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## Measuring social exclusion in routine public health surveys

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## **Chapter 7**

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Summary and general discussion

## SUMMARY AND MAIN FINDINGS

The main aim of this dissertation is to develop a reliable and valid instrument to measure the multidimensional concept of social exclusion (SE) in public health surveys, more specifically as embedded in the Public Health Monitor conducted by the GGDs in the Netherlands. This can facilitate the systematic identification of population groups at high risk for ill health so that resources for public health can be used more efficiently and effectively and health inequalities can be addressed with appropriate health and social policies.

We started in Chapter 1 with the observation that although SE appears to be a promising concept to help with understanding and tackling health inequalities, the concept has been ill defined in health research, a generally accepted measure was lacking, and the evidence base was not well developed. In the current project, we took significant steps towards improving the knowledge base: we carried out a systematic review on the association between SE and health (Chapter 2), we constructed and validated a multidimensional measure for SE, the Social Exclusion Index for Health Surveys (SEI-HS) (Chapters 3, 4 and 5), and we explored a possible application of the SEI-HS in public health (Chapter 6).

In chapter 2, we described a systematic review of the evidence base for the association between social exclusion or social inclusion (SI) and health in EU and OECD countries. Six hypotheses were evaluated, i.e., that high SE/low SI is associated with (i) adverse mental health outcomes, (ii) adverse physical health outcomes and (iii) adverse general health outcomes in both (a) the general population and (b) populations at high risk of SE. We operationalised SE as the accumulation of deprivations in four dimensions, i.e., social, economic, political and cultural [1] and SI as the accumulation of involvement in these dimensions. Twenty-two observational studies were included in the review, both using a multidimensional operationalisation of SE or SI and testing the relationship between SE/SI and one or more health outcomes. In the general population, our study confirmed the association between SE/SI and mental and general health but not physical health. In groups at high risk of SE, we found clear confirmation for an association between SE/SI and mental health but not general health. For physical health, the evidence was inconclusive, both in the general population and in groups at high risk of SE.

In chapter 3, we explored whether the multidimensional concept of SE could be validly approximated with items available in the Public Health Monitors (PHM) of the four major cities in the Netherlands: Amsterdam, Rotterdam, The Hague and Utrecht (G4). The Netherlands Institute for Social Research (SCP) social exclusion index of Hoff & Vrooman [2, 3] was used as the gold standard. This 15-item instrument measures the overall degree of SE in a single index score as well as scores on four dimensions of SE: 1) Limited social participation, 2) Material deprivation, 3) Inadequate access to basic social rights, and 4) Lack of normative integration. Analyses were performed

on data from the 2008 PHM, which was completed by 20,877 adults. As the content of the questionnaires differed among cities, three different indices were constructed using nonlinear canonical correlation analysis. The psychometric properties of the constructed indices were adequate to good. The content validity, however, was only moderate. Our study showed that a measure for social exclusion could be constructed with available health questionnaires. Recommendations were made to enhance content validity by adding extra items from the SCP social exclusion index to the PHM.

In chapter 4, we followed the recommendations made in the previous chapter. Nineteen of the 26 GGDs, covering over 70% of the Dutch population, included extra SCP items on material deprivation, access to basic social rights and normative integration in their 2012 PHM. Data from 258,928 respondents aged 19 years or older were thus obtained. The dataset was randomly divided in half: a development sample and a validation sample. Nonlinear canonical correlation analysis in the development sample produced an overall index and four dimension scales, the SEI-HS, containing 9 PHM items and 8 SCP items. The internal consistency, internal structure and construct validity were satisfactory to good and in line with the original SCP social exclusion index, and the content validity was good. Replication of the SEI-HS in the validation sample confirmed its generalisability. Both index and dimension scores were trichotomised into 'moderate to strong', 'some' and 'no' exclusion based on the 95th and 90th percentiles in the Dutch adult population to facilitate their application in public health monitoring and policy. The SEI-HS enables researchers to take the next step in advancing our much needed knowledge on SE and health.

