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## Measuring social exclusion in routine public health surveys

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# Chapter 1

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General introduction

## **Introduction**

People living in the Netherlands and other Western countries are living longer, better educated, more self-reliant and healthier than ever before [1, 2]. This, however, does not apply equally to all citizens. In general, the lower a person's socioeconomic position is, the poorer his or her health and shorter his or her life is [3, 4]. Health inequalities in Western countries are persistent and possibly even worsening over time [5-8]. Some groups at the bottom of the social ladder are seriously lagging behind. They rely on food banks or support from churches [9, 10], experience homelessness [11], suffer from severe mental illness without access to specialised care [12], and endure severe loneliness [13] or marginal positions in society [14]. Social exclusion (SE) is considered one of the driving forces of health inequities [15-18]. People have become isolated from the opportunities that mainstream society has to offer and lack the ability to fully participate in society, which may lead to a loss of control over their lives and ultimately even to homelessness [19, 20]. Measuring SE in routine public health surveys may help to identify and quantify at-risk groups and gain better insight into their characteristics and health risks. Reliable information obtained thusly, would help policy makers develop more effective policies to tackle health inequities, provide a baseline from which to monitor and assess the effects of policies and programs, and raise the profile and visibility of socially excluded groups and their problems [16, 17].

The introductory chapter of this dissertation starts by elaborating on the concept of social exclusion, its use in social exclusion policies, definitions and models of SE and the measurement of social exclusion. This is followed by an outline on the relation between social exclusion and health and an introduction to the Dutch Preventive Care Cycle and public health monitoring in the Netherlands. Finally, the aim and outline of this dissertation are presented.

### **The concept of social exclusion**

In general, social exclusion refers to the inability of people to participate fully in the society in which they live. The question 'what exactly constitutes full participation?' is, however, answered in different ways at different times. The historical origins of the concept of social exclusion go as far back as Aristoteles. He introduced the concept of an impoverished life, i.e., a life without the freedom to undertake important activities that a person has reason to choose and to take part in the life of the community [21].

In recent history the concept was rediscovered by the French Secretary of State, René Lenoir [22]. His book, 'Les Exclues', published in 1974, is widely regarded as the origins of the modern conception of social exclusion within the context of European social policies [23-25]. Lenoir uses the term 'excluded' for groups at the margins or at the bottom and fringes of society, such as mentally and physically handicapped individuals, those with substance abuse issues, those who commit crimes and those living in multi-problem households [22, 25].

Since the 1990s, the concept of social exclusion has been widely applied in the policy contexts of European and other Western countries. In Australia, a comprehensive plan was launched to tackle SE and build an inclusive nation in which all Australians have the opportunity to participate and be treated with dignity and respect [26]. Canada's social policy focuses on groups at risk of SE, such as recent immigrants, persons with disabilities, and sexual, religious and racial minorities [27]. The fight against poverty and social exclusion has taken a central place on the EU's social agenda [28, 29]. Social exclusion has also been adopted as a priority by international organisations such as the World Health Organization (WHO) and the United Nations Development Programme UNDP [15, 17, 30-32].

In the Netherlands social exclusion has been a recurrent theme in national politics and social policy from 1995 onwards. It stood for insufficient willingness and ability to participate in economic and social relationships [33]. Social exclusion has been linked to the threaten of social dichotomy and seen as both a social phenomenon and an individual characteristic [5, 33]. Currently, social exclusion policies in the Netherlands are limited to targeting poverty reduction, ensuring financial self-sufficiency and boosting labour market participation [34-36]. However, at the municipal and regional levels, social exclusion has found a place in policies on social care for vulnerable groups such as multi-problem families, persons with serious mental illness and people experiencing homelessness [37]. Social exclusion is depicted as a downward spiral of loss and disaffiliation rooted in an interplay between society (insufficient access to social and community resources) and the individual (inadequate self-regulation).

In short, social exclusion is primarily a political term, and the meaning given to the term reflects particular institutional, political, historical and geographic contexts [24, 25, 38].

