehabilitation Unit has to meet</td>
</tr>
<tr>
<td></td>
<td><strong>Appendices</strong></td>
<td><strong>characterized the organizational health literacy in Randers Rehabilitation Unit (the Heart Team)</strong></td>
<td><strong>these needs</strong></td>
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<tr>
<td></td>
<td><strong>Relevance</strong></td>
<td>How you succeeded? Why (not)?</td>
<td>Has health literacy been a good starting point for identifying these needs? Why (not)?</td>
</tr>
<tr>
<td>3</td>
<td><strong>Co-design approach.</strong> In all activities at all stages relevant stakeholders engage collaboratively to design solutions</td>
<td>Have we included all relevant stakeholders in the process and have their participation produced ownership and better solutions?</td>
<td>The Heart Skills Project has involved citizens, staff and you as leaders in different phases. What has been the significance of the participation of you and others in the Heart Skills Project?</td>
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<tr>
<td></td>
<td><strong>Ownership</strong></td>
<td>What has it meant to the process that so many have been involved? And what does it mean to you as a leader? Try to verbalize how you have experienced the Heart Skills Project compared with other improvement projects you have participated in.</td>
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<tr>
<td>2</td>
<td><strong>Equity driven.</strong> All activities at all stages prioritize disadvantaged groups and those experiencing inequity in access and outcome</td>
<td>Has there been focus on the most vulnerable during all phases of the process?</td>
<td>Now we are going to talk about vulnerability and vulnerable citizens. Vulnerability is important for a person’s possibilities to participate in and obtain a good outcome of a health offer such as a rehabilitation pathway.</td>
</tr>
<tr>
<td></td>
<td><strong>Relevance</strong></td>
<td>Has the Heart Skills Project</td>
<td></td>
</tr>
<tr>
<td></td>
<td><strong>Outcome focused.</strong></td>
<td>Has the process and the intervention improved the quality of the offer to citizens referred to Randers Rehabilitation Unit after heart disease? Has it improved the quality for the most vulnerable citizens?</td>
<td>From your perspective, has the process with the Heart Skills Project changed the quality of the offer to citizens referred after heart disease? How?</td>
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<tr>
<td>1</td>
<td>Improved health and reduces health inequities</td>
<td>Relevance</td>
<td></td>
</tr>
<tr>
<td>7</td>
<td><strong>Responsiveness.</strong> Recognise that health literacy needs and</td>
<td>To which extent has the process reflected the</td>
<td>Do you think you will use the concept health literacy in the future? If yes, in which way; if</td>
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Experiences of the effects of the process

Now we have talked a lot about the process you have been through. You are welcome to add something if you wish to elaborate on something we have missed.

We are now going to talk about the impact of the process. I do not only think about the initiatives you have tested this autumn and their results, but also the impact the process has had for you, the team and for Randers Rehabilitation Unit.

1. **Outcome focused.** Improved health and reduces health inequities
2. **Responsiveness.** Recognise that health literacy needs and

Has Heart Skills impacted on the way you think about vulnerability and vulnerable citizens? If yes, how?

Has vulnerable citizens played a role in the process you have been through with Heart Skills? If yes, how?
<table>
<thead>
<tr>
<th>Question</th>
<th>Response</th>
<th>Relevance</th>
</tr>
</thead>
<tbody>
<tr>
<td>appropriate responses vary across individuals, contexts, countries, cultures and time</td>
<td>identified needs? What are the prospects of responding to health literacy at Randers Rehabilitation Unit in the future?</td>
<td>no, what do you think prevents you from doing that?</td>
</tr>
<tr>
<td>Systematically applied. A multilevel approach in which resources, interventions, research and policy are organized to optimize health literacy</td>
<td>How has our project become relevant for other parts of the health care system?</td>
<td>Here is a number of questions I would like to ask you concerning your immediate attitude and afterwards I will ask you to elaborate: Has Heart Skills been important for:</td>
</tr>
<tr>
<td></td>
<td></td>
<td>- Your organizational culture and values? If yes, how? If no, why not?</td>
</tr>
<tr>
<td></td>
<td></td>
<td>- Your organizational strategy and work procedures? If yes, how? If no, why not?</td>
</tr>
<tr>
<td></td>
<td></td>
<td>- Access to your offer? If yes, how? If no, why not?</td>
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<td>- The why you communicate with the citizens? If yes, how? If no, why not?</td>
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<td></td>
<td></td>
<td>- Staff competences? If yes, how? If no, why not?</td>
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<td></td>
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<td>- Your collaboration with other teams, external collaborators and persons or organizations</td>
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</tbody>
</table>

At which levels have changes happened at Randers Rehabilitation Unit: Culture and values? Strategy and process? Access? Communication? Employee competencies? External collaborators/local community?

