Turning the tide: countering syndemic vulnerability in a Dutch fishermen community

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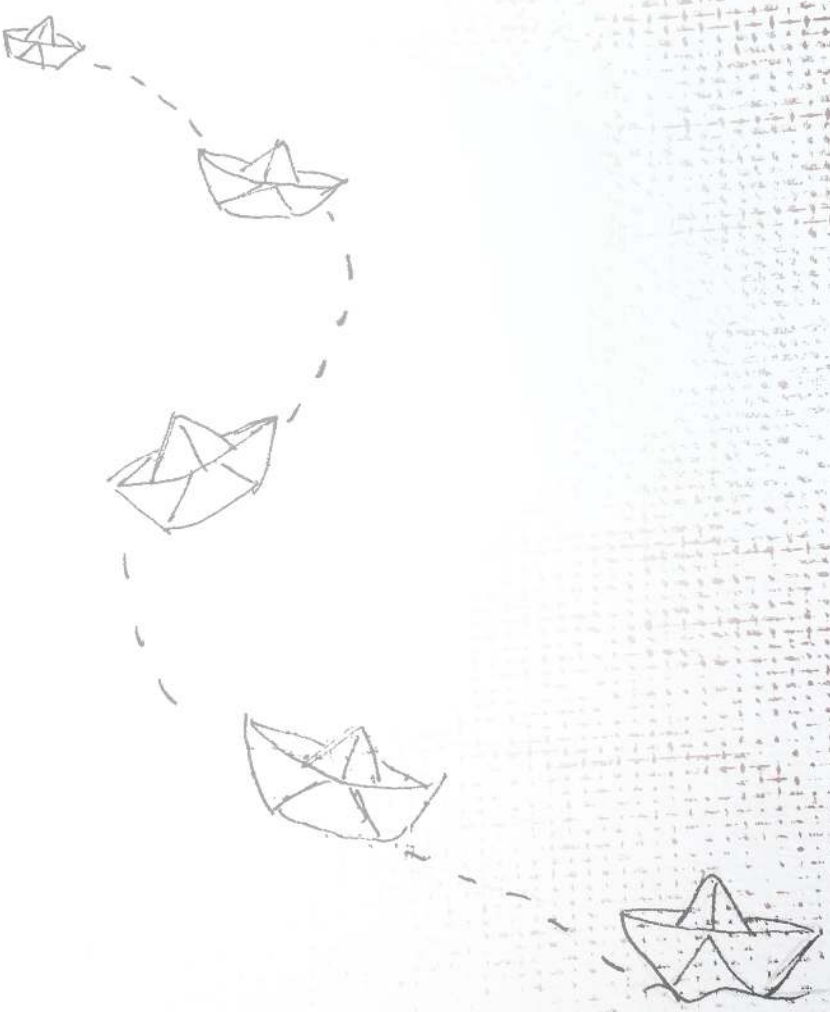

Chapter 1

General Introduction

PERSISTENT HEALTH DISPARITIES

Families in low income areas are often disproportionally affected by poor health (Gilson et al., 2007; Mackenbach et al., 2008). In the Netherlands, an affluent country that is a strong welfare state, lower-educated groups have a significantly lower life expectancy at birth (up to 6.5 years less) and disability-adjusted life years (up to 15.5 years less) compared with higher-educated groups (Broeders et al., 2018). Such health disparities have been shown to be persistent in other European welfare states (Mackenbach, 2012; Mackenbach et al., 2008).

Health disparities are linked to the circumstances under which people grow, live, work and deal with ill health (Commission on Social Determinants of Health, 2008). Populations with a lower socioeconomic position in the Netherlands persistently report more morbidity than those with higher positions (Hoeymans et al., 2010). In these populations, continuous stress often underlies a cascade of life-shortening chronic health conditions (Berger et al., 2019; Everson et al., 2002; Kivimäki et al., 2015). Notable socioeconomically patterned health conditions include non-communicable diseases such as diabetes, depression, cardiovascular disease, and musculoskeletal pain. These non-communicable diseases account for the highest number of deaths and disabilities in populations generally, and in socioeconomically disadvantaged populations in particular (World Health Organisation, 2019).

Despite decades of scientific research into the processes and mechanisms that contribute to health disparities (Bouchard et al., 2015; Cash-Gibson et al., 2018) and various policy efforts to close the health-disparity gap within one generation (Cheng et al., 2016; Commission on Social Determinants of Health, 2008), progress has been limited (Gilson et al., 2007; Mackenbach, 2012). Children continue to grow up in adverse social circumstances, which puts them at a greater risk of suffering from poor health later in life.