## Defining social exclusion

A scientific approach to social exclusion requires a clear definition and an operationalisation that closely reflects the underlying concept. Scholars have identified a number of key elements shared among the wide variety of meanings given to the concept of social exclusion. General consensus exists across the literature that social exclusion is multi-dimensional, dynamic, relative, relational and recognises agency [16, 17, 21, 31, 33, 39, 40].

1. Multi-dimensional. Social exclusion encompasses social, political, cultural and economic dimensions, and operates at different social levels including micro (individual, household), meso (neighbourhoods) and macro (nation state, global regions).
2. Dynamic. Social exclusion is understood as a dynamic process which impacts people in various ways and to different degrees over time.
3. Relative. Social exclusion is context specific and gradual. There is no natural boundary between being excluded or not.

4. Relational. Social exclusion is the product of social interactions characterised by differential power.
5. Agency. Social exclusion lies beyond the narrow responsibility of the individual concerned. It implies an act or acts by an agent or agents, e.g., societal institutions, businesses or citizens.

The above elements are reflected in the definition of social exclusion by the World Health Organization (WHO). The WHO defines social exclusion as:

*'dynamic multidimensional processes driven by unequal power relationships interacting across four main dimensions - economic, political, social and cultural - and at different levels including individual, household, group, community, country and global levels'* [18].

This definition provides a wider lens to understand the causes and consequences of social exclusion and avoids the stigma of labelling particular groups as 'excluded'. Instead, social exclusion is understood as a continuum rather than a dichotomous construct.

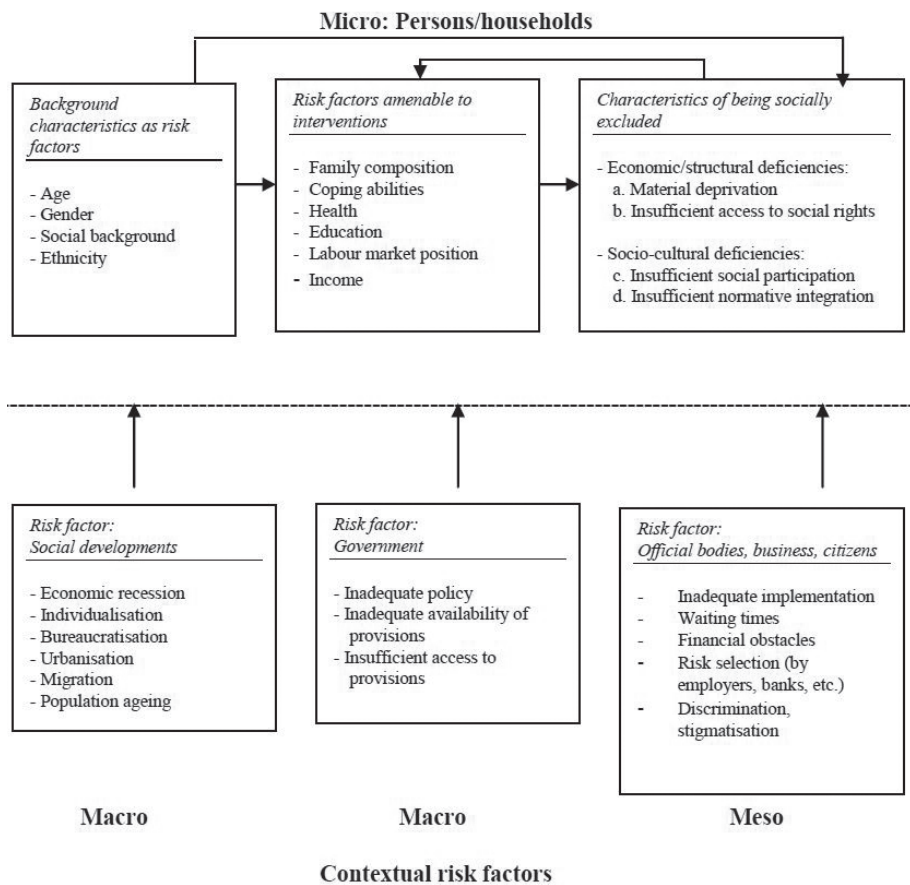
The most commonly used definition of social exclusion in the Netherlands was developed by the Netherlands Institute for Social Research (SCP) on the basis of comprehensive research [33, 41]. The SCP concluded that in essence, all definitions come down to a distinction between two main domains: relational/immaterial versus distributional/material aspects. The relational approach finds its origins in the French tradition, which builds upon Durkheim's theories of social cohesion and solidarity, the importance of collective values and norms, and the risk of social alienation (anomie) [41]. Social exclusion refers here to the socio-cultural aspects of people's lives, the extent to which people are integrated into society and their connection with others. The distributional approach comes from the Anglo-Saxon line of thinking, which centres around the notion of 'relative deprivation': the idea that people typically regard themselves as badly off or well-to-do based on the comparison with others they deem important (their reference group). Social exclusion refers here to the structural-economic aspects of people's lives, relative deprivation and unequal access to income, basic goods, public services and citizen rights.

