Health and social burdens of people living in an economically and health-deprived area

Jane Murray Cramm

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Cramm Jane Murray.

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Als het stormt, zoals nu
ik liet de wind
mijn zorgen dragen
en in de windstille dagen
viel het wakker worden zwaar.

Ik liet de wind
mijn zorgen dragen,
waai ze mee
net als mijn haar

iedere luwte is onrust!

Kyra Fooy

1974-2009

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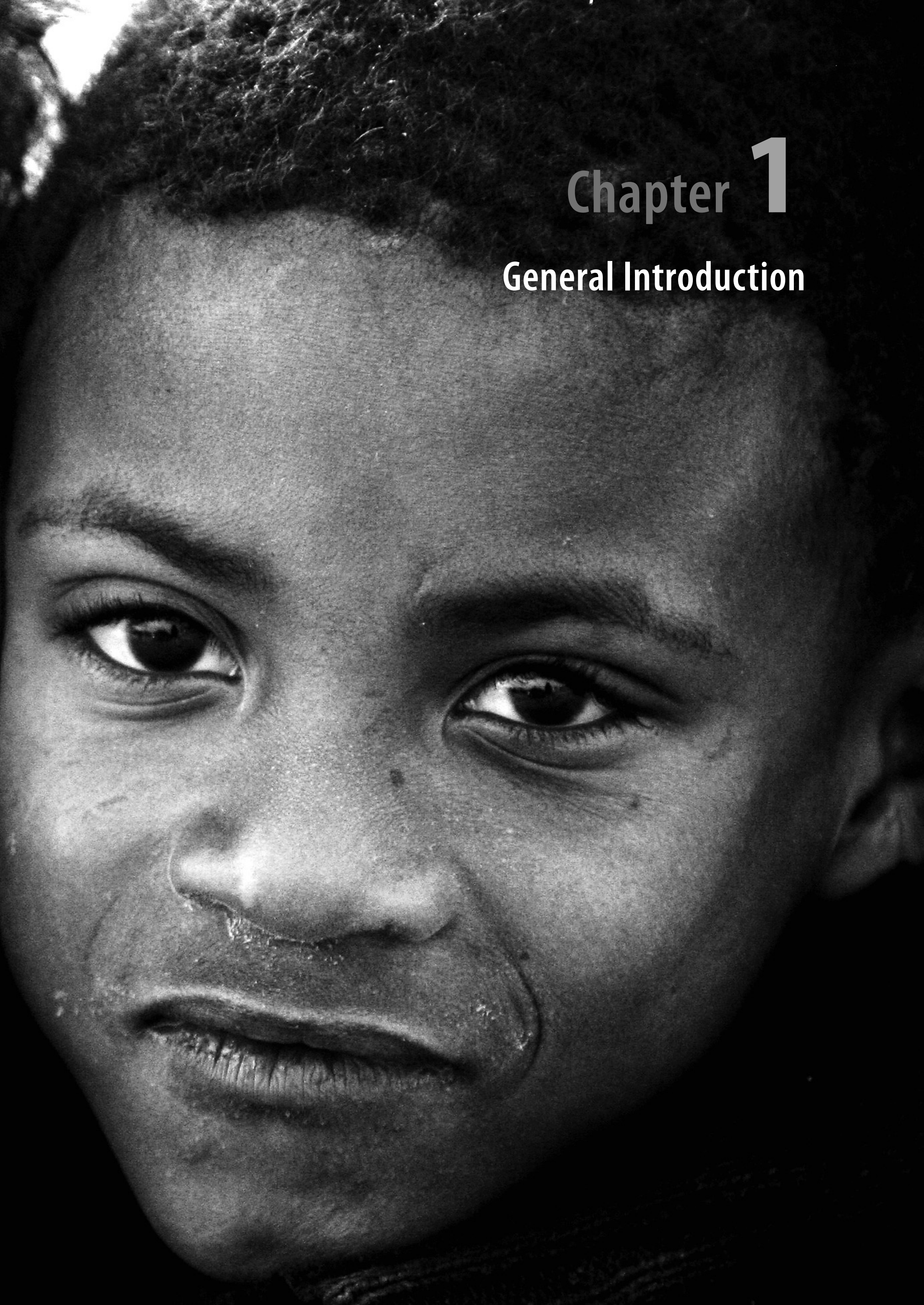
Chapter 1

General Introduction



Introduction

To be poor is by definition to have less of the good things in life, including health and longevity. Obtaining equal access to care is a major step in improving health, however, improved access to health services is only part of the solution for advancing health, avoiding illnesses and enhancing well-being. The fact remains that people at the bottom of society are faced with the worst living conditions and report the worst health outcomes. Regardless the country these poor people live in, what type of health insurance they have or do not have, and the level of health care they receive, they still have the worst health of all.[1] These disparities cannot be explained by biological differences. The World Health Organization holistically viewed the social determinants of health, concluding that global health and illness follow a social gradient; lower socioeconomic positions are consistently correlated with poorer health. These avoidable health inequalities arise because of the circumstances in which people are born, live, work, and age, including the adequacy of health care systems. The conditions in which people live and die are, in turn, shaped by social and economic forces. Together, the structural determinants and conditions of daily life constitute the socioeconomic determinants of health.[2] These are responsible for a major part of health inequities between and within countries, and constitute one form of social injustice. Global action focused on the socioeconomic determinants of health is necessary to achieve health equity. Since neighbourhoods and communities are amendable to intervention, they are the most appropriate social levels at which to improve the health of populations.

Most human development programs seek as a primary goal to improve the subjective well-being of those most affected by poverty. In 2000, 189 countries signed the United Nations Millennium Declaration, which set eight Millennium Development Goals (MDGs) to be achieved by 2015. These MDGs aim to decrease poverty, inequality and improve health and subjective well-being;[3] the latter is increasingly recognized as an important additional source for the evaluation of broad societal and economic development.[4] Communities and neighbourhoods with high levels of subjective well-being are essential for health equity.[2] An accumulating body of knowledge has shown that subjective well-being is a strong predictor of physical health and longevity, spurring growing interest in this factor.[5]

Health and health equity may not be the aim of all social and economic policies, but these factors may be fundamentally impacted by nearly every policy that is implemented. Inequity appears in the conditions of early childhood and schooling, the nature of employment and working conditions, the physical form of the built environment, and the quality of the natural and social environment in which people reside. The nature of these environments produces variation in the experiences of material conditions, psychosocial support, and behavioural options that result in differential vulnerability to poor health. Social stratification leads to the inequitable promotion of health, disease prevention, and illness recovery and survival.

It is important to identity the factors affecting a population's health and how the social gradient operates. Coherent action is essential for the improvement of health equity; policies and interventions must complement rather than contradict each other in relation to the production of health and health equity. Policy makers, healthcare organization, care providers and community health workers must realize that disease-related stigmas harm health. In many developing countries, disease-related stigmas hamper health promotion and health intervention outcomes.[6-8] These stigmas not only pose negative consequences for the infected individuals and their households, but also affect public attitudes toward prevention, service provision, and health-related policies.[7]

The social origins of health disparities, including social capital, may influence health and behaviour through their effects on psychosocial processes. A growing body of evidence suggests that the social environment plays an important role in shaping people's health, and the quality of this environment may be an important socioeconomic condition affecting health and well-being.[9-13] A widely-used definition of social capital is the following: "the set of cooperative relationships between social actors that facilitate collective actions".[14] Social capital may shelter people from the harmful effects of unemployment and poverty.[15,16] In this regard, it is worthwhile to investigate the role of social capital on health and well-being outcomes, especially in a poor community.

