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Work in Progress: A Report on Health Literacy in Denmark and the Netherlands

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Abstract
This report focuses on the development of health literacy in two European countries, Denmark and the Netherlands. Denmark is part of the Nordic region, while the Netherlands is situated in the Western part of Europe. The report includes examples on Danish and Dutch health literacy research and lessons learned from practice. In Denmark, supported by health literacy research, health literacy developments have been advanced within some areas of practice. Health literacy advocacy initiatives promoted by the Danish Health Literacy Network and the Danish Society of Public Health provide promising perspectives for the future of health literacy in Denmark. In the Netherlands, the Dutch Health Literacy Alliance, researchers, and other relevant stakeholders are actively integrating health literacy in research and practice – both clinically and in communities. The vibrant Dutch health literacy community advocates for further national health literacy efforts to achieve governmental support.

1. Introduction

This report focuses on the development of health literacy in two European countries, Denmark and the Netherlands. Denmark is part of the Nordic region, while the Netherlands is situated in the Western part of Europe. Although similar in geographical size, their populations differ significantly. Denmark has a population of 6.3 million inhabitants compared to 17 million in the Netherlands.

The health systems also are different as the Danish system is primarily tax-based via the so-called Beveridge model, while Dutch financing is based on the Bismarck model through a social insurance system. Historically, the Netherlands is one of the front runners in the European health literacy field

with activities that began almost two decades ago. The Danish health literacy community evolved more slowly. The report includes examples on Danish and Dutch health literacy research and lessons learned from practice.

2. Denmark

Health literacy is gaining momentum in Denmark after a comparatively slow start. Although a status report was provided by the Danish Health Agency in 2009, health literacy did not really catch on within the Danish health system until recently. One of the reasons was the challenge to translate the term 'health literacy' into the Danish language [1]. In Danish, health literacy can be translated to 'Sundhedskompetence,' which is now a commonly used term.

The initial suggestions to advance health literacy in Denmark focused on research [2-3]. An Internet mapping study in 2013 suggested health literacy's integration had begun in the diverse areas outlined in Table 1. Health literacy activities included these arenas [4]:

- Denmark's policy arena, which was dominated by municipalities and regional governments, who applied health literacy in guidelines and local interventions as part of their health prevention and promotion efforts. Various ministries also were represented as well as international policymakers, such as the European Commission and the European Centre of Disease Control.
- Participation in Denmark's educational arena included stakeholders in primary schools, secondary schools, university colleges, universities, and institutions working on lifelong learning.
- Denmark's research arena was represented by all five universities as well as several university colleges and national research institutions.
- Denmark's communication arena included stakeholders from national and local newsletters, television, web services, and blogs.
- Denmark's arena for capacity building was characterized by diverse stakeholders including the trade unions for doctors, nurses, physiotherapists, and engineers as well as the Danish Society of Public Health.

[Table 1]

- Denmark's arena of civic engagement suggested some health literacy stakeholders were involved in some non-governmental organizations, especially patient organizations.
- Denmark's business participation included the pharmaceutical industry and smaller consultancies.
- Finally, Denmark's healthcare service health literacy participation included a few hospitals active in relation to quality of care, immigrant health, patient education, adherence and compliance.

2.1. The Nordic Health Literacy Network

The lack of data and inconsistent stakeholder commitment encouraged Danish health literacy stakeholders to join the Nordic Health Literacy Network. The Nordic Network began in 2012 to facilitate a health literacy knowledge exchange across Nordic countries and work with international colleagues. The Nordic Network hosted several meetings in Norway, Sweden, and Denmark during its first five years.

More recently, the Network mostly has been active in European health literacy activities, such as the 2nd European Health Literacy Conference that took place in Aarhus, Denmark in 2014 and the establishment of the WHO action network on Measuring Population and Organizational Health

Literacy (M-POHL: https://mpohl. net/). Denmark is slated to be part of the next European Health Literacy Survey coordinated by M-POHL called HLS19. Danish and Norwegian colleagues also developed two of seven WHO National Health Literacy Demonstration Projects (NHLDPs), which address HL needs in the European region.

2.2. The Danish Health Literacy Network

The Danish Health Literacy Network was launched in 2016 for professionals engaged in policy, research, and practice. The Danish Health Literacy Network hosts bi-annual membership meetings across the country and the first national conference will occur in spring 2020.

In terms of agenda setting, the Danish Health Literacy Network's recent project is a joint initiative launched in 2019 with the Danish Society of Public Health. Through a participatory process including members and designated key health stakeholders, a policy brief was developed with eight recommendations about how to improve health literacy as a path towards health equity [5]. All the Network's recommendations can be integrated within current health strategies, including ongoing efforts to achieve the U.N. Global Goals for Sustainable Development.