Social exclusion is then defined as the accumulation of deficiencies in four dimensions:

- Socio-cultural dimension:
  1. insufficient social participation;
  2. insufficient normative integration (insufficient compliance with core norms and values associated with active social citizenship);
- Economic/structural dimension:
  3. material deprivation;
  4. insufficient access to social rights (education, housing, health care, safety etc.). [33]

In the SCP conceptual model (Figure 1), a clear distinction is made between the features of social exclusion (status characteristics) and factors that increase the risk of social exclusion (process) [33]. A low income, for example, is a risk factor and not a constituent part of social exclusion. Low income increases the chance of social exclusion, but social exclusion occurs only if material deprivation actually results (payment arrears, debts, insufficient money for daily necessities) [33]. Risk factors operate at the micro level of the individual, at the meso level of formal and informal organisations and social settings, and at the macro level of government and society at large [42]. Risk factors at the macro level include GDP, income inequality, expenditures on social protection and life expectancy [42].

In short, in this dissertation, we use the multidimensional definition of social exclusion and the corresponding conceptual model as developed by the SCP.



**Figure 1.** SCP conceptual model: risk factors and characteristics of being socially excluded [42].

## Social exclusion and health

Social exclusion is one of the structural drivers of health inequities and forms part of the WHO Social Determinants of Health framework [3, 16, 43]. Inequities in health arise because of the circumstances in which people grow up, live, work, and age and the systems put in place to deal with illness [43]. The conditions in which people live and die are shaped by political, social, and economic forces [43]. The individuals involved are not necessarily passive victims of these social processes; they may actively resist exclusionary processes and the ensuing negative consequences [17].

Several theories exist about how social determinants impact health. Brunner and Marmot propose a link between social structure and health through material, psychosocial and behavioural pathways, in combination with genetic, early life and cultural factors [44]. Diderichsen identifies three main processes: differential exposure (e.g. residential conditions and physical environment), differential vulnerability (e.g. clustering and interaction of other risk factors and earlier exposures) and differential disease consequences (e.g. barriers to access to care and the job market) [45].

The WHO Social Exclusion Knowledge Network specifies two pathways linking SE to health: constitutive and instrumental. The constitutive perspective looks at the intrinsic value of social inclusion: the experience of inequality and exclusion tends to have pronounced psychological effects and negatively impacts health, well-being and agency [19, 46-49]. The instrumental perspective looks at the circumstances associated with SE: material deprivation, social isolation, poor housing – often in deprived neighbourhoods – and reduced access to care all have a negative impact on health. Additionally, disease and ill health can themselves generate and reinforce exclusionary processes [17].