The lack of adequate data often withholds recognition of the nature and depth of health inequity. Good understanding of the relationships between socioeconomic conditions and health is essential. Comprehensive data are most lacking in countries with the worst health problems.[2] It is thus necessary to strengthen our understanding of the relationship between health and socioeconomic conditions, especially in economically and health-deprived communities.[17,18] However, most funding for health research remains overwhelmingly focused in Western developed countries and on the biomedical fields. Traditional hierarchies of evidence (which favour randomized controlled trials and laboratory experiments) are usually not appropriate for research on the social determinants of health.[2]

Outcomes of widely implemented top-down disease programs in sub-Saharan Africa falls short of expectations making it unlikely to reach the MDGs.[2,3] In-dept understanding of the relationships between individual and environmental social and economic conditions within a local context is necessary to increase our understanding of the specific situation people living in these deprived areas are faced with. [19-21] Greater in-dept understanding of the specific situation and needs in a local context will enable health and development organizations to develop programs based on the local situation. This dissertation aimed to identify the relationships between individual and environmental social and economic conditions and health and subjective well-being within one economically and health-deprived community in Rhini, a small township of Grahamstown, in the Eastern Cape province of South Africa. High levels of poverty and unemployment characterize this community. Furthermore, this region reports one of the worst TB cure rates in South Africa and one of the highest TB incidence and prevalence numbers. Therefore, this community represents an interesting population for the purposes of this dissertation. Increased in-dept understanding of the relationships between individual and environmental social and economic indicators and health and well-being among a community in consistent economic deprivation may enable development agencies, healthcare organization and governments to develop more effective policies and programs. Such programs may enhance health, promote a healthier environment, intensify primary prevention, and influence public policies in all sectors to address the root causes of (environmental) threats to health and subjective well-being. This study is part of a three-year project (2006-2008) on TB Stigma and Quality of Life in the Eastern Cape and builds upon earlier held in-dept interviews with TB patients on treatment and further extensive qualitative research in the first phase of the research project. Møller and Erstad (2006,2007) reported detailed qualitative description of these results.[22,23]

Outline of the Dissertation

Chapters 2 and 3 of this dissertation seek to identify the relationships between social and economic conditions and health and TB prevalence within a poor community. These chapters present multilevel analyses of the compositional and contextual socioeconomic factors related to health in general (Chapter 2) and tuberculosis (TB) in particular (Chapter 3). A number of multilevel studies in Western developed areas and a few in developing countries have identified compositional and contextual conditions that affect TB prevalence and health outcomes. These studies have all been conducted at higher geographical levels of aggregation (i.e. countries, states/provinces or large regions) and compared economically deprived areas to more affluent regions. South Africa is known for its unusual high level of income inequality and while the link between income inequality and TB may hold in high-inequality settings,[24-27] in line with inequality and health outcomes in general[28,29] the generalization of these results to low-inequality settings is unclear. The relationships reported in earlier multilevel analyses may be limited when looking at poorer regions with less variation in absolute income. A multilevel study investigating socioeconomic conditions related to TB prevalence and health outcomes in lower geographical levels of aggregation within economically deprived communities is lacking. A smaller spatial unit of analysis and consistent economic deprivation may dramatically affect the variables that contribute to the development of health, illness and disease, so it is essential that these areas be examined. It is unclear whether these compositional and contextual factors still account for differences in health and TB within a smaller spatial unit of analysis and consistent deprivation. South Africa's historic experience of spatial planning along racial lines may have led to TB epidemiology and poor health in these settings (mostly townships) differing from elsewhere. This research builds on multilevel research and seeks to identify relationships between socioeconomic risk factors and household level TB experience and poor health in an Eastern Cape township.

Chapters 4, 5 and 6 investigate TB within the context of the impacts of human immunodeficiency virus (HIV) in a region highly burdened by both diseases. Although existing literature on TB has been written almost entirely from a biomedical perspective, recent studies have shown the importance of recognizing lay perceptions when seeking to improve TB outcomes.[30] With the understanding that public health promotion, (cost-) effective treatment provision, individual well-being, and social welfare must take individual and community perceptions of TB into account,[17,18] it is important to gain insight into the views of people regarding TB, especially among high risk populations such as the Eastern Cape. Achieving a high level of TB awareness is crucial for the success of prevention and treatment efforts in high risk populations and represents a key challenge for public health initiatives. Since the Eastern Cape is known as a province with high TB incidence, prevalence and with one of the worst TB cure rates of South Africa, its inhabitants can be considered lay experts when it comes to TB. Therefore, we investigated perceptions among an Eastern Cape population. The aim of Chapter 4 was to gain better insight into what influences health seeking behavior and adherence to TB treatment by investigating knowledge and perceptions regarding TB patients, health seeking behavior and adherence to TB treatment. Chapter 5 examines the relationship between (stigmatizing) ideas in this community and health-seeking behaviour. It remains unclear how HIV/AIDS and TB stigmas affect public attitudes toward TB treatment, and consequently affect access and treatment outcomes. In this chapter, we thus seek to identify the pervasiveness of these stigmas and explore how these belief systems work. We focused on the relationship between stigmatizing ideas and lay public TB treatment preferences, with the goals of facilitating TB program design and improving treatment outcomes. In Chapter 6 we present the results of an investigation of views on the determinants of adherence with TB treatment conducted among TB patients in the Eastern Cape. The greatest problem facing TB control programs is ensuring that patients complete treatment. Given the increased transmission rates, morbidity and costs to TB control programs engendered by poor adherence and frequent interruption of treatment, the determinants of (non-) adherence from the patient perspective are explored in Chapter 6. One of the contributions of this study is that we specifically address interaction of social and economic factors from the patients' perspective. Our study aims to identify how compliers and non-compliers value these social and economic factors relative to each other, and whether this interaction works differently for compliance and non-compliance with treatment. As a result, this study contributes to a better understanding of TB patients' choices regarding their treatment, and provides directions for refining TB treatment programs and improving compliance.

Improving the subjective well-being of the poorest of the poor is often framed as a goal of human development programs. Chapters 7 and 8 focus on socioeconomic conditions associated with subjective well-being within a poor South African community. The study in Chapter 7 investigates the relationships between income, social capital, health and crime experience and subjective well-being in this poor community. It also addressed the question whether social capital may act as a buffer. The mean well-being score (0-10) for this community is 4.6,[31] which is substantially lower than that reported for the whole nation of South Africa (5.7).[32] This community, therefore, represents an interesting population for the purpose of the study reported here. In addition to the compositional relations between socioeconomic conditions and subjective well-being studied in Chapter 7, in Chapter 8 we also investigate the contextual socioeconomic conditions related to subjective well-being using a multilevel analysis. The already disadvantaged people living in deprived neighbourhoods and dealing with poverty, (infectious) diseases and the many other struggles of life may even be more burdened with additional negative neighbourhood conditions. These act to further compound problems of concentrated disadvantage and social exclusion. The relationships between multilevel characteristics and individual well-being, and the extent to which each indicator at each level is associated with individual well-being, are currently unknown. It would be helpful to identify multilevel conditions that are related to subjective well-being, especially within poor communities. Recognition of the multiple levels of intervention may enable policymakers, healthcare organizations and development agencies to better design programs that help communities and thereby achieve greater subjective well-being for a greater number of people.

A summary and reflection on the main findings and methodological issues are presented in Chapter 9. Furthermore, implications for future research and practice are described.