In chapter 5, we presented the results of a cross-cultural validation study of the SEI-HS. In the four cities, Amsterdam, Rotterdam, The Hague and Utrecht, particularly high levels of SE were found among non-Western immigrant groups, e.g., 20%, 21% and 29% of adults of Surinamese, Moroccan and Turkish origin, respectively, were found to have moderate to strong SE; only 4% of adults of native Dutch origin were found to have the same. A sequential explanatory mixed methods design was used to explore the possible cultural bias of the SEI-HS. Data from the 2012 PHM were used to evaluate the structural validity and differential item functioning of the SEI-HS in three major immigrant groups in the G4. For each SEI-HS item, semantic, conceptual and contextual connotations were compared between the three immigrant groups and native Dutch based on semi-structured interviews with 11 Surinamese, 9 Moroccan, 10 Turkish and 22 Dutch respondents with high scores on the SEI-HS. Confirmatory factor analysis corroborated the 4-factor structure of the SEI-HS in all three immigrant groups, and no substantial differential item functioning was found for migration background. The interviews uncovered some methodological shortcomings, but these did not substantially impact the excess of social exclusion observed in the immigrant groups. Our study confirmed the cross-cultural validity of the SEI-HS in three major immigrant groups in the Netherlands. The high levels of SE among non-Western immigrants in the G4 proved to be real and not a methodological artefact. Our conclusion was that policy measures to enhance social inclusion and reduce exclusion are urgently needed.

Finally, in chapter 6, we explored possible applications of the SEI-HS. We tested the SE, measured with the SEI-HS, against four traditional social stratifiers (low education, low income, low labour market position and non-Western migration background) in terms of their ability to identify high-risk/high need population segments. We compared the relative risks (RR) and (hypothetical) population attributable fractions (PAF) for cardiovascular risk, cancer, low self-rated health, anxiety and depression symptoms, and low personal control and studied their overlap and their combined effect. Data from the G4 PHM 2016 were used for this study (N=33,285).

The analyses showed significant associations of SE with all health indicators and personal control, with particularly strong RRs for anxiety and depression symptoms (7.95) and low personal control (6.36). The corresponding PAFs were 42% and 35%, respectively. The SEI-HS was significantly better at identifying population segments with anxiety and depression symptoms and low personal control than the four traditional stratifiers were and performed equally well in identifying other health problems. The combination of SE and low labour market position proved to be most impactful: this population segment accounted for 67% of all adults exhibiting anxiety and depression symptoms and 60% of all those exhibiting low personal control, as well as substantial proportions of the other health indicators, while making up only 19.5% of the adult population in the G4. These findings have implications for health care practice, public health and social interventions in large cities.

## GENERAL DISCUSSION

To date, there has not been a generally accepted measure of SE in national and international public health research and monitoring. This dissertation presents the construction and validation of a short index for SE suitable for embedding in the Dutch PHM. The SEI-HS makes use of items that are already present in the PHM, i.e., on loneliness, social capital, financial situation and housing. The number of additional items to be included is thus limited, and by preventing overlap, respondent acceptance is not jeopardised. The psychometric measurement properties of the SEI-HS were found to be satisfactory to good, although there is still some room for improvement in one of the four dimension scales, i.e., the Normative Integration scale (Chapter 3).

In this dissertation, we show evidence for the association between high SE/low SI and adverse mental health outcomes (Chapter 2). Where other researchers became stuck in a forest of divergent ideas, a lack of definitions and different ways of measuring SE, by delineating the concept of SE, we were able to synthesise the existing evidence on the relation between SE and health. The findings from our own research confirm the association between SE and adverse mental health and strengthen the plausibility of the association between SE and adverse physical health, i.e., with severe functional limitations (Chapters 3 and 4) and diabetes, high blood pressure, obesity and cancer (Chapter 6).

An important outcome of this dissertation is the utility of the SEI-HS for identifying high-risk/high-need population segments (Chapter 6). As we had hoped for at the start of this study, measuring SE can thus help identify and quantify at-risk groups and gain better insight into their characteristics and health risks. This information is important for guiding public health policy and resource allocation. Embedding the SEI-HS in the PHM is a good choice, as data on SE can now be collected every four years, analysed by GGD epidemiologists, and presented and discussed with local policymakers. Some municipalities, such as Delft, use the SEI-HS in their municipal (omnibus) survey that takes place every two years.