The relationship between SE and health is theoretically well founded but lacks systematic empirical evidence. A number of literature reviews have been published on SE or social inclusion (SI) and health [17, 38, 50-53], but due to a general lack of clarity and diversity of the meanings ascribed to SE/SI, the wide variety of SE/SI measures and the complexity and sheer magnitude of the literature, no inferences could be made. Most reviews have therefore been limited to describing and discussing the concepts, operationalisations and instruments used to measure SE or SI [17, 38, 53, 54] and/or the characteristics of the retrieved studies, e.g., research designs, countries, years of publication [51, 52]. One study systematically reviewed the impact of interventions on SI in adults with intellectual disabilities [50]. None of the reviews reported systematically on the relationship between SE/SI and health.

In short, the relationship between SE and health is theoretically well founded but lacks systematic empirical evidence.

## Measuring social exclusion

Not surprisingly, given the information in the previous paragraph, a generally accepted measure of social exclusion is lacking in health research [17, 38, 51, 53, 54]. The most common approach to measuring social exclusion is to use indicator lists with data that are usually drawn from pre-existing datasets [38]. The number, type and dimensions of indicators used to define exclusion vary greatly [17, 38, 55, 56]. Usually, measures focus either on participatory aspects of SE, social relationships and networks or on poverty and labour market participation [17, 38, 56]. The whole construct of SE is rarely represented. A further issue is the general lack of clarity as to whether the items included are risk factors or outcomes of SE, i.e., indirect or direct indicators of SE [17, 38]. Studies rarely attempt to quantify SE using indicators across a number of domains or dimensions [38]. Typically, no composite measure is calculated, or simple sum scores are used with equal weights given to all items or dimensions, which is unlikely to be empirically correct [57]. Few or none of the measures of SE identified were formally validated [38, 54].

Over the past two decades, significant research has been done by the SCP on the measurement of SE in social and economic policy research [29, 33, 41, 42, 58]. In this dissertation, we build on the knowledge and experience gained in this process. In particular, the SE index developed by Hoff and Vrooman [29, 59] has the potential to be developed as a standard in the health domain if adapted to the needs and preferences of users.

This index, here referred to as the SCP social exclusion index, consists of 15 items measuring the four dimensions of SE, ‘lack of social participation’, ‘material deprivation’, ‘lack of normative integration’ and ‘inadequate access to basic social rights’. The selection of items was not defined a priori but was determined empirically.

Four focus groups were conducted with ‘average citizens’ to test the relationship between the SCP theoretical concept and the everyday meaning of social exclusion in the Netherlands. Persons with low levels of education and/or low income were overrepresented. Some typical answers on what social exclusion in the Netherlands currently means, were: *‘being very lonely, breaking down a little day by day’, ‘having no contacts’, ‘having no respect for other people’, ‘not holding the door for somebody, not saying ‘thank you’ when receiving change’, ‘being in debt’, ‘not having much money, because that means you have fewer opportunities’, and ‘people who are disabled or don’t know the language, or who have no idea where to turn to’* [29]. In each session, the participants evaluated whether the items of a lengthy master questionnaire gave an accurate and complete picture of the subject matter. Based on their comments, questionnaire items were supplemented, reformulated or removed. The amended version then served as input for the next group session.

In the next step, individual cognitive interviews were held with eight ‘average citizens’ to test the interpretation and comprehensibility of the questions and answer options.



Finally, the revised questionnaire was administered to a sample of the Dutch population (N=648). The questionnaire contained 45 items on social participation e.g. on sports, culture, leisure and other activities outside the house, voluntary work, informal care, membership of clubs and associations, frequency of contacts with family, friends and acquaintances, and feelings of loneliness; 26 items on material deprivation i.e. difficulty of making ends meet, debts and payment arrears, ownership of consumer durables, insurance against risks and insufficient means for basic necessities; 81 items on access to basic social rights e.g. on right to health care, housing, education, a safe and clean living environment, equal treatment and access to business and social services; and 38 items on normative integration e.g. on work ethic, abuse of social security, voting, and beliefs about ‘being a good citizen’.

For each of the dimensions, a subscale containing three to four items was constructed using nonlinear canonical correlation analysis. The 15 items form a general index that measures the degree of social exclusion at the individual level, with a higher index score for persons simultaneously deprived in several dimensions [29, 59]. The SCP social exclusion index was validated in the same sample and replicated in a new sample two years later [60].