In Chapters 2, 3, 4, 5, 7 and 8 the same method (a survey was administered to 1020 respondents by means of a stratified sample design) was applied to answer the research questions. Only in Chapter 6 a different method was used (Q-methodology). Therefore, the method section within six chapters is quite similar and readers can skip this part when reading this dissertation. The method section is included in each chapter in case people are interested in reading just one or two chapters.

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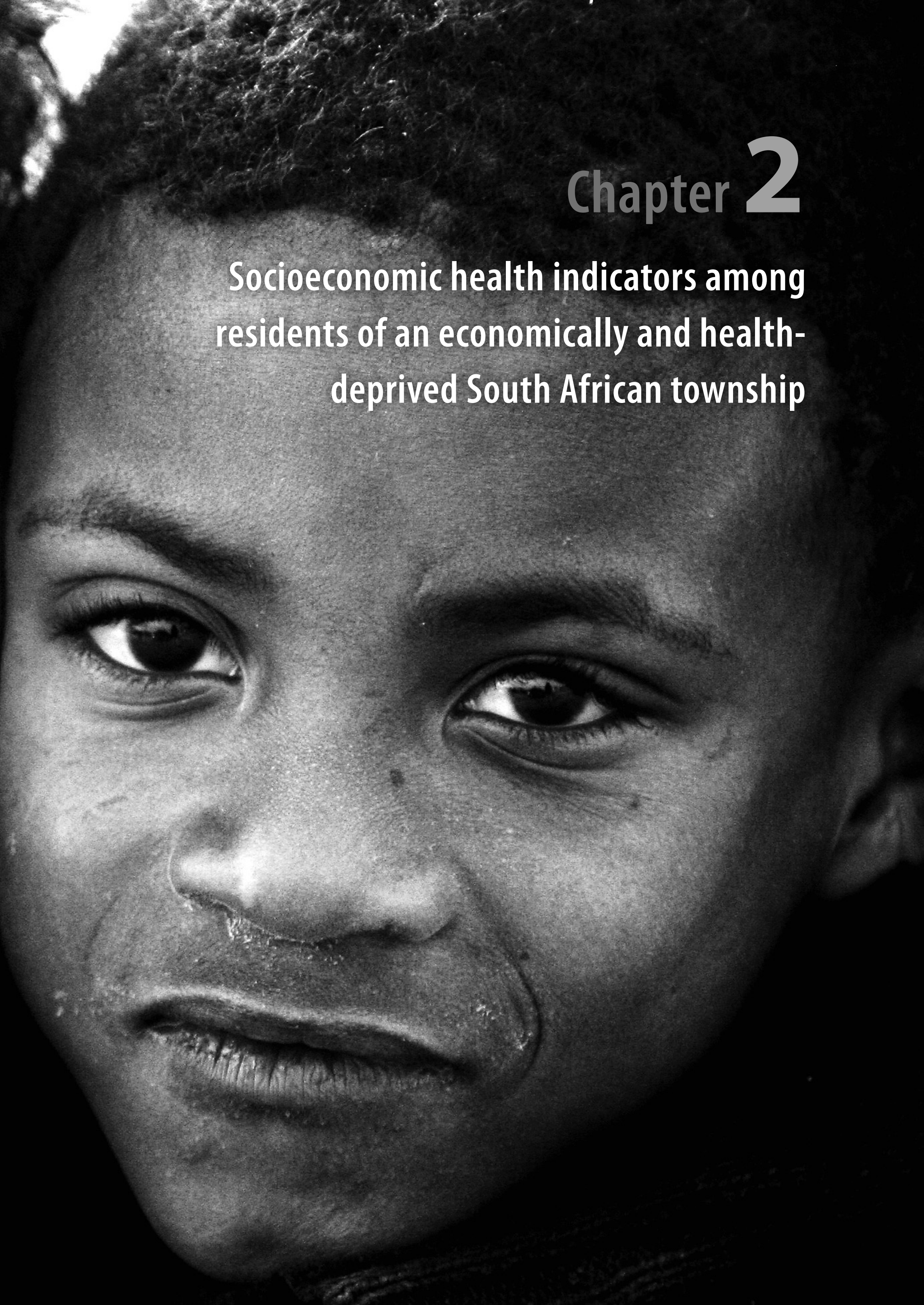

Chapter 2

Socioeconomic health indicators among residents of an economically and health-deprived South African township

Abstract

Purpose Surprisingly few studies have investigated the interplay of multiple factors affecting health outcomes in developing countries. Comprehensive data are most lacking in countries with the worst health problems. It is necessary to strengthen our understanding of health inequity, the social indicators of health, and the most effective means of improvement, especially in economically and health-deprived communities. This study aimed to identify the underlying compositional (individual) and contextual (environmental) social and economic health indicators for residents of an economically and health-deprived community in the Eastern Cape of South Africa.

Methods A hierarchical multilevel regression analysis of health was conducted on data from 1,020 respondents at level 1, and nested within 20 neighbourhoods at level 2.

Results Our study found that education was positively correlated with good health, whereas unemployment and advanced age were associated with poor health. We found no significant relationship between self-rated health and the contextual, neighbourhood-level indicators of socioeconomic status and income inequality. The residents of this South African township are deprived by national standards, but not in comparison with their neighbours.

Conclusion With this article we wish to highlight the influence of employment and education on health, and to suggest that health outcomes may most likely be improved through interventions beyond the health system aimed at creating job opportunities, strengthening educational systems, and promoting universal educational access. Policy makers should consider the benefits of such programmes when addressing health outcomes in financially poor districts.

Introduction

Since the establishment of the United Nations' Millennium Development Goals, health inequalities between the rich and poor in developing countries have received much attention from researchers and policy makers. The World Health Organization has uncovered pronounced inequalities in health care systems around the world. Taking a holistic view of the social determinants of health, the WHO has concluded that health and illness follow a social gradient in countries at all levels of income and development; lower socioeconomic positions are correlated with poorer health. These avoidable health inequalities arise from the circumstances in which people grow, live, work, and age, and from the systems currently in place to deal with illness. The conditions in which people live and die are, in turn, shaped by social and economic forces. Together, the structural determinants and conditions of daily life constitute the social determinants of health and are responsible for a major part of health inequities between and within countries. Health systems will not be able to achieve health equity without the implementation of interventions, including those beyond the health sector.[1]

Good data on the social determinants of health and the distribution of health inequalities are essential to understand the scale of the problem, and to monitor progress by assessing the effects of implemented actions and programmes. Comprehensive data are most lacking in countries with the worst health problems.[2] Policy makers must understand the factors that affect a population's health and the operation of the social gradient. It is important that international development organisations and national health promotion programmes acknowledge the contextual differences in and interactions among health-related socioeconomic and environmental risk factors.