The findings of this dissertation are also relevant outside of the Netherlands. Although the main focus of this dissertation was on Dutch local health monitoring and policy, we firmly positioned our research in a broader international context, with particular reference to the theoretical framework of the World Health Organization (WHO) on the social determinants of health [4] and the definition of SE developed by the WHO Social Exclusion Knowledge Network [1, 5]. This work bridges social sciences and health research, which we further enhanced by publishing only in open access journals indexed in PubMed. The articles in this dissertation are regularly cited by health researchers from countries all over the world, such as the United Kingdom [6], Spain [7], Finland [8], Croatia [9], Switzerland [10], Czech Republic [11], Ukraine [12], Cameroon [13], Brazil [14], Hong Kong [15], the United States [16] and Lebanon [17]. In particular, reference is made to the use of nonlinear canonical correlation analysis, to the results of our systematic review, and the definition, operationalisation and measurement of SE.

## STRENGTHS AND LIMITATIONS

### Strengths

A major strength of this dissertation is that we were able to build on many years of theoretical and empirical research conducted by the SCP. We adopted its definition and operationalisation of SE and used the SCP social exclusion index of Hoff & Vrooman [2, 3], as the standard for measuring SE in the Dutch adult population.

Another strong point of this study is that we had three large datasets at our disposal: 2008 PHM data for the G4 (N=20,877), 2012 PHM data for 19 GGDs nationwide (N=258,928) and 2016 PHM data for the G4 (N=33,285). Not only were we able to adapt and improve the SE index based on 2008 data in the 2012 dataset, but our results were also stable and reliable, likely replicable not due to coincidence or p-hacking [18]. The use of nonlinear canonical correlation analysis for the construction of the SEI-HS is a strong point as well. In comparison with, for example, factor analysis, nonlinear canonical correlation analysis yields scales with fewer items and a broader scope, resulting in a more concise measure with higher content validity [2].

## Limitations

In this study, we faced several limitations. First, the current state of the relevant research did not allow us to quantify the strength of the association between SE and specific health outcomes. The method we used in chapter 2 to summarise the evidence is based on P-values. P-values give an indication of the compatibility of the data with the null hypothesis of each manuscript but not of the effect size or the importance of the results. Due to the great diversity in health outcomes, we classified them into broader groups: mental health, physical health and general health. The classification was not always straightforward, particularly not for general health.

Second, we have to mention potential bias due to selection in the studies in chapters 4, 5, 6 and 7. Persons without a fixed address or living in an institutional setting were a priori excluded from the sample. This group is estimated at approximately 0.2% and 1.6-1.8%, respectively, of the Dutch adult population (CBS Statline). As these tend to be vulnerable people with a high risk of SE, such as people experiencing homelessness, incarcerated people and frail, older people, this may lead to an underestimation of the prevalence of SE in the population. Selective non-response is another potential source of bias. In the Netherlands, the response rates in survey research are low and have decreased over time [19, 20]. Despite the use of strategies to reduce non-response rates concentrated on hard-to-reach groups and despite oversampling in deprived neighbourhoods and weighting to adjust for non-response bias, the possibility of some bias cannot be ruled out. The PHM is no exception: average response rates in the G4 declined from 50% in 2008 to 33% in 2016. Again, the tendency is towards an underestimation of the SE prevalence rates.

Third, the classification of the SEI-HS index and dimension scores into categories involved a certain degree of arbitrariness. SE is a continuous phenomenon with no natural boundaries between being excluded or not or between some, moderate and strong exclusion. The main reason for classifying the SEI-HS was to enhance its applicability in public health policy. Policymakers require clear and simple data, and continuous scale scores will not do. We opted for the use of 85th and 95th percentile values in the Dutch adult population as cut-off scores. These fit the right-skewed distribution of the index and dimension scores, with the largest part of the population having low scores, a small part having very high scores, and a modest group in the middle. Our choice is also in line with the cut-off point of 1 SD above the mean used by Gijsbers [21] to define social exclusion.

Fourth, widespread research across the Netherlands allowed us to extend the generalisability of the SEI-HS to the whole Dutch adult population, both urban and rural, but the generalisability to populations in other countries may be limited. The items of the SEI-HS measure aspects of SE in the Dutch context. Bottle banks, for example, are unknown in large parts of Turkey, and in southern countries such as India, the item “I have enough money to heat my home” is irrelevant. In low- and middle-income countries, items such as access to electricity, pipe water and sewerage as well

as the presence of dirt floors, overcrowding and illiteracy may be more pertinent for SE [22]. In high-income countries, a single adjustment of the items and a re-scaling of weights and factor loadings may be required. The method used in chapter 4 can accomplish this.