In short, the social exclusion index developed by Hoff and Vrooman [29, 59] is used as the gold standard for measuring the multidimensional concept of social exclusion.

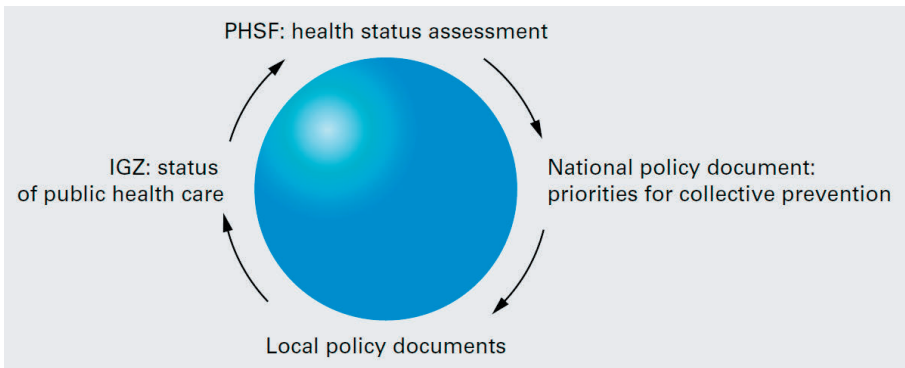
## **Local public health policy: the preventive care cycle and monitoring**

### *Preventive care cycle*

According to the Dutch Public Health Act (In Dutch: Wpg), municipalities in the Netherlands are tasked with protecting, monitoring and promoting the health of their inhabitants based on epidemiological analyses. The relationship between national and local governments is formalised in a four-year preventive care cycle. As shown in Figure 2, the national policy document on health – which sets out governmental health policy ambitions – is based on the Public Health Status and Forecasts Report (PHSF). This report is published every four years by the National Institute for Public Health and the Environment (RIVM) and gives an overview of the current state of public health in the Netherlands, including an estimation of what the situation will be in ten to twenty years based on the results of the most recent national and local monitoring efforts by Statistics Netherlands and the GGDs (community health services) [61].

The next step in the preventive care cycle occurs on a local level: municipalities and GGDs develop local health policies based on the main priorities and recommendations of the national health policy and epidemiological data provided by the GGD about the local health situation.

At the end of the cycle, the IGZ assesses the state of the public health system, and its findings are used as input for the next PHSF document. [62]



**Figure 2.** Preventive care cycle in the Dutch health system.

### *Public Health Monitor*

The Public Health Monitor (PHM) is a large-scale survey conducted by the Association of Regional Public Health Services (GGD GHOR Nederland), the RIVM and Statistics Netherlands (in Dutch: CBS). It provides data to the PHSF and guidance for setting national and local public health policies. Once every four years, approximately half a million Dutch citizens age 19 or older are contacted to participate.

The survey uses a ‘mixed-mode’ design, i.e., a combination of several survey modes (online, in writing, face-to-face or by telephone). In the four major cities, translated questionnaires and foreign language interviewers are available. [63] A stratified sample is used to allow for analyses at the neighbourhood level and with subpopulations. To account for the complex sampling design and selective non-response, sample weights are calculated by Statistics Netherlands based on a linear model with 9 sociodemographic variables and their interaction terms [64].

The questionnaire covers a broad spectrum of health outcomes and (social) determinants. In addition to a mandatory national set of questions on gender, age, education, chronic conditions, height, weight, loneliness, smoking habits, alcohol consumption and informal care, some extra topics can be included to address local policy priorities formulated by municipalities. By linking the dataset to other datasets from Statistics Netherlands, the PHM dataset is enriched with data on, for example, standardised household income (in quintiles) and migration background. [63]

Its central place in the preventive care cycle, wide coverage and high-quality standards make the PHM a unique vehicle for measuring social exclusion in the health domain. The space in the PHM for extra local topics is, however, limited, and competition is fierce. Important considerations for GGDs when choosing the extra items are the

relevance of the topic for local public health, the length of the questionnaire and need to avoid unnecessary overlap with the mandatory national set. These are the challenges tackled by this dissertation.