More specifically, the Network's eight recommendations are to:

1. Integrate health literacy in Danish health policies and strategies. Given the increasing complexity of health information, health literacy directly or indirectly needs to be addressed by all Danish national and local health policies and strategies.
2. Develop health literacy throughout the life course. Health literacy should be integrated into and across sectors inside and outside the health care delivery system to ensure HL needs are met throughout all life course stages.
3. Include health literacy in health education curricula. Health literacy should be prioritized and integrated into educational curricula in pre- and postgraduate training of healthcare professionals.
4. Integrate health literacy at organizational levels. Organizational health literacy responsiveness should be developed at all levels in the Danish healthcare system – municipal, regional and national as well as in private and voluntary organizations.
5. Integrate health literacy into partnerships and co-creation processes. In crosssectional collaborations and partnerships, health literacy builds bridges between different stakeholders and fosters a common ground for communication and reference.
6. Measure and monitor health literacy using local and national data. Routine analysis of individual health literacy and organizational health literacy responsiveness should be implemented nationally and locally among the general and vulnerable populations. Digital health literacy also should be assessed where appropriate.
7. Develop, test, and evaluate health literacy interventions. More interventions with a focus on health literacy should be developed, tested, and assessed in different contexts and settings. Interventions should foster dynamic interactions between practice and research.
8. Consider health literacy principles within all forms of health communication in Denmark. All verbal, written, and digital health communication should consider potential differences in people's health literacy needs [5].

2.3. Research

To date, Denmark's health literacy research has focused on measurements and interventions. For example, the first study from Denmark was a population-based assessment of dimensions of health literacy related to understanding health information, which engaged healthcare providers to use the Health Literacy Questionnaire (HLQ) [6]. The latter study was followed by an evaluation of health literacy in people with long-term health conditions (diabetes, cardiovascular disease, chronic

obstructive pulmonary disease, musculoskeletal disorders, cancer and mental disorders) [7]. The immediate findings were compared to levels in the general population to note associations among health literacy, socioeconomic characteristics, and comorbidity within each long-term condition group [7]. Meanwhile, a team validated the Test of Functional Health Literacy in Adults' (TOFHLA's) adaptation to Danish health care settings and culture. The use of TOFHLA to measure HL was seen as acceptable among Danish patients with chronic obstructive pulmonary disease (COPD) as well as a case group example [8].

A study additionally assessed the level of health literacy among Danish students who attended one of the four full university health programmes and investigated the association of health literacy with sociodemographic backgrounds. Student health literacy levels were measured using HLQ [9]. Kayser and colleagues also tested the HLQ for eHealth consumer use and developed the eHealth Literacy Questionnaire (eHLQ), which is a multi-dimensional tool based on a well-defined a priori eHLF framework. The questionnaire is designed to be used to understand and evaluate health consumer interactions with digital health services [10]. In two recent studies, Aaby et al. suggested large diversity in Denmark's population health literacy profiles [11]. Similarly, Svendsen and colleagues found diverse population-wide health literacy among Danish citizens using the HLS-EU-Q [12]. They also included patients with heart disease for comparative purposes [12].

2.4. Educational Interventions

Danish schools have been identified as central settings for health literacy interventions. For example, an educational programme, IMOVE, advances student health literacy by focusing on physical activity. IMOVE contributed to the development of functional health literacy in Denmark by suggesting health literacy could be boosted by encouraging participant awareness of everyday physical activities, which included step numbers [13]. Furthermore, intervention projects have been launched at organizational and community levels based on the OPHELIA approach [14].

In recent years, some universities and university colleges have started to integrate health literacy as part of their capacity building and education programmes in the form of lectures, modules, thesis topics, etc. Thus, health literacy is taught at university level at Aarhus University and Copenhagen University to health professionals in the schools of public health science. In addition, some nursing schools have integrated health literacy within their educational efforts. The Global Health Literacy Academy also offers courses and workshops on health literacy. It is expected that the educational efforts will increase in the future due to the increased awareness of the importance of health literacy in research, policy, and practice.

3. The Netherlands

The first comparative national study of health literacy in seven European nations (HLSEU) found the lowest percentage of inhabitants with inadequate or problematic health literacy (28.7%) was in the Netherlands [15]. The findings, which were published in 2012, proved to be both a blessing and a curse. For example, Dutch researchers, professionals, and policy makers were pleased with their nation's achievement. From a public health perspective, health literacy in the Netherlands was superior to six other European countries. However, the appreciation of success resulted in no official measures taken by the Dutch national government to either improve the level of health literacy or to set targets for a more tailored care system. In fact, between 2012-2018, the Netherland's Minister of Health, Welfare and Sport perceived that policy initiatives as well as interventions to target limited health literacy were the sole responsibility of nongovernmental stakeholders.