## IMPLICATIONS FOR PUBLIC HEALTH MONITORING

Now that there is a reliable and valid SE measure available for use in the local PHM conducted every four years, the next challenge will be to increase the utilisation of the SE data in local public health policy. A recent study among GGD epidemiologists and local policymakers identified three main barriers to the utilisation of SEI-HS data in local public health policy: 1) the abstractness of the concept of SE, 2) difficulty in translating the SEI-HS results into policy actions and 3) the limited reach of the SEI-HS [23].

### *Barrier 1: Abstractness of the concept of SE: a storytelling approach*

The first barrier to the research application mentioned by GGD epidemiologists and local policymakers is the abstractness of the SE concept. Local policymakers indicate that they find the SE concept vague, broad and difficult to interpret. Epidemiologists find it difficult to make the results tangible for policymakers.

*'It is an abstract concept. Municipalities in our region, if they read something like that, they think: "What is that, what can we do with it?" [GGD policy advisor] [23]*

The current research focused primarily on the delineation of the concept of SE, its reliable and valid measurement and the systematic mapping of the scientific evidence base. As a consequence, the language we used in this research was abstract, the findings were interpreted cautiously, and particular emphasis was placed on limitations and possible pitfalls. We think the time has come to shift the focus from methodological and conceptual discussions to the people affected by social exclusion using a storytelling approach.

Behind the abstract figures on SE lies the often-harsh reality of people experiencing social exclusion and its consequences in everyday life. As Taket et al. [24] state, 'the concept of social exclusion attempts to help us make sense out of the lived experience arising from multiple deprivations and inequities experienced by people', and the concept should certainly not obscure this reality. According to the WHO Social Exclusion Knowledge Network, the complexity of the nature and impact of exclusionary processes can only be adequately 'represented' by using both quantitative and qualitative data – through indicators and stories [5]. Cairney et al. state that successful engagement in 'evidence-based policymaking' requires pragmatism, the combination of scientific evidence and governance principles, and persuasion to



translate complex evidence into simple stories [25]. This last step, translation into simple stories, has been missing until now.

The interviews with socially excluded citizens in Utrecht, Amsterdam and The Hague presented in Chapter 6 painted a picture of the daily lives and aspirations of people, the problems they are facing, how they are dealing with these problems and what support they need (Chapter 6). It is in the lived experience of people that theory becomes tangible and concrete. As one of the professionals pointed out in response to the interview results:

*‘This is certainly recognisable. We see these people every day’.* [26, 27]

*Barrier 2: Translation of results into local public health policy: a larger policy story*

The second barrier to the research application mentioned by GGD epidemiologists and local policymakers is the difficulty of translating the SEI-HS results into policy actions. Translating epidemiological data into public health policy is generally complicated. Regarding public health in the Netherlands, De Goede et al. explained this by the complexity of the local policy process, in which the knowledge, opinions, and interests of multiple actors have to be taken into account, and epidemiological findings cannot be transformed directly into action [28]. For a broad concept as SE, this is all the more true:

*‘The domains are sometimes that kind of broad, that it is difficult for municipalities to take concrete measures on the basis of the index.’* [GGD epidemiologist] [23]

Another complicating factor is that to tackle SE and its impact on health, an integrated approach<sup>5</sup> is required in which the public health sector collaborates with other local policy sectors. Involving the appropriate policy sectors, e.g., housing, spatial planning, education, work, participation and income, and welfare, in the local public health policy dialogue is, however, difficult to achieve [29].

*‘If you really want to have an effect, then the presentation of the SE results should be given at different tables inside a municipality.’* [GGD epidemiologist] [23]

Some GGDs solve this problem by translating the SE results into terms more aligned with current local policies, such as loneliness and poverty. However, what gets lost in this approach is the essence of SE – its multidimensionality, accumulative character and clustering of problems.