There is a need to build forward for improved approaches to persistent health disparities (Gilson et al., 2007; Wilderink et al., 2022). Unfortunately, health care systems intended to break the cycle of intergenerational poor health often do not reach their potential (Gilson et al., 2007). First, the majority of actions to address health disparities are directed towards a single health condition, for example, diabetes or depression, but these health conditions often co-occur in socioeconomically disadvantaged populations. It remains largely unknown how health conditions cluster and influence each other in adverse socioeconomic contexts (Singer et al., 2017). Second, while the link between the lives of parents and children is well known (Cheng et al., 2016; Jones et al., 2019), the majority of public health interventions focus on only one generation, for example, lifestyle interventions for children or adults (Cheng et al., 2016; Cheng & Solomon, 2014; Jones et al., 2019). Third, efforts to address health disparities predominantly focus on solutions targeting downstream factors (Box 1.1), overlooking mid- and upstream factors that are also known to significantly affect the health of populations and local communities (Acheson, 2001; Braveman & Gottlieb, 2014). In short, how to build a way forward that can effectively address persistent health disparities in a holistic/contextual way is an important question that has yet to be answered.

Upstream factors refer to the circumstances in which people are born, grow, live, learn and age; the broader political, economic and social conditions that shape vulnerability for poor health.

Midstream factors, such as health behavioural norms and health care organisations, are intermediate factors that affect neighbourhoods and local communities.

Downstream factors refer to factors at the individual or family level, such as behavioural risk factors or parental health.

Box 1.1 Upstream, midstream and downstream factors affecting population health

A NOVEL PUBLIC HEALTH APPROACH

Syndemics theory is a novel, actionable framework to understand and address health conditions that arise and persist under conditions of social inequality (Singer et al., 2017; Singer et al., 2006). The field of syndemics looks at the clustering and interaction of multiple diseases, with particular attention to mid- and upstream factors that contribute to disease clustering within a given population and context (Singer, 2000). This theory posits that these intertwined health problems produce a stronger and more intense overall adverse health outcome than when each of the conditions or maladies are experienced separately (Singer, 2000). At its core, syndemics theory is concerned with "how upstream factors and experiential dimensions affect 'how people get sick, where they get sick, and why they get sick'" (Minicucci et al., 2021:2).

Anthropologist Merrill Singer introduced the syndemics theory in the 1990s, at the height of the HIV/AIDS epidemic (Singer, 1996). In Hartford, Connecticut, he observed that the Puerto Rican community was disproportionally affected by that epidemic. Building on mixed method research (ethnography, interviews and epidemiological data) among this inner-city population, Singer found that people who tended to suffer from AIDS also suffered from substance abuse and violence. He was the first to describe how substance abuse, violence and AIDS (SAVA) clustered within a specific population, showing how these health and social conditions are closely linked and work as interdependent threats to health. In other words, with syndemic theory, Singer elaborated an epidemiological framework that allows for the description of complex health problems resulting from the interaction between epidemic diseases and endemic adverse social conditions (Singer, 2000; Weaver et al., 2016). This framework was introduced in the midst of long-standing and well-documented debates on the single disease framework, comorbidity (Mendenhall, 2016a; van den Akker et al., 1996; Weaver et al., 2016) and multimorbidity (Lefèvre et al., 2014; Marmot et al., 2012; Navickas et al., 2016; Singer & Clair, 2003; van den Akker et al., 1996).

Until recently, the majority of studies in the field of syndemics have focused on HIV/AIDS (Singer et al., 2020). However, in the past few years, an increasing number of syndemics studies have also looked at population-level clustering of non-communicable diseases (Lerman, 2015; Mendenhall, 2012, 2016a; Mendenhall et al., 2017; Singer et al., 2020). Many syndemics studies have been focused on marginalised groups, such as minority racial/ethnic groups (Hossain et al., 2021; Singer et al., 2020) and men who have sex with men (Herrick, 2011; Mustanski et al., 2014; Stall et al., 2008).

Emily Mendenhall (Mendenhall, 2016b) was the first to identify and describe the clustering of depression and diabetes among Mexican immigrant women in the United States who also experienced harmful social conditions of violence and abuse. She coined the term VIDDA to describe the clustering of health and social problems among Mexican immigrants: violence, immigration-related stress, depression, diabetes and abuse. The clustering of diabetes and depression has subsequently been found in numerous contexts worldwide, often among populations that experience social and economic hardship (Lerman, 2015; Mendenhall et al., 2017; Trainer et al., 2017; Weaver & Mendenhall, 2014).