To effectively promote good health, programmes are challenged to target specific populations.[1] Because neighbourhoods and communities are amenable to intervention, they present opportunities to substantially improve the health of populations and reduce health inequality. The effective conceptualisation and focus of such interventions, however, must be based on research that explains the underlying mechanisms of health.[2-8] To strengthen our understanding of health inequity, the social determinants of health, and the most effective means of improvement, studies must be conducted in economically and health-deprived communities.[9,10]

By definition, the poor enjoy less of the good things in life, including health and longevity. People in the lowest socioeconomic status levels are faced with the worst living conditions and report the worst health outcomes, regardless of their country of residence or available health services.[11] Sen[12-14] has criticised the focus on income in the existing poverty and inequality literature. His capability approach proposes that social arrangements should be primarily evaluated according to people's extent of freedom to lead a valuable life. Within this framework, poverty is defined as the failure of basic capabilities to reach minimally acceptable levels. Poverty is thus a multidimensional concept encompassing much more than the lack of adequate income.[12,13] In this approach, development can be seen as a process of freeing people by strengthening these capabilities.[13,14] Health is among the basic capabilities that give value to human life, accounting for values such as longevity and freedom from disease. Health promotion should emphasise prevention and treatment among those most deprived or at risk of health deprivation.[15] Therefore, health capabilities should be the focal variable for the assessment of equity and efficiency in development programmes. A nuanced understanding of the predictors of health is crucial for the improvement of such programs.

Sen has argued that humans have diverse internal (e.g. age, gender, health status) and external (e.g. education, employment, income, physical and social environments) characteristics that should inform the assessment of equity, especially because equity requires society to aid those in proportion to their degree of disadvantage.[13,14] This point is particularly important in efforts to provide individuals with the resources necessary to improve their functional capabilities.[15] Individual health is affected by factors of socioeconomic status (education, employment, income) and by individual-level experiences of the quality of the environment, the compositional indicators of health. The physical features of the environment (e.g. neighbourhood quality) and the average quality of housing (e.g. leaking roof) are contextual factors that affect individual health. In addition to these material and infrastructural resources, neighbourhood-level social features (e.g. crime experience, social capital) also appear to affect individual health status. Neighbourhood crime experience serves as an indicator of the perceived threat to personal safety and environmental stress experienced by residents.[3] Several hypotheses have been postulated to investigate the degree to which social capital produces health benefits.[16,17] Rogers' diffusion of innovations theory[18] posits that social capital within communities and neighbourhoods may promote the diffusion of health-related knowledge and interventions.[18,19] The psychological components of social capital, including provision of affective support and mutual respect, may also be important factors affecting health.[17]

Besides individual-level socioeconomic status, several multilevel regression analysis (MLRA) studies have demonstrated that low area-level socioeconomic status and high income inequality are significant contextual conditions affecting individual health status.[4] Many researchers have observed that inequality in the distribution of income among individuals is correlated with lower average individual health status. Income inequality leads to the erosion of social capital and stressful social comparison, factors that diminish health.[20-22] These studies have compared residents of economically deprived areas with those living in non-deprived areas. Studies of more localised neighbourhood settings within the same city are scarce,[7] as are those conducted in developing countries. It is not currently clear whether contextual factors similarly account for differences in individual health status within these deprived areas.

Study aims

This study aimed to identify the underlying compositional (individual) and contextual (environmental) social and economic health indicators among residents of Rhini, an economically and health-deprived community in the Eastern Cape of South Africa. South Africa's historical pattern of racially segregated spatial planning may have led to poor health in these settings (mostly townships) that differs from the health patterns of other regions. Rhini is characterised by high levels of poverty and unemployment,[23] and multiple deprivation domains such as income, education, employment, and health.[24] To better understand the potential compositional and contextual influences of socioeconomic status on poor health, we constructed a hierarchical random-effects model to investigate the relationships between neighbourhood-level socioeconomic risk factors, individual-level socioeconomic measures and poor health in Rhini.

Setting and methods

Neighbourhoods in Rhini

The survey forming the foundation of this study covered the black residential areas within the Grahamstown municipal district, referred to as Grahamstown East or Rhini. Under democratic rule, considerable progress has been made in service delivery to formerly disadvantaged segments of South African society. Housing and infrastructure became a major priority for the new government after 1994. A new wave of housing development and service provision has been launched in Grahamstown East with each subsequent change of government. Each neighbourhood is thus characterised by a mosaic of infrastructural approaches, building materials, and standards of services.[26,27] In the late 1980s and 1990s, informal settlements and backyard shacks became a feature of the South African urban landscape. The occupants of informal dwellings in both formal housing areas and informal settlements are typically a mix of 'overspill' from overcrowded township dwellings and in-migrants from the surrounding rural areas. In time, informal settlements have been recognised as permanent fixtures in the urban landscape, and the municipality has upgraded their legal status.

The 20 neighbourhoods in Grahamstown have been distinguished on the basis of service provision, housing quality, and neighbourhood quality. Some neighbourhoods are considered 'elite', others are 'newer', and some are typical informal settlements.[28] Three types of informal housing areas are present in Rhini: shack 'infill' in the older established neighbourhoods, shacks erected on the borders of official housing sites, and land invasions. Some shack infill sites were to become permanent housing under previous government plans, and some neighbourhoods consist of emergency housing built in the early post-apartheid period that has become permanent. Housing quality in these informal settings is lower than that in the more affluent neighbourhoods with formally constructed houses.[26,27] The neighbourhoods are also characterised by different combinations of service provision, including access to electricity, piped water, water-borne sewerage, and toilet systems. Informal settlements that lack legal status receive no services.[28] Given these circumstances, we expected individual socioeconomic conditions to be more homogeneous within neighbourhoods and heterogeneous among neighbourhoods.

Participants and sampling

Systematic sampling techniques were employed to sample the 11,127 plots located in the 2,500 square kilometres of Grahamstown East.[28] Public structures such as civic offices, schools, churches, and crèches were omitted. All neighbourhoods were proportionately represented by population size in the sample. Sampling started from a randomly chosen point and moved systematically through each of the 20 neighbourhoods of Rhini. Every tenth household was selected for inclusion in the sample, resulting in 1,042 targeted households. This method ensured that all households in all neighbourhoods of Rhini stood an equal chance of being included in the survey. Respondents were then identified in each targeted household.

Eligible respondents were 18 years of age or older and had resided in Rhini for at least 6 months of the past year. One respondent from each targeted household was selected using a Kish grid, to ensure that all eligible persons in the household stood an equal chance of being included in the survey.[29] The selected respondent was then interviewed, either immediately or at a later time. Up to four attempts were made to interview selected respondents. An interview was obtained in 1,020 (97.9%) of the 1,042 targeted households. The researchers did not achieve an interview in the remaining cases because respondents were absent from the home during the four attempted visits, were impaired by old age or poor health, or expressed disinterest or unwillingness.

Survey instrument

Staff from Development Research Africa, an organisation with experience in national probability-based sampling in deep rural and urban areas, administered the questionnaires. Most items were closed-ended, with a supplied set of response options. The interviewers gathered demographic information about the participants, including gender, age, health status, education level, living arrangements, and employment. A detailed description of this study population can be found in Møller.[28,30]

Outcome measurement

This study measured self-rated health, which is considered a valid and robust measure of general health status.[3] A large body of evidence has demonstrated that self-reported health assessment has high predictive validity for mortality, physical disability, and chronic disease status. Self-assessed health has also been shown to be a stronger predictor of mortality than physician-assessed health.[31-33] In this study, respondents were asked to rate their perceived health on a five-point ordinal scale. For simplicity and ease of interpretation, and following previous studies,[8,34] the outcome variable was dichotomised into 'poor' (1, 2) and 'good' (3, 4, 5) responses.

Compositional indicators

Neighbourhood quality was estimated with the following two survey items: 'residents in this neighbourhood get value for their rental rates' and 'there is not a lot of crime in this neighbourhood'. Respondents could rate their level of agreement on a four-point scale.

Housing quality was assessed with two survey items: a dichotomised item ('has the roof leaked in the past year?') and an item asking respondents to identify whether their house is formally (brick/cement block) or informally (shack/traditional pole/mud house) built.