De Goede et al. [28] suggest that given the complexity of the policy process, it is probably better not to focus too much on the use of epidemiological data for

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<sup>5</sup> Outside the Netherlands this approach is more commonly known as Health in All Policies [29].

concrete policy actions (instrumental use) but to aim for higher awareness and better understanding of the provided epidemiological results (conceptual use):

*'Ultimately, if the conceptual use of research is high during the policy process and applies to multiple policy actors, this can eventually lead to more instrumental use.'* [28]

However, instrumental use should not be the measure of success [30]. Epidemiological knowledge contributes to the improvement of the policy process if findings are taken into account and discussed, whether it leads to policy changes or not [30]. We recommend presenting a larger policy story of SE, aiming at a deeper understanding, rather than piecemeal approaches. The SCP SE framework presented in Chapter 1 can serve as an example here. In our experience, this model is well understood by professionals and policymakers and leads to insightful discussions on meso and macro risk factors that enhance individual problems and vulnerabilities and to ideas about how to tackle these [26, 27].

### *Barrier 3: Limited reach of the SEI-HS: additional research*

GGD epidemiologists play an important role in deciding whether to include the SEI-HS in the PHM [23]. The fact that the SEI-HS does not measure SE in high-risk population groups, such as people experiencing homelessness or living in institutions and undocumented immigrants, is perceived as a major barrier to its use by some GGD epidemiologists [23]. As such, this barrier is not due to the SEI-HS itself but to the exclusion of the mentioned groups from the PHM and applies equally to other health and social problems that are common among these groups, such as loneliness [31] and poverty [32, 33]. The people most affected are not included in the PHM or in population surveys in general and are usually excluded from mainstream policy as well. It is therefore important to supplement the PHM with additional research on high-risk groups, with, for example, register-based research [34], population estimates [35], on-site research [32, 33] or peer research [36].

This does not mean that the PHM does not provide valuable information. The qualitative interviews with socially excluded citizens in Utrecht, Amsterdam and The Hague showed that the PHM reached a diverse group of vulnerable people with non-institutional addresses, including persons leading very isolated lives, victims of violent incidents such as armed robbery or rape, people with drug addiction or aggression disorders, perpetrators of domestic violence, and people who have just been released from prison (Chapter 6). These are important target groups for public health policy and policies to prevent homelessness. Thanks to the SEI-HS, these otherwise invisible groups do not remain completely out of sight.

*'With the PHM, we do not reach the real vulnerable citizens, but the outcome measures visualise an image of the size of the group that is possibly vulnerable and can become vulnerable more easily [GGD epidemiologist].'* [23]

## IMPLICATIONS FOR FUTURE RESEARCH

Based on this dissertation, some potential directions for future research on SE and health are outlined below.

First, the large amount of SE data that are collected as part of PHM are currently underutilised. In 2020, the SEI-HS was administered for the third time in the G4 and a number of other GGD areas. Large amounts of data are thus available to help identify risk groups, assess relations with health outcomes, compare cities and rural areas, identify (syndemic) clusters and monitor developments over time. Until now, data analysis by GGDs has been limited to descriptive reports of the number and characteristics of socially excluded persons per municipality or neighbourhood [23]. It would be useful to develop a joint research agenda for in-depth analyses, for example, in the context of the Academic Collaborative Centre for Public Health G4 USER, and to share the outcomes.

Second, a new round of qualitative interviews with PHM respondents with a high score on the SEI-HS and focus groups with professionals would be useful. The interviews and focus groups described here were conducted in 2014, just before the introduction of the social neighbourhood teams in January 2015. The interviews portrayed a diverse group of people, but despite their diversity, they all faced similar problems, such as an inability to solve certain problems on their own and inadequate care utilisation. A new round of interviews can shed light on the situation of socially excluded citizens in 2022 and on the role of the social neighbourhood teams in reaching these underserved groups.

Third, it would be worthwhile to investigate whether the SEI-HS data can be made available as microdata by Statistics Netherlands, as part of the PHM dataset (GEMON) or via the CBS respondent number included in the GGD data files. This would offer opportunities to combine SE and PHM data with information from other databases, such as prescription reimbursement data, hospital admission and diagnosis data and mortality data [37], employment and social security data [38] and Dutch census data [39]. Data linkage allows one to follow developments over time and investigate, for example, the risk of a downward spiral of disadvantage into unemployment, poverty, family breakdown, deteriorating health, and homelessness, as described in the literature [40, 41]. An additional advantage is that SE data would become accessible to third parties, which could lead to wider use of the data.

Last, regarding the application of the findings at an individual level, in clinical practice, for example, an SE index could be developed on the basis of the available registration data and possibly supplemented with a short questionnaire. A data infrastructure such as that of the 'Healthy and Happy The Hague' initiative may offer opportunities here [42].