In short, the PHM is the best vehicle to measure social exclusion, given its wide coverage and prominent place in the preventive care cycle at the national and local levels.

## **Aim and outline of the dissertation**

The aim of this dissertation is threefold: a) to systematically review the evidence base for the association between the multidimensional concept of SE, as defined in this study, and health; b) to develop a reliable and valid instrument to measure social exclusion in public health surveys, more specifically in the Public Health Monitor conducted by the GGDs in the Netherlands; and c) to explore the potential use of this instrument for public health research and policy.

In Chapter 2, we start with a systematic review into the association between SE and health. As we saw above, the relationship between SE and health is theoretically well founded but still lacks systematic empirical evidence. The problem is not that there are no studies on SE and health; the opposite seems more the case. It is the wide variation in the concepts used and the operationalisation of SE that severely limit the synthesis of the evidence in these studies. To circumvent this obstacle, we confine our review to only one concept and operationalisation of SE and of its antipode, social inclusion (SI).

In Chapter 3, we explore, as a first step in the development of a reliable and valid instrument to measure SE in routine public health surveys, whether the multidimensional concept of social exclusion can be validly approximated with items that are already used in the PHM.

In Chapter 4, we describe the construction and validation of the Social Exclusion Index-for Health Surveys (SEI-HS). In this step, we address the limitations of our previous study. We requested that GGDs include an extra set of items in their 2012 PHM questionnaire and used these data to construct a national index.

In Chapter 5, we examine whether the stronger SE among adults with Surinamese, Moroccan and Turkish backgrounds compared with native Dutch citizens in the four largest cities of the Netherlands (G4) can be explained by shortcomings in the cross-cultural validity of the SEI-HS. In this study, we use a sequential explanatory mixed methods design, combining quantitative analyses of 2021 PHM data and interviews with respondents with a high score on the SEI-HS from different migration backgrounds.

In Chapter 6, we explore possible applications of the SEI-HS in public health monitoring, research and policy. We test SE, as measured with the SEI-HS, against traditional social stratifiers in terms of the ability to identify high-risk/high-need population segments. For this study, we use G4 2016 Public Health Monitor data.

Chapter 7 summarises the main findings, reflects on the limitations and strengths of the study, and discusses its main findings. Finally, implications for local public health monitoring as well as future research, policy and practice are discussed.