Social capital was assessed with three statements for which respondents rated their level of agreement on a four-point scale: 'people in this neighbourhood are friendly', 'people in this neighbourhood help each other without having to be asked', and 'people in this neighbourhood trust their neighbours'. The Cronbach's alpha of this scale was 0.87.

The questionnaire further probed unemployment, income, age, gender, marital status, and education.

Contextual indicators

The Townsend deprivation index[34,35] has been widely used in academic health research,[36] and has been shown to be valid and reliable.[37] This index is used to determine neighbourhood-level socioeconomic status effects on individual-level health status. It includes four variables: unemployment (lack of material resources and insecurity), overcrowding (material living conditions), lack of owner-occupied accommodation (a proxy indicator of wealth), and lack of car ownership (a proxy indicator of income). These four variables combine to form an overall score, which is a summation of the standardised scores (z scores) for each variable (scores > zero indicate greater levels of material deprivation). The Townsend index allows neighbourhoods in the sample to be comparatively ranked; a higher score indicates a more deprived and disadvantaged neighbourhood. This score is a reliable and viable indicator of material deprivation, and was therefore used in this study to investigate whether neighbourhood-level differences in socioeconomic status are associated with individual-level health status.

The Gini coefficient of inequality was used to measure income inequality. The coefficient ranges from 0 (complete equality) to 1 (complete inequality) and has been shown to be valid and reliable.[24]

Data analysis

We generated descriptive summary statistics, and applied a multilevel logistic regression model to account for the hierarchical structure of the data and the dichotomous outcome variable. We generated odds ratios (ORs) for untransformed (crude) and standardised (adjusted) variables to describe associations with poor health. The hierarchical structure consisted of 1,020 individuals (level 1) nested in 20 neighbourhoods (level 2). Individuals were excluded if observations were missing for any outcome, which led to the inclusion of 929 individuals in our MLRA. With these analyses we sought to verify the impact of individual- and neighbourhood-level effects on health.

Results

The majority (73%) of respondents were women, and their median age was 38 years (range: 18-98 years). Just over half (52%) were single, about one-third (33%) were married, and the others were widowed (9%) or separated/divorced (6%). Only 8% of respondents had no formal schooling and 27% had received only primary education. Forty percent had received some secondary education and 18% had matriculated. Approximately 7% had received post-matriculation education and training. Housing quality indicators showed that 51% of respondents had a leaking roof in the past year; 72% lived in a formal house, 12% in an informal house (shack), and 16% in a traditional mud dwelling. Table 1 provides descriptive statistics for the compositional variables and Table 2 shows descriptive statistics for the contextual variables used in the MLRA.

Table 1. Descriptive statistics for the compositional variables used in the regression analyses (*n* = 1,020).

Model	Mean	SD	Min	Max
Health	3.55	1.01	1.00	5.00
Crime in the area	2.98	0.89	1.00	4.00
Residents get value for their rental rates	2.81	0.74	1.00	4.00
Social capital	2.04	0.54	1.00	4.00
Income	5,713	1,863	0.00	>7,001

The MLRA model was used to simultaneously evaluate the relationships of neighbourhood-level socioeconomic status, income inequality, housing quality, neighbour-

Table 2. Summary descriptive statistics for contextual neighbourhood-level indicators.

Neighbourhood	Townsend score	Gini coefficient
1	2.29	0.20
2	-0.66	0.17
3	-4.67	0.19
4	0.39	0.19
5	-0.47	0.19
6	-2.94	0.18
7	-2.24	0.16
8	-8.27	0.16
9	-0.09	0.17
10	-0.08	0.21
11	0.12	0.23
12	0.74	0.18
13	3.44	0.25
14	1.29	0.19
15	1.97	0.22
16	1.21	0.21
17	1.40	0.14
18	1.42	0.24
19	2.53	0.24
20	0.47	0.20

hood quality, social capital, unemployment, income, and demographics on individual self-rated health. The MLRA explained 28.7% of variance in this sample. Table 3 presents crude and adjusted ORs of poorer self-rated health.

These analyses revealed that unemployment and increasing age significantly contributed to poor health status within this community, while education significantly promoted good health. No significant multilevel correlations were found between self-rated health and the contextual variables of neighbourhood-level socioeconomic status and income inequality within neighbourhoods. We also did not find a significant relationship between self-rated health and the compositional variables of housing quality, neighbourhood quality, social capital, income, gender, or marital status (Table 3). The OR for unemployment was 2.23, indicating that the ratio of the odds increased by 2.23-fold for the unemployed compared to the employed, assuming all other factors in the model remained constant. Similarly, an increase in age by one year was related to a 0.08 OR increase. Higher education was related to a decreased probability of poor health, as indicated by a 0.77 OR. Adjusted ORs for unemployment (1.48), increasing age (3.61), and education (0.75) show that the relative strength of the association was greatest for age and weakest for education.

Table 3. Crude and adjusted odds ratios of poorer self-reported health based on multilevel logistic regression analyses.

Model	Crude odds ratio	(95% CI)			Adjusted odds ratio	(95% CI)		
Townsend score	0.96	0.88	1.05		0.91	0.73	1.14	
Gini coefficient	0.00	0.00	11.28		0.85	0.67	1.08	
Crime in the area	0.87	0.72	1.05		0.88	0.75	1.04	
Residents get value for their rental rates	1.03	0.82	1.30		1.02	0.86	1.21	
The roof has leaked in the past year	0.90	0.63	1.29		0.95	0.80	1.14	
Housing quality (formal/informal)	0.87	0.59	1.29		0.94	0.79	1.12	
Social capital	0.85	0.62	1.16		0.92	0.77	1.08	
Unemployment	2.23	1.51	3.28	**	1.48	1.22	1.78	**
Income	1.02	0.93	1.12		1.04	0.86	1.27	
Age	1.08	1.07	1.10	**	3.61	2.91	4.48	**
Gender	1.14	0.78	1.65		1.06	0.90	1.25	
Marital status	1.16	0.82	1.64		1.07	0.91	1.26	
Education	0.77	0.65	0.92	*	0.75	0.62	0.92	*

Notes: $^{*}p \leq 0.01$; $^{**}p \leq 0.001$.

Discussion

This research used a MLRA to identify contextual and compositional socioeconomic status risk factors at the individual and neighbourhood levels for individual-level health in a South African township. MLRA allowed us to differentiate between compositional individual- and contextual neighbourhood-level mechanisms affecting the relationship between socioeconomic status and self-rated health.

Our study found that the compositional indicator of education was positively correlated with good health, whereas unemployment and advanced age were correlated with poor health. These results are consistent with Sen's capability approach,[12-14] which identified poverty and development as multidimensional concepts and argued that interventions must be aimed at improving people's capabilities to lead valuable lives. The capability approach applies differently in varying contexts and situations. In this study, we identified education and employment as important external capabilities that allow the residents of Rhini to lead healthier and more valuable lives. We expect that interventions focusing on these external capabilities are most likely to promote internal health capabilities.