## IMPLICATIONS FOR POLICY AND PRACTICE

In Chapter 6, we have showed a serious accumulation of ill health, social problems and low agency in a relatively small urban population segment. Although more research can be done on this issue, these results emphasise the importance of paying attention to this group in health care practice, public health interventions and social care services. At the core of SE lies the inability of persons to participate fully in society and make full use of the benefits that society offers. SE reinforces feelings of powerlessness, alienation, demoralisation and a lack of self-esteem [43, 44]. Policymakers must take these factors into account when formulating policies, and professionals must do so when providing care and support. In Chapter 6, some examples were given of services in the G4 that take agency into account. We mention here stress-sensitive municipal services in Utrecht that are based on the principles of Mobility Mentoring® [45]; the Powerful Basic Care approach (Krachtige Basiszorg), which aims at a collaborative response by primary and social care givers to the health needs of patients in deprived areas in the G4, [46]; and Pathways to Empowerment (Krachtwerk), a programme for a wide range of people who, temporarily or more permanently, experience a loss of control in their lives and are confronted with an accumulation of risk factors for social exclusion [47]. Another example is the involvement of peer support workers to make care and assistance more accessible and foster people's self-management [26]. We hope these examples will inspire others to pursue similar goals.

## FINALLY

In this research, we took significant steps towards improving the knowledge base on the relation between SE and health. We largely confirmed the hypotheses derived from theory and practice that SE is associated with poor mental and general health. With the construction of the SEI-HS, there is now a reliable and valid instrument available to GGDs for measuring SE in the adult population, including the main non-Western migrant groups. As we hoped at the start of the study, the SEI-HS identifies a high-risk/high-need population segment in which social problems, low agency and ill health coincide. These findings can be used to guide public health policy and resource allocation. In particular, the high prevalence of low agency is an important factor to consider in choosing, designing and implementing interventions and services.

To increase the utilisation of the SEI-HS data in local public health policymaking, we suggest combining quantitative data with qualitative data on the lived experience of socially excluded people, giving a human face to an abstract concept, and interpreting the results in a broader contextual perspective. SE is not just an individual problem. A lack of social cohesion as well as discrimination and stigma, deprived neighbourhoods, complex bureaucratic procedures, individualization, high demands on people's self-reliance and lagging social benefits are all factors that affect SE and health. We further suggest that public health monitoring incorporate other methods in addition to the PHM to reach those who otherwise remain excluded from the picture. No one method is sufficient by itself. As one of the G4 policymakers put it:

*'Even though policy is not made one-to-one with these results, keep measuring social exclusion. The combination with other data contributes to a more complete image for complex problems in vulnerable groups [policymaker G4].' [23]*

Last, we want to encourage researchers to use the wealth of data on SE collected by the GGDs and, where applicable, to combine this with other data sources.

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### **Stacey**

Stacey (31) woont in een benedenwoning in de Haagse Schilderswijk. Haar grote passies zijn lezen en reizen. Als er aanbiedingen zijn, trekt ze er met de trein op uit. Maastricht is haar favoriete bestemming. *'Even een andere omgeving. Even andere mensen om je heen.'*

Stacey heeft een hersenbloeding gehad en kon daardoor haar HBO opleiding niet afmaken en niet werken. *'Mijn leeftijdsgenoten hebben gewoon een vaste baan, huisje, boompje, beestje. Mijn leven speelt zich af in het ziekenhuis en in dat wereldje. En dat is vrij eenzaam. En een moeilijk bestaan.'*

Sinds zij op haar zesde vanuit Suriname naar Nederland kwam, woont Stacey al in de Schilderswijk. *'Ik weet niet hoe het in andere buurten is, maar dit is geen beste buurt, laten we eerlijk zijn.'* Haar huis is klein en het sanitair, de leidingen en stopcontacten zijn dringend aan vervanging toe. Verhuizen zit er voor haar niet in. *'Omdat ik moeite heb met plekken herkennen. Van punt a naar punt b gaan dat lukt me niet in mijn eentje. In een vreemde wijk.'*

Stacey heeft weinig verwachtingen voor de toekomst. Zij leeft met de dag. *'Twee jaar geleden is er weer een nieuwe tumor ontdekt. Dus ik ben daar een beetje huiverig voor.'*

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