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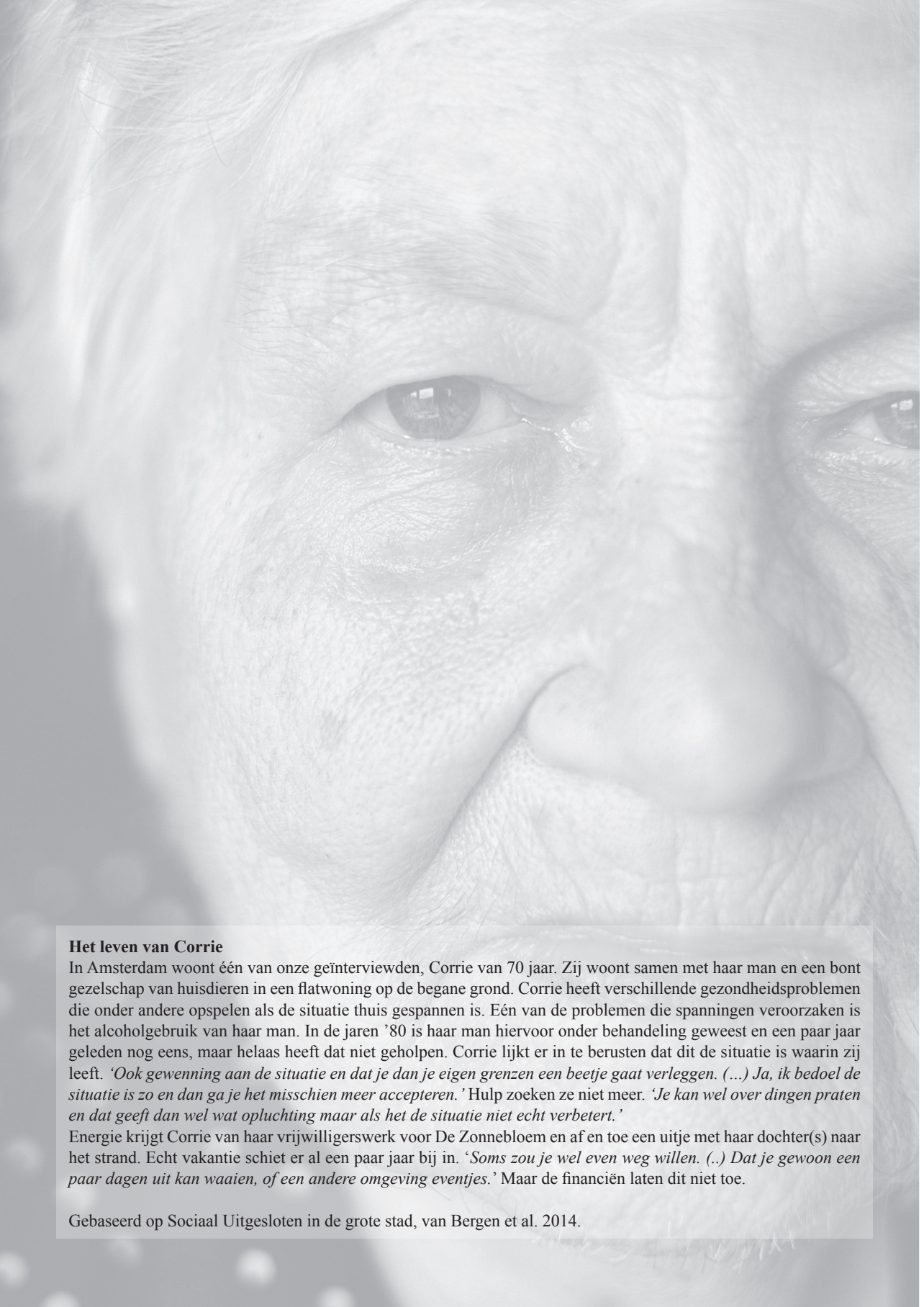
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### **Het leven van Corrie**

In Amsterdam woont één van onze geïnterviewden, Corrie van 70 jaar. Zij woont samen met haar man en een bont gezelschap van huisdieren in een flatwoning op de begane grond. Corrie heeft verschillende gezondheidsproblemen die onder andere opspelen als de situatie thuis gespannen is. Eén van de problemen die spanningen veroorzaken is het alcoholgebruik van haar man. In de jaren '80 is haar man hiervoor onder behandeling geweest en een paar jaar geleden nog eens, maar helaas heeft dat niet geholpen. Corrie lijkt er in te berusten dat dit de situatie is waarin zij leeft. *'Ook gewenning aan de situatie en dat je dan je eigen grenzen een beetje gaat verleggen. (...) Ja, ik bedoel de situatie is zo en dan ga je het misschien meer accepteren.'* Hulp zoeken ze niet meer. *'Je kan wel over dingen praten en dat geeft dan wel wat opluchting maar als het de situatie niet echt verbetert.'*

Energie krijgt Corrie van haar vrijwilligerswerk voor De Zonnebloem en af en toe een uitje met haar dochter(s) naar het strand. Echt vakantie schiet er al een paar jaar bij in. *'Soms zou je wel even weg willen. (...) Dat je gewoon een paar dagen uit kan waaien, of een andere omgeving eventjes.'* Maar de financiën laten dit niet toe.

Gebaseerd op Sociaal Uitgesloten in de grote stad, van Bergen et al. 2014.