EPIDEMIOLOGICAL PUZZLE OF KATWIJK

To date, syndemics studies in high-income countries such as the Netherlands remain scarce. The studies in this dissertation were therefore conducted in Katwijk, a former fishing village on the west coast of the Netherlands. In the past, Katwijk had one of the largest fishing fleets in the Netherlands (Deursen, 2011). For centuries, the village was known for its occupation, orthodox Protestant religious traditions, close-knit families, and a distinct social structure in which men often worked off-shore for weeks or months while women stayed on shore and took care of the family (Deursen, 2011).

The community has experienced rapid contextual changes over the past five decades due to welfare reforms, climate change and globalisation (Deursen,

2011). Since the 1960s, as a result of fishing bans, quotas and outsourcing, the fishing industry rapidly deteriorated in Katwijk. Subsequently, following mass unemployment, men shifted to other blue-collar occupations on shore, which brought about great changes in families' everyday lives.

The existing cross-sectional data for the village presented an epidemiological puzzle of intertwined adverse physical and mental health outcomes. Among women in Katwijk, yearly mortality rates are higher compared to the rest of the region and compared to the Dutch population as a whole (34). Moreover, a preliminary analysis indicated that 34% of adults presented with two or more health conditions (multimorbidity) (Municipal Health Organization for Preventive Healthcare, 2009; Slagboom et al., 2016). Cardiovascular diseases, diabetes and musculoskeletal pain often co-occurred within individuals and in the population. Forty percent of the total adult population in Katwijk reported one or more health conditions in this cluster (Municipal Health Organization for Preventive Healthcare, 2009; Slagboom et al., 2016). While such multimorbidity could be expected among the elderly population, it was striking that among those ages 19–34, 20% already suffered from one or more of these conditions.

These observations of multimorbidity across multiple generations prompted questions about the intergenerational nature of disease clustering in populations like Katwijk. Since non-communicable diseases such as cardiovascular disease and diabetes are rare among young people, the data regarding the youth (age < 18) of Katwijk could not answer questions about the clustering of these health conditions in the youngest generation. However, preliminary analyses showed that a higher proportion of youth in Katwijk were overweight, and had higher rates of smoking, alcohol and drug use than those in neighbouring communities (GGD Hollands Midden, n.d.). The data also showed a clustering of health behaviours (smoking, binge drinking, limited physical activity and poor dietary intake) among adolescents in Katwijk. This health behaviour cluster went hand in hand with poorer self-rated health and more social problems: higher rates of skipping classes and school ab-

sence. While these data indicate that health and social problems co-occur in Katwijk, the life histories behind these data remain unknown.

SYNDEMIC RESEARCH IN KATWIJK

Former fishing communities such as Katwijk are likely to be vulnerable to syndemic interactions due to their history of harsh working conditions and occupational hazards (Dolan et al., 2005; Matheson et al., 2001), as well as the adverse socioeconomic conditions in which the people in such communities typically live, including income uncertainty and poor access to health care (Turner et al., 2018; Woodhead et al., 2018). Given the high prevalence of multimorbidity and the village's history of adverse social conditions and rapid contextual change, the epidemiological profile of the former fishing village of Katwijk raises questions about syndemic processes and the possibility of breaking the cycle of poor health.

This dissertation explores the health profile of Katwijk through a syndemic lens. The research questions on syndemics indicators, contextual drivers for syndemics, the intergenerational nature of syndemics and possibilities for interventions are described below and illustrated in Figure 1.

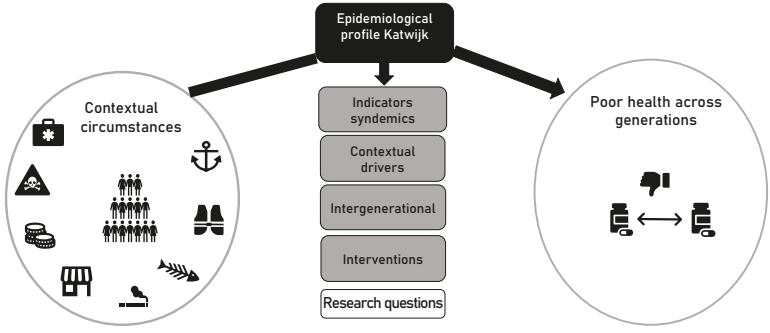

Figure 1. Research questions using a syndemics lens

CLUSTERING, INTERACTION AND CONTEXT

The case of poor health in Katwijk touches upon a key methodological question in syndemics scholarship: does the clustering of non-communicable diseases in this population indicate the presence of a syndemic? As syndemics theory is increasingly applied in medicine, public health and anthropology, for example in studies of Covid-19, the call to rethink methodological questions has become stronger (Mendenhall & Singer, 2019; Singer et al., 2022; Singer et al., 2020; Singer et al., 2021; Tsai, 2018). The debates centre around the three criteria to establish a syndemic (Singer, 1996; Singer et al., 2017), as described below in Box 1.2.