We found no significant relationship between the contextual indicators and self-rated health in the small analytical unit of a single South African township with consistent economic deprivation. While earlier studies found that neighbourhood-level income inequality contributed to health outcomes, Wilkinson and Pickett[38] found that the degree of correlation differed substantially according to whether inequality was measured in large or small areas/neighbourhoods. The authors therefore suggested that studies of income inequality would find that health inequality is explained by greater income variance in large neighbourhoods, where inequality measures the scale of social stratification or extent of hierarchy. Contextual factors did not lead to differences in individual health status within the poor South African township examined in the present study. Gini coefficients in Rhini ranged from 0.14 to 0.25, indicating a much lower level of income inequality than the national value of 0.58.[39] The residents of this community are deprived by national measures, but not in comparison with each other. Investigation of a larger region that included the more affluent and predominantly white neighbourhoods in Grahamstown West might produce different results. In addition, South Africa's unique history of social arrangements (e.g. provision of disability grants) may also have alleviated some of the adverse impacts of progressively greater income disparities. The municipality of Grahamstown East has embarked on an extensive programme since the onset of the democratic era to provide access to services, and residents are gradually achieving a higher standard of living.[28]

To overcome health inequality, policy makers need to understand the factors that account for poorer health at the national and community levels. Wen et al.[3] have proposed that low income leads to the erosion of social capital, and therefore to poor health. This could explain the lack of positive correlation between social capital and health status in our study. Rhini is characterised by high levels of poverty[25] and multiple deprivation domains such as income, education, employment, and health.[5] The community is also likely socially deprived. In comparison to other communities, the residents of Rhini are thus severely deprived. The deprived status of the community as a whole likely explains the lack of significant contextual influence on subjective health in this research.

Several limitations must be considered when interpreting our study findings. First, the majority of respondents were women and their median age (38 years) exceeded that of the community as a whole. These biases may be related to the inherent limitation of the conventional Kish grid,[29] which often selects for a higher proportion of women and older people. Second, the cross-sectional nature of the data has limited our ability to draw causal inferences or determine the directionality of associations. Our establishment of significant associations is an important step for further studies investigating directionality. Ultimately, neighbourhood- and individual-level effects on health are likely to be complex and interconnected.[6] Third, some researchers have argued that Townsend scores are biased in economically deprived areas due to the inclusion of car ownership.[40] Such a bias could explain the lack of correlation between this indicator and differential health outcomes in more and less deprived neighbourhoods. Fourth, our study was restricted to a single Eastern Cape township, limiting the applicability of our findings to other areas. They may apply, however, to the many areas with similar neighbourhood characteristics in developing African countries. To our knowledge, this study is the first to use MLRA in a small economically and health-deprived area. Our results therefore need confirmation, especially from similar African areas.

In conclusion, the present study demonstrated a high degree of explained variance that positively correlated employment and education with improved health outcomes in the South African township of Rhini. These findings are important in the effort to reduce health inequities and alleviate the struggles of the lowest socioeconomic stratum. Our results support the WHO's conclusions that social injustice between and within countries, especially within developing countries, promotes health inequality and that health equity can only be achieved beyond the healthcare system, through the social determinants of health. Commitment and interventions beyond the health sector are therefore necessary.[1] With this article we wish to highlight the impact of employment and education on health, and to suggest that health equity is likely to be improved with interventions that seek to create job opportunities, strengthen educational systems, and promote universal educational access.

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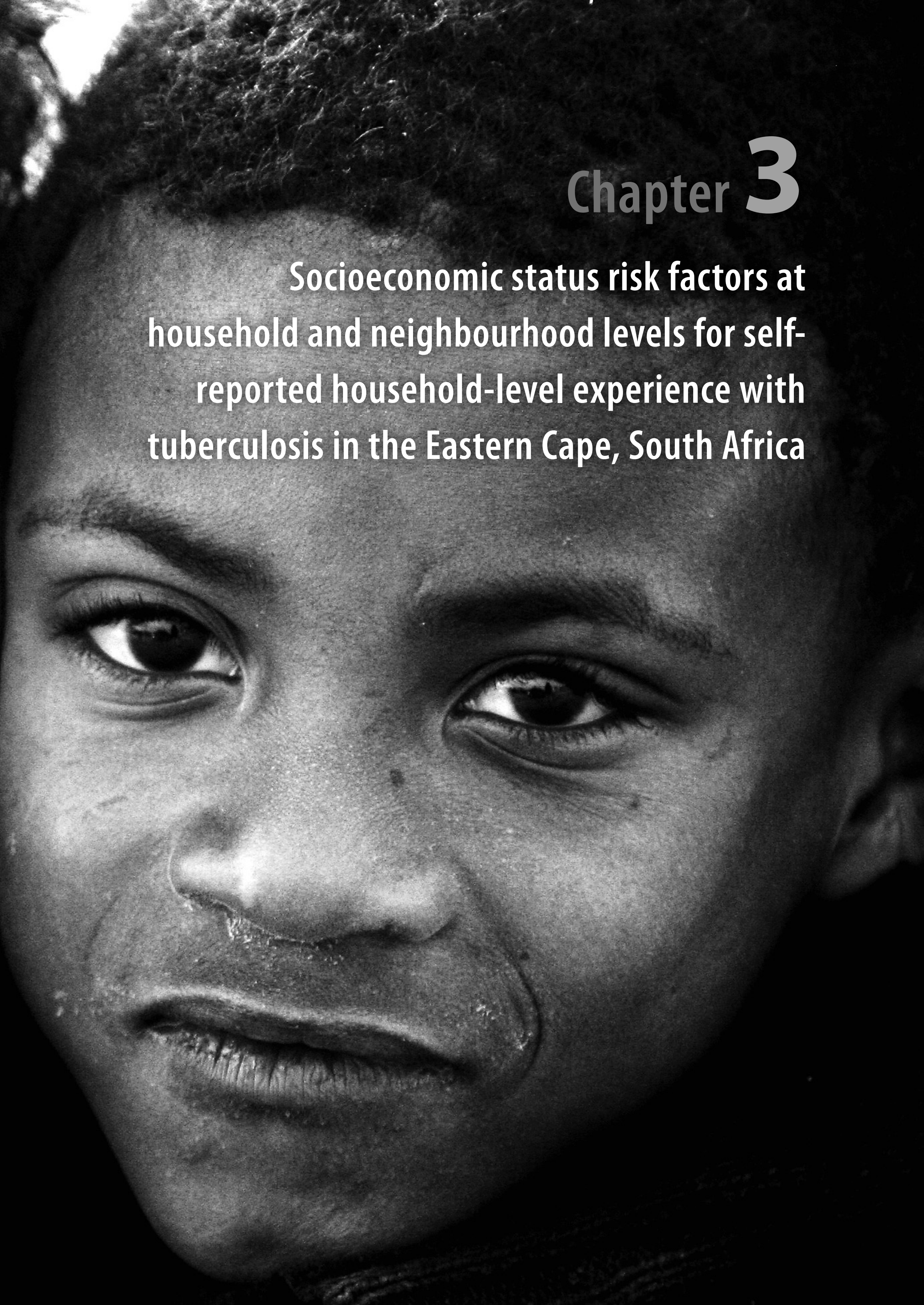

Chapter 3

Socioeconomic status risk factors at household and neighbourhood levels for self-reported household-level experience with tuberculosis in the Eastern Cape, South Africa

Abstract

Background Surprisingly few studies have investigated the interplay of multiple factors affecting the prevalence of tuberculosis in developing countries. The compositional and contextual factors that affect health and disease patterns must be fully understood to successfully control tuberculosis.

Methods This study investigated the influence of socioeconomic status on household experience with tuberculosis in South Africa at the household (overcrowding, leaky roof, social capital, unemployment, income) and neighbourhood (Gini, unemployment rate, headcount poverty rate) levels. A hierarchical random-effects model was used to assess household-level and neighbourhood-level effects on self-reported tuberculosis experience. We included 1020 households within 20 neighbourhoods of Rhini, a suburb of Grahamstown in the Eastern Cape, South Africa.