Long-term
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<th>sustainability</th>
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<td></td>
<td>Possibilities for dissemination and spreading</td>
<td>in the local community? If yes, How; if no, why not?</td>
</tr>
<tr>
<td>6</td>
<td><strong>Sustainable.</strong> Optimal health literacy practice becomes normal practice and policy</td>
<td>Is health literacy integrated in the local practice and politics – is our effort sustainable?</td>
</tr>
<tr>
<td></td>
<td><strong>Long-term sustainability</strong></td>
<td>How do you think it is possible to sustain the changes as a result of Heart Skills in the heart team and Randers Rehabilitation Unit in the future? Which barriers do you see?</td>
</tr>
<tr>
<td></td>
<td>Possibilities for dissemination and spreading</td>
<td>Can other organizations or other municipalities in Denmark learn anything from the Heart Skills Project?</td>
</tr>
</tbody>
</table>

**Round-off**

I have no further questions but if you have anything else to say about the Heart Skills Project, please come forward.

*(time for this)*

Before you leave, I would like to thank you for your help. We are grateful for all your perspectives and thoughts and they are very important for our possibility to evaluate the Heart Skills Project to benefit the rehabilitation unit and others.

If you regret your participation, you can withdraw your consent at any time. If your do, we delete all information about you and the interview you have participated in.

If you have doubts or questions after today, you are welcome to contact us. Contact information is available in the information material handed out in the beginning of the interview.

Thank you again.

Now I turn off the dictaphone.
Interview guide for user representatives

Information before the interview:

I would like to give you some information, before we start the interview. I also need some basic information about you.

The purpose of this interview is to collect information on your experiences and reflections in connection with the process Randers Rehabilitation Unit and in particular the Heart Team have undergone since the project management team was established in relation to the Heart Skills Project back in the summer of 2018.

- A lot has happened during the project and people may have experienced this in different ways. It is important for me to say that there are no right and wrong answers; we are just curious about your perspectives
- Some questions during the interview may be easier to answer than others. It is perfectly okay if you need time to think during the course of the interview
- When you have worked closely together on a project it can be difficult to be critical afterwards. It is important for the value of our results that you are honest – also about things that have not been optimal and things that have not had the desired effect.

Before we start, I ask you to sign this consent form (handing out consent form). With your signature you consent to my use of your statements in future scientific dissemination. You will not be mentioned by name; however, we need to describe your role in the project and the unit and full anonymity is thus not possible. I am obliged to maintain confidentiality and it will only be a limited number of researchers who describe and analyse the interview. These researchers are also obliged to maintain confidentiality and the information is only used to communicate results of the Heart Skills Project. First of all, information will be disseminated in scientific journals, but quotations and summary results may also be used in presentations and popular science communication.

(Obtain consent before moving on!!!)

Thank you!

Now I switch on the dictaphone.

Before we start the actual interview, I would like some basic information about you. Please, introduce yourselves and state your name, age and current or former position.
Introduction

We are going to talk about the project ‘Heart Skills’.

‘Heart Skills’ has been an ongoing project since 2017 and you have been a part of the project since the autumn 2018 where you joined the project group with Anna, Sanne and Poul/Inge.

You have participated in the planning of workshops, analysis of results and selecting and designing the interventions which have later been tested. You have also taken part in the goal setting for the tests and in the adjustment of processes during the project. You have done this based on your experience as a participant in a former rehabilitation course at Randers Rehabilitation Unit.

We would like you to relate to the entire process you have experienced as a part of the project group.

For a start, please describe in your own words your experiences with the process since you joined the project group in 2018.

How much have you been involved?

Do you attach specific importance to some experiences?

Or have you thought about what your believe characterizes your experience?

Remember there are or wrong answers. We are just interested in hearing YOUR experiences.