In contrast, lower health literacy scores on the HLS-EU in Austria and Germany created a sense of urgency, which led to national support for new research, care innovations, and policy initiatives. In 2018, a new survey suggested the level of limited health literacy in the Dutch population was much

higher than found in 2012 - 36.4% [16]. Of the persons surveyed, 9.5% had inadequate and 26.9% problematic health literacy. Similar to other countries, there is a social gradient in the Netherlands with regard to health literacy: 54,7% of lower educated persons have limited health literacy, compared to 27.2% among those with higher educational levels [16].

Perhaps as a result of the revised limited health literacy estimates, the attention to health literacy (in Dutch 'Gezondheidsvaardigheden') is growing both in terms of policy and recent initiatives from Dutch healthcare organizations. Although the Dutch national government still has no official policy with respect to health literacy, the topic is sometimes being integrated in other efforts, such as efforts to improve patient shared decision making. In addition, some smaller grants have been awarded for research and networking. Moreover, a conceptual change in the Netherlands has shifted the focus of health literacy initiatives from literacy or cognitive skills to the motivation, confidence, and skills for citizens to put health related knowledge into practice ('the capacity to act') [17]. The latter shift in focus is partially linked to recent research that suggests knowledge alone is insufficient to persuade persons to take a more active patient role and/or change one's lifestyle [18].

3.1. Dutch Health Literacy Alliance

A nationally based initiative began in 2010 with the establishment of the Dutch Health Literacy Alliance ('Alliantie Gezondheidsvaardigheden'). The Dutch Health Literacy Alliance represents a network of organizations, institutions, companies, and individuals. The Alliance was started by a group of healthcare providers and researchers who sought to draw attention to the problem of limited health literacy. The Alliance's priorities include agenda setting and networking and it now contains 80 partner organizations. Several Dutch NGO's have hosted the Alliance including Pharos (Dutch Centre of Expertise on Health Disparities). The Alliance has a website, organizes semi-annual network meetings and there are three active working groups devoted to research, education, as well as patient experiences and participation [19].

3.2. Research

In the years around and following the HLS-EU assessment, several Dutch researchers developed an interest in health literacy. Initially, since most health literacy studies were conducted in the U.S., the question arose whether the measurement instruments developed within an American context were empirically valid and reliable in the Netherlands. Accordingly, several measurement instruments were translated and validated in Dutch including: the Rapid Estimate of Adult Literacy in Medicine (REALM), Set of Brief Screening Questions (SBSQ); Functional Communicative and Critical Health Literacy (FCCHL); Newest Vital Sign (NVS); and the Health Literacy Questionnaire (HLQ) [19-21].

Once these instruments were translated and validated, the next generation of Dutch research focused on: the association between health literacy and health outcomes; provider choice and healthcare use; seeking and use of health information preferences for and participation in screening activities; shared decision making; and health self-management [22-32]. The results of these studies were consistent with research from the U.S. and other countries: Dutch participants with limited health literacy in general have worse outcomes and are less active throughout the trajectory from health prevention through clinical care. Since more elaborate health literacy measurements instruments were used in Dutch research, it became clear that functional health literacy explains only some of the disparities between limited and other health literacy populations – and communicative and critical skills also are important.

Intervention studies, which focus on the development, implementation, and evaluation of interventions (in healthcare and prevention), also have begun in the Netherlands. Some interventions have been developed and implemented on a small scale [33-34]. These interventions

target mostly the micro-level (patient-provider, personal use of eHealth) or the meso-level (improving a healthcare organization, and the broader training of health providers and staff).

Since there is no governmental or other central policy regarding health literacy in the Netherlands, health literacy initiatives are not necessarily coordinated, and project insights are not always shared. Since some interventions are not thoroughly evaluated, it is difficult for other Dutch health literacy professionals and policymakers to determine which interventions are (cost)-effective within specific circumstances. Hence, in 2018, the Dutch Ministry of Health, Welfare and Sport and the Netherlands Organization for Health Research and Development invested in the draft of a coherent research agenda on health literacy, specifically aimed to improve research about health care services for persons with limited health literacy [34]. The ensuing research agenda covers challenges at the micro- (patient-provider), meso- (organization) and macro-level (society). However, at present the funding for a more comprehensive health literacy research agenda is unavailable in the Netherlands.

3.3. Other Interventions

Most of the health literacy activities and interventions that are developed and initiated in Holland are in the domain of healthcare (rather than schools or in the workplace). In the international HEALIT4EU study, which was commissioned by the European Commission in 2015, all interventions on a national or regional level in European countries were inventoried. At that time, nine examples of programs and activities were found in the Netherlands [34].