(1) *Disease clustering*: Two (or more) diseases or health conditions cluster within a specific population.
(2) *Disease-disease interaction*: clustering of diseases results in adverse disease interaction, either biological or social or behavioural, increasing the health burden of affected populations.
(3) *Disease-context interaction*: Contextual and social factors create the conditions in which two (or more) diseases or health conditions cluster.

Box 1.2. Three criteria for a syndemic

A number of review studies have addressed the ongoing methodological and conceptual struggles over the best way to define and identify a syndemic (Pirrone et al., 2021; Singer et al., 2020; Tsai & Burns, 2015; Tsai & Venkataramani, 2016). In Singer's review of studies between 2015–2019, only 30% of nearly 200 publications used the syndemics concept as originally defined (Singer et al., 2020). Another study, by Tsai and Burns, observed that while many studies provided rich observational data on disease clustering, very few studies used the appropriate methods to test synergistic disease interaction, thereby lacking empirical evidence of this distinguishing feature of syndemics (Tsai & Burns, 2015).

One instance of a gap in syndemics research is the fact that the synergistic interaction of non-communicable diseases, such as diabetes and depression in the VIDDA syndemic, remains largely unconfirmed (Singer et al., 2021). Focusing on the disease-context criterium, Pirrone and colleagues' review (Pirrone et al., 2021) revealed that syndemic researchers tend to emphasise local contextual factors that promote disease interaction rather than broader contextual factors (i.e., upstream factors). For example, syndemics studies were more likely to explore local living and working conditions than the political or policy environment that shapes local living and working conditions.

Relatedly, Mendenhall and Singer have warned against a tendency to gloss over local histories of inequity and oppression. For example, in response to a surge of studies that approached Covid-19 as a (global) syndemic (Courtin & Vineis, 2021; Horton, 2020; Huizar et al., 2021; Mendenhall et al., 2022; Mendenhall & Singer, 2019; Minicucci et al., 2021; Neira et al., 2021; Shrinivasan et al., 2020), the authors argued that 'syndemic arrangements are always unique to communities' and should be studied as regional rather than global public health events (Singer et al., 2022; Singer et al., 2021). This position rests on the argument that the contexts that promote ill health can vary from one place to another. To account for the abovementioned methodological issues that are faced when researching syndemics, mixed-methods scholarship—which triangulates population data, life-course histories and ethnography—is recommended (Mendenhall et al., 2022; Tsai, 2018; Tsai & Venkataramani, 2016).

In Katwijk, the available existing data could not provide the information needed to assess the three criteria for syndemics (Box 1.2). Knowledge about the prevalence of specific disease clusters in the population was lacking, there was no empirical proof of synergistic interaction between frequently occurring non-communicable diseases and knowledge on the living circumstances and history of people who suffered from one or more diseases was limited.

Consequently, the first two research questions of this dissertation are:

1. *Which indicators are present for syndemics in the population of Katwijk?*
2. *Which contextual conditions drive vulnerability to disease clustering and adverse disease interaction in the population of Katwijk?*

POOR HEALTH OUTCOMES ACROSS GENERATIONS

The Katwijk case also prompts questions about the intergenerational nature of syndemics, which remains poorly understood. The existing epidemiological data for Katwijk consist of cross-sectional data covering different age groups but did not provide information on families. Therefore, it remains unknown whether vulnerabilities for multimorbidity are present across generations within a single family. However, as mentioned before, a preliminary analysis indicated a clustering of health behaviour and social problems among adolescents.