Main questions

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<tr>
<th>5</th>
<th>Driven by local wisdom. Intervention development and implementation is grounded in</th>
<th>Does our intervention build on local needs, possibilities and values? Have we</th>
<th>Has your knowledge/experience as a patient with heart disease played a role in Heart Skills? If yes, how?</th>
</tr>
</thead>
<tbody>
<tr>
<td>3</td>
<td><strong>Co-design approach.</strong>&lt;br&gt;In all activities at all stages relevant stakeholders engage collaboratively to design solutions</td>
<td>Have we included all relevant stakeholders in the process and have their participation produced ownership and better solutions?</td>
<td>The Heart Skills Project has involved both a group of citizens, staff and leaders in the rehabilitation unit in different phases of the project. From your perspective as a part of the project group, what is the significance of the many different people who have participated in The Heart Skills Project? Could it have been an advantage to include more? If yes, who and how?</td>
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<td>4</td>
<td><strong>Needs-diagnostic approach.</strong>&lt;br&gt;Participatory assessment of local needs using local data</td>
<td>Have we identified what characterizes health literacy among citizens referred to rehabilitation in Randers? Have we characterized the organizational health literacy in Randers</td>
<td>When you think about Heart Skills, do you think the project has considered the needs citizens experience when referred to cardiac rehabilitation? If yes, how? Helpful questions: 1) Has the project identified the citizens’ needs? If yes, how? 2) Has the project acted on the citizens’ needs? If yes, how?</td>
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<td></td>
<td><strong>Rehabilitation Unit (the Heart Team)</strong></td>
<td><strong>Relevance</strong></td>
<td><strong>Equity driven.</strong></td>
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<td>7</td>
<td><strong>Responsiveness.</strong> Recognize that health literacy needs and appropriate responses vary across individuals, contexts, countries, cultures and time</td>
<td>To which extent has the process reflected the identified needs? What are the prospects of responding to health literacy at Randers Rehabilitation Unit in the future?</td>
<td>Now we are going to talk about vulnerability and vulnerable citizens. Vulnerability is important for a person’s possibilities to participate and to obtain a good outcome of a health offer such as a rehabilitation pathway. According to you, who are the most vulnerable citizens referred to the rehabilitation unit?</td>
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<td>2</td>
<td><strong>Equity driven.</strong> All activities at all stages prioritize disadvantaged groups and those experiencing inequity in access and outcome</td>
<td>Has there been focus on the most vulnerable during all phases of the process?</td>
<td>The citizens you have just been telling about may have diverse challenges. Some of them may find it difficult to understand their disease and the information they get at the health centre; others find it difficult to make themselves heard and tell about their needs or suggestions.</td>
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<td></td>
<td><strong>Outcome focused.</strong> Improved health and reduces health inequities</td>
<td>Has the process and the intervention improved the quality of the offer to citizens referred to Randers Rehabilitation Unit after heart disease? Has it improved the quality for the most vulnerable citizens?</td>
<td>From your perspective, do you think Heart Skills has changed the quality of the offer to citizens referred after heart disease? If yes, how? And what do you think has been particularly important for the change in quality?</td>
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<td>1</td>
<td><strong>Relevance</strong></td>
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<td>6</td>
<td><strong>Sustainable.</strong> Optimal health literacy practice becomes normal practice and policy</td>
<td>Is health literacy integrated in the local practice and politics – is our effort sustainable?</td>
<td>Do you think other municipalities or organizations (i.e. hospitals, general practitioners, health centres and health offers) can learn something? If yes, what (and who can learn something)?</td>
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<td><strong>Long-term sustainability</strong></td>
<td></td>
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<td></td>
<td><strong>Possibilities for dissemination and spreading</strong></td>
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<tr>
<td>8</td>
<td><strong>Systematically applied.</strong> A multilevel approach in which resources, interventions, research and policy are</td>
<td>How has our project become relevant for other parts of the health care system?</td>
<td>Even though you do not benefit yourself from the initiatives developed in connection with Heart Skills, has the project had any significance for you personally? If yes, how?</td>
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</table>
### The Heart Skills Study

<table>
<thead>
<tr>
<th>organized to optimize health literacy</th>
<th>At which levels have changes happened at Randers Rehabilitation Unit:</th>
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<tr>
<td></td>
<td>Culture and values?</td>
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<td>Strategy and process?</td>
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<td>Access?</td>
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<td>Communication?</td>
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<td>Employee competencies?</td>
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<td>External collaborators/local community?</td>
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<td></td>
<td><strong>Long-term sustainability</strong></td>
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<td></td>
<td><strong>Possibilities for dissemination and spreading</strong></td>
</tr>
</tbody>
</table>

### Round-off

I have no further questions but if you have anything else to say about the Heart Skills Project, please come forward.

(time for this)

Before you leave, I would like to thank you for your help. We are grateful for all your perspectives and thoughts and they are very important for our possibility to evaluate the Heart Skills Project to benefit the rehabilitation unit and others.

If you regret your participation, you can withdraw your consent at any time. If you do, we delete all information about you and the interview you have participated in.
If you have doubts or questions after today, you are welcome to contact us. Contact information is available in the information material handed out in the beginning of the interview.

Thank you again.

Now I turn off the dictaphone.