Results About one-third of respondents (n = 329; 32%) reported that there had been a tuberculosis case within the household. Analyses revealed that overcrowding ($p \leq 0.05$) and roof leakage ($p \leq 0.1$) significantly contributed to the probability of a household TB experience, whereas higher social capital ($p \leq 0.01$) significantly reduced this probability.

Conclusions Overcrowding, roof leakage and the social environment affected tuberculosis prevalence in this economically disadvantaged community. Policy makers should consider the possible benefits of programmes that address housing and social environments when addressing the spread of tuberculosis in financially poor districts.

Background

An estimated 9.4 million new cases of tuberculosis (TB) and 1.8 million TB-related deaths (including 500 000 people with HIV) occurred in 2008, making TB the world's deadliest curable infectious disease. While TB is a major cause of illness and death worldwide, the effects of this disease are particularly evident in low- and middle-income countries.[1,2] Many countries are adequately managing the issue of TB, but South Africa lags behind.[3] The human immunodeficiency virus / acquired immune deficiency syndrome (HIV/AIDS) epidemic has aggravated an already severe TB situation to create a global health concern.

TB is traditionally regarded as a disease of poverty that is affected by many aspects of low socioeconomic status, such as overcrowding, poor housing quality, and ownership of goods.[4-7] Despite the acknowledgement that TB has strong socioeconomic determinants, surprisingly little epidemiological research has explored the pathways through which socioeconomic status affects the prevalence of TB.[6] Ecological studies conducted in the United States and Britain have found associations between regional TB rates and high levels of poverty, social deprivation, and income inequality.[8,9] Public health research has increasingly focused on the quantitative analysis of social and economic factors as determinants of health outcomes. This field of social epidemiology recognises the importance of household- and neighbourhood-level socioeconomic risk factors.[6,10] Public health prevention efforts must gather contextualised data and consider the multilevel nature of the growing problem of poor TB outcomes. Prevention efforts targeting risk behaviours have shown inadequate success, partly because of their reliance on individual-level interventions that do not consider the context within which such behaviours occur.

The social origins of health disparities, including social capital, may influence health and behaviour through their effects on psychosocial processes.[11] A growing body of evidence suggests that the social environment plays an important role in shaping people's health, and the quality of this environment may be an important socioeconomic condition affecting TB outcomes.[11,13] Social capital is defined as, 'the set of cooperative relationships between social actors that facilitate collective actions'.[14] It is a collective resource that benefits communities and is distinct from the individual-level health effects of social networks and support.[15,16]

While social capital is recognised to have an important influence on health, the specific mechanisms of this association remain incompletely defined. Several hypotheses have been postulated to explain the mechanism by which social capital produces health benefits;[10] it may shelter people from the harmful effects of unemployment and poverty,[17,18] or provide a buffer against the adverse effects of stress and poverty.[19,20]

Because social capital reflects the social processes, norms, and trust among community members, it is an important resource for community health promotion. Rogers' diffusion of innovations theory[21] suggests that social capital may promote the diffusion of health-related knowledge and interventions within communities and neighbourhoods. This theory is supported by research demonstrating that individuals obtain health information primarily through social connections,[22] and that communities with high levels of social capital can more effectively exercise social control over health behaviours.[10] Poortinga[23] demonstrated that social capital is an important determinant of health and healthy behaviour, and suggested that healthy behaviours mediate the relationship between social capital and health. Social capital may also affect psychological processes, including the provision of affective support and mutual respect,[10,24] that may discourage deviant health behaviours.[23]

While social capital is significantly associated with health, healthy behaviour,[23,25] and improved awareness of health and HIV-related issues,[26] its relationship with TB outcomes has been inadequately examined. It remains unclear whether higher levels of social capital also affect TB awareness and healthy and TB-preventive behaviour, and thus TB prevalence. The influence of social capital may be especially beneficial for diseases such as TB that are related to unhealthy behaviours such as smoking and drinking.

Surprisingly few studies have investigated the interaction of multiple factors affecting the prevalence of TB in developing countries.[27,29] Successful control of TB requires a full understanding of the environmental factors that affect disease patterns.[30] Several multilevel studies in developed Western regions, and a few in developing countries,[2,6,7] have identified the contextual conditions that affect TB prevalence.[12,31,32] These studies have all been conducted at higher geographical levels of aggregation (i.e. countries, states/provinces, or large regions), and have compared economically deprived areas to more affluent regions. South Africa is known for its unusually high level of income inequality. While TB and income inequality are associated in high-inequality settings,[2,5-7] as are inequality and health outcomes in general,[33,34] it is unclear whether this association may be generalised to low-inequality settings. The relationships reported in these multilevel analyses may be limited in poorer regions with less inequality and variation in absolute income and relative income inequality.

TB prevalence has not been thoroughly examined at lower geographical levels of aggregation, such as within a single economically deprived community. A smaller spatial unit of analysis and consistent economic deprivation may dramatically affect the variables that contribute to the development of the disease, so it is essential that these areas be examined. It is further unclear whether contextual factors will continue to account for differences in the development of TB at smaller spatial units of analysis characterised by consistent deprivation. South Africa's historical pattern of racially segregated spatial planning may have led to a TB epidemiology in these settings (mostly townships) that differs from those of other regions.

This multilevel research seeks to identify the socioeconomic risk factors that are associated with household-level TB experience in Rhini, a small township of Grahamstown in the Eastern Cape province of South Africa. This community is characterised by high levels of poverty and unemployment.[35,36] Furthermore, this region reports one of the worst TB cure rates in the world with high TB incidence and prevalence numbers.[3,37] While individual-level factors, such as HIV infection, may increase a person's susceptibility to TB, the differential prevalence of TB among various population subgroups can be better explained by the quality of the physical and social environments inhabited by these subgroups.[12,13] We thus investigated socioeconomic environmental risk factors instead of host-related risk factors (e.g. HIV status, age, gender, smoking). With this research, we sought to identify variables that could improve TB outcomes at the neighbourhood and household levels in a highly burdened township. We also investigated the influence of social capital on TB prevalence within this community. To better understand the potential compositional and contextual influences of socioeconomic status on TB risk, we conducted a multilevel analysis of the relative importance of household-level socioeconomic risk factors and neighbourhood-level socioeconomic measures in predicting TB prevalence in Rhini.

Methods

Participants and sampling

This study used a neighbourhood-level stratified sampling design. Every tenth household in each of the 20 Rhini neighbourhoods was selected for inclusion in the sample, resulting in 1,042 targeted households. This method ensured that all households in all neighbourhoods of Rhini stood an equal chance of being included in the survey. Respondents were then identified in each targeted household.

Eligible respondents were at least 18 years of age and had resided in Rhini for at least 6 months of the past year. A Kish grid was used to select one respondent from each targeted household, to ensure that all eligible persons in the household stood an equal chance of being included in the survey. The selected respondent was then interviewed, either immediately or at a later time. Up to four attempts were made to interview selected respondents. An interview was obtained in 1,020 of the 1,042 targeted households (97.9%). The researchers did not achieve an interview in the remaining cases because respondents were absent from the home during the four attempted visits, were impaired by old age or poor health, or were unwilling to participate.