More recent surveys of tools and methods suggest additional interventions are used routinely in some Dutch healthcare contexts [33-34]. For example, a health literacy toolkit was developed by the National Association of General Practitioners (LHV), for use by Dutch general practitioners and practice nurses. The toolkit provides information that helps providers improve their communication with patients with limited health literacy skills. The toolkit helps with medical admittance, medical consultations, medication prescriptions, and patient referrals. The toolkit includes tips to increase the accessibility of health care practices. Pharos also invests in various projects that improve healthcare provision to patients and caregivers with limited health literacy, such as the use of the 'teach back' method for providers.

In addition, a recent survey of healthcare providers in the Netherlands suggests 41% do not adapt their communication style to the needs of patients with limited health literacy [34]. And 50% do not adapt written, oral or digital information to assist persons with different levels of health literacy. The principle reasons why providers do not tailor health care are:

- Lack of time
- Unfamiliarity with limited health literacy
- Lack of personal responsibility
- Problem is not considered to be relevant
- Unaware of strategies and support for communication and information
- Lack of appropriate strategies and support
- Do not know how to apply strategies and support [33].

Since many strategies and tools already exist for patients with limited health literacy, the last three reasons provide a foundation to advance the education of providers and pay more attention to the tailored dissemination of health materials using internationally derived methods. More positively, some Dutch healthcare providers recommend the following five strategies: the teach back method; use of visual aids; more provider or organizational time; involve family or friends in the consultation and care; and the use of plain language [35]. The teach back method especially seems

promising as it is a generic strategy that can be used in many settings and situations within the Netherlands [35].

As aforementioned, most health literacy interventions in the Netherlands currently are not systematically evaluated. The ensuing knowledge gap provides an important national challenge since Dutch healthcare managers and insurers seek to implement and pay only for evidence-based interventions. As a result, a gradual shift to intervention research and assessment is the key to further implementation and to foster better quality of care for persons with limited health literacy in Holland.

3.4. Educational Interventions

In the Netherlands, the topic of health literacy is not yet structurally integrated in the basis curriculum of health professionals. However, there is an increasing number of initiatives (theses, research internships) and lectures at Universities of applied sciences (a.o. Fontys Hogeschool, Hogeschool Utrecht) and academic universities (a.o. University of Amsterdam, Free University Amsterdam, Maastricht University). Maastricht University further hosts a yearly summer school on health literacy and has an endowed professor of ‘health literacy and patient participation’. Several Ph.D. students are in the process of doing research and writing a thesis on aspects of health literacy.

A working group within the Dutch Health Literacy Alliance also initiated an effort to advance health literacy in Dutch higher and other education. The working group suggests areas of attention for educators and ten learning goals regarding health literacy for health care professionals are targeted for diverse educational levels. However, most current, Dutch health literacy educational activities focus on postgraduate professional education. As a part of further training and continuing education, many professional groups as well as health care institutions integrate health literacy in the programs of their symposia and congresses.

4. Conclusion

This report describes health literacy developments in Denmark and the Netherlands and highlights some contrasts between two countries in two adjacent European regions.

While Denmark had a comparatively slow start, health literacy developments were advanced within some areas of clinical practice, which were later supported by clinical research. Nationally, a new policy brief has raised awareness about health literacy among Danish decision-makers and the Ministry of Health is supporting Denmark´s participation in the next wave of the European Health Literacy Survey. The latter developments suggest a new era of national governmental interest and support, which may provide more focus on health literacy, health equity, and sustainability research and practice. It is especially hoped that the eight recommendations from The Danish Health Literacy Network (outlined in section 2.2 above) will generate a new range of national health literacy activities and actions.

In contrast, the comparatively favorable data from the 2012 European Health Literacy Survey fostered paradoxical governmental inattention to health literacy in the Netherlands. After 2012, the Dutch national government’s engagement in the health literacy was comparatively weak - perhaps because senior officials interpreted the European Health Literacy Survey findings as confirmation of prior policies that did not directly support comprehensive health literacy initiatives. However, more recent population data from the Netherlands suggests more than 30% of the population has limited health literacy. Hence, the Dutch Health Literacy Alliance, researchers, and other relevant stakeholders are advocating the importance of a national health literacy effort with accompanying support for governmentally supported health literacy strategies throughout the Netherlands.

In closing, as the 21st century enters its third decade, there is a critical mass of dedicated health literacy stakeholders in Denmark and the Netherlands, who support the expansion of health literacy

research and practice. Dutch and Danish stakeholders also are internationally oriented and readily share their views and experience, which supports both the further development of health literacy within their own countries as well as in Europe and more globally.

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Tables

Table 1: Stakeholders involved in health literacy in Denmark [4].