Evidence from other settings suggests that behavioural pathways may lead to the development of cascading health conditions later in life (Lerman, 2015; Mendenhall, 2016b). Moreover, growing up amid parental stress related to income, work, social exclusion, and poor health—which is likely for youth in former fishing communities like Katwijk—is known to increase the risk for poor health later in life (Berger et al., 2019; Kivimäki et al., 2015). To address the intergenerational nature of syndemics, the third research question of this dissertation is:

3. *Which contextual conditions drive vulnerability to disease clustering and adverse disease interaction across generations in the population of Katwijk?*

To examine the contextual conditions that drive disease clustering and adverse disease interactions over the life course and across generations,

this dissertation combined syndemics and life-course theory. The life-course framework, developed on the basis of Elder's (Elder Jr, 1974) study of families of the Great Depression, has been widely adopted to study health trajectories among historically socioeconomically disadvantaged families and populations (Jones et al., 2019).Therefore, the four core notions of life-course theory—historical time and place, timing in lives, linked lives and human agency—were used to guide the data collection for multiple generations in Katwijk and the analysis of the ethnographic data (Elder Jr, 1994; Elder Jr & Shanahan, 2006).

Overall, to assess the indicators of syndemics and processes that might drive diseases to cluster in Katwijk, we built on an explanatory sequential design which consisted of a quantitative and qualitative arm (Creswell & Clark, 2017). In the quantitative arm of the study, we examined disease clustering, adverse disease interaction and explanatory factors for the presence of disease clusters. In the qualitative arm of the study, which triangulates oral histories, interviews and participant observation among families, we turned our lens to shared experiences/exposures that might predispose the population of Katwijk to persistent poor health.

TRANSLATION INTO CARE

The Katwijk case prompted numerous questions about early intervention, in particular, what the possibilities for early intervention might be, if the population-level clustering and the contextual factors that contribute to it were identified and better understood. While experts have advocated for syndemic interventions (Singer et al., 2021; Singer et al., 2017) —multicomponent interventions combining non-medical social interventions as well as clinical interventions— to date, there is little published evidence that such an approach has been implemented (Singer et al., 2020; Singer et al., 2021). This leads to the fourth and final question guiding this dissertation:

4. *How can findings from syndemic studies be translated into early public health interventions?*

To examine how findings from syndemics studies can be translated into early interventions, we will build on the qualitative research method known as participatory action research approach (Minkler & Wallerstein, 2011), a widely used method to collaboratively learn about, and collaboratively address, health disparities (Giachello et al., 2003; Olshansky et al., 2005; Wallerstein & Duran, 2006). Following our examination of indicators for syndemics, as described above, researchers, families and professionals from the social, medical and policy domain in Katwijk collaborated to restructure existing early interventions. In a joint effort, existing care activities were adapted to pay attention to the social circumstances of the family as a whole.

OBJECTIVE AND OUTLINE OF THE DISSERTATION

As shown above, this dissertation addresses a wide range of research questions that will be answered throughout the following four chapters. As a whole, this dissertation explores the contribution of the syndemics framework for understanding and addressing persistent health disparities. The methodology employed for each of the four studies will be described in detail in each chapter.

Chapter 2 assesses the three syndemics criteria in the epidemiological data of Katwijk. This cross-sectional study examines the prevalence and co-occurrence of non-communicable disease in Katwijk, estimates whether disease interaction contributes to self-rated health, and identifies which contextual variables are associated with interacting clusters of non-communicable diseases.

Chapter 3 investigates the intergenerational nature of syndemics by examining themes and patterns related to syndemic vulnerability across families and generations in Katwijk. This chapter traces processes leading to or from syndemic vulnerability by studying and comparing the life histories of seven families.

Chapter 4 provides an example of translating findings regarding syndemic vulnerability into an early intervention. For this pilot study, we integrated an intergenerational approach into the Gezamenlijk Inschatten Zorgbehoefte (GIZ), a frequently used and shared assessment tool for children's care needs in child preventive health care in the Netherlands. With the help of local professionals, the GIZ methodology was adapted to address parents' strengths and needs concerning changing their own behaviour and/or helping their children with behavioural change. The aim of this study was twofold: first, to monitor the effects of this family-engagement tool on the health behaviour and wellbeing of both children and their parents and second, to explore and understand the different dynamics of health behavioural change within a family.

Chapter 5 provides a contextual analysis of the low uptake of weight-related health promotion for children for a fuller understanding of processes leading up to persistent health disparities in the setting of Katwijk. Building on the notion of subversion, the study examines whom and what is protested against when weight-related health promotion is contested.

Chapter 6 discusses the findings of these studies separately and in relation to each other, addresses new and open research questions, presents methodological reflections and highlights what the syndemic lens adds to understanding, and ultimately addressing, persistent health disparities. Based on the discussions described above, this final chapter also provides a roadmap for future research and interventions.