Neighbourhoods in Rhini

The survey forming the foundation of this study covered the black residential areas within the city of Grahamstown, Makana Municipality, referred to as Grahamstown East or Rhini. Under democratic rule, considerable progress has been made in service delivery to formerly disadvantaged segments of South African society. Housing and infrastructure became a major priority of the new government after 1994, and a new wave of housing development and service provision has been launched in Grahamstown East with each subsequent change of government. Each neighbourhood is thus characterised by a mosaic of infrastructural approaches, building materials, and standards of services.[38] In the late 1980s and 1990s, informal settlements and backyard shacks became common features of the South African urban landscape. Informal dwellings are located in both formal housing areas and informal settlements; their occupants are typically a mix of 'overspill' from overcrowded township dwellings and in-migrants from the surrounding rural areas. Informal settlements have been recognised over time as permanent fixtures in the urban landscape, and the municipality has upgraded their legal status.

The 20 neighbourhoods in Rhini have been classified on the basis of service provision, housing quality, and neighbourhood quality. Some neighbourhoods are considered 'elite' neighbourhoods, others are 'newer', and some are typical informal settlements.[39] Three types of informal housing areas are present in Rhini: shack 'infill' in the older established neighbourhoods, shacks erected on the borders of official housing sites, and land invasions. Some shack infill sites were to become permanent housing under previous government plans, and some neighbourhoods consist of emergency housing built in the early post-apartheid period that has become permanent. Housing quality in these informal settings is lower than that in the more established neighbourhoods containing formally constructed houses.[38,40] The neighbourhoods are also characterised by different combinations of service provision, including access to electricity, piped water, water-borne sewerage, and toilet systems.[39] Given the differing histories of neighbourhood development, we expected the socioeconomic conditions of individuals to be more homogeneous within neighbourhoods and heterogeneous among neighbourhoods.

Ethical approval

This study was approved by the Rhodes University Ethical Standards Committee. All personal identifiers have been removed or disguised.

Survey instrument

Staff from Development Research Africa, an organisation with experience conducting national probability-based sampling in deep rural and urban areas, administered our questionnaire to the respondents. It contained closed-ended questions with a supplied set of response options. The interviewers also gathered demographic information from the participants, including gender, age, health status, educational level, living arrangements, and employment. A detailed description of this study population can be found in Møller.[39,41]

Measurements

Outcome measurement

TB prevalence was assessed by a dichotomised lifetime tuberculosis item that stated, 'There has been a case of TB in this household'. We did not assess individual-level experience with TB because the interview was held face-to-face; given the stigmatisation of TB, we felt that respondents might not answer such questions truthfully. The investigation of host-related indicators was additionally beyond the scope of this work, which investigated the compositional and contextual effects of socioeconomic status on TB risk at the household and neighbourhood levels. Household TB experience was therefore the most appropriate scale for our inquiries.

Under apartheid there was no choice in housing. Thirty-four percent of the respondents in our sample had lived in the same house for over 20 years, and 99.5% had lived in the Eastern Cape their entire lives. These data indicate constant socioeconomic conditions during the participants' lifetimes,[39] and led to our investigation of lifetime TB experience. A recent nationwide multilevel analysis of self-reported TB experience in South Africa revealed no differences in risk factors between self-reported lifetime TB experience and TB experience within the last year.[6]

Household-level indicators

TB spreads easily in damp and crowded conditions, which are common among township households. Water incursion from internal (e.g. leaking pipes) or external sources (e.g. rainwater) causes dampness, which becomes problematic when a leaking roof causes structural materials (e.g. walls, ceiling) to become wet for extended periods of time. Housing quality was thus assessed with a dichotomised item ('has the roof leaked in the past year?'). To measure overcrowding, respondents were asked to state the number of people in the household and the number of rooms in the house. Overcrowding was then calculated by dividing the number of household members by the number of rooms.

Following Putman, we measured social capital though respondents' perceptions of the norms of reciprocity and their trust in others, factors that facilitate cooperation for mutual benefit.[15] Social capital was assessed with three statements for which respondents rated their level of agreement on a four-point scale. These statements read, 'People in this neighbourhood are friendly'; 'people in this neighbourhood help each other without having to be asked'; and 'people in this neighbourhood trust their neighbours'. The Cronbach's alpha of this scale was 0.87.

We used a household assets index to measure the possession of household goods (radio, television, car, refrigerator, stereo, telephone or cell phone, computer). The questionnaire further assessed unemployment ('none of the household members is employed') and income (respondents were asked to report the household's average monthly income).

Neighbourhood-level indicators

The Gini coefficient of inequality was used to measure income inequality. The coefficient ranges from 0 (complete equality) to 1 (complete inequality) and has been shown to be valid and reliable.[37] The Gini coefficient is a standardised measure of the absolute differences between each household's size-adjusted income and every other household's size-adjusted income. The headcount poverty rate measured the proportion of targeted households in each neighbourhood earning less than R500 per adult equivalent per month. Children were valued as 0.5 adults. The unemployment rate was determined by the proportion of households without an employed adult member.

Data analysis

Our data analysis sought to verify the influence of household- and neighbourhood-level variables on self-reported household TB experience. We generated descriptive summary statistics and used Spearman's rank correlations to explore univariate associations between the independent variables and household TB experience. To account for the hierarchical structure of the study design and the dichotomous nature of the responses, we fitted a multivariable multilevel logistic regression model. We generated odds ratios for untransformed (crude) and standardised variables (adjusted) to describe associations with household TB experience. This analysis used binominal logistic regression with a hierarchical random-effects model to account for multiple levels of data and intra-neighbourhood correlation that might compromise the efficiency of neighbourhood-level parameter estimates. The hierarchical structure comprised 1,020 households (level 1) nested in 20 neighbourhoods (level 2). Households were excluded if observations were missing for any outcome, which led to the inclusion of 977 households in our multilevel regression analyses.

Results

About one third (32.3%) of the respondents mentioned there had been a TB case within the household. Just over half (52%) were single, a third (33%) were married, and the others widowed (9%) or separated/divorced (6%). Sixty-two percent of the respondents were unemployed and 51% stated that the roof had leaked in the past year. Table 1 provides descriptive statistics for the other household-level independent variables of TB experience, and Table 2 provides this information at the neighbourhood level.

Table 1. Descriptive statistics (N = 977).

Model	Mean	SD	Min	Max
Overcrowding (number of persons per room)	1.65	1.20	0.20	8.00
Social capital	2.04	0.54	1.00	4.00
Income	5713	1863	0.00	>7001

Table 2. Summary descriptive statistics for neighbourhood-level indicators.

Neighbourhood	TB experience	Headcount poverty rate	Unemployment rate	Gini coefficient
1	29.3	76.3	66.4	0.20
2	28.0	72.5	53.7	0.17
3	45.0	75.0	40.0	0.19
4	53.3	89.7	56.7	0.19
5	37.4	65.2	57.1	0.19
6	20.0	37.9	40.0	0.18
7	34.6	69.2	57.7	0.16
8	16.0	44.0	57.6	0.16
9	28.8	74.2	30.0	0.17
10	24.0	84.0	57.6	0.21
11	35.6	68.2	52.0	0.23
12	36.7	70.0	66.7	0.18
13	30.3	83.3	66.7	0.25
14	40.5	68.3	71.2	0.19
15	34.3	88.2	75.0	0.22
16	41.7	86.1	85.7	0.21
17	40.0	95.0	77.8	0.14
18	13.3	100.0	70.0	0.24
19	31.0	68.0	66.7	0.24
20	25.0	77.8	64.3	0.20

Univariate analyses of the effects of overcrowding, leaky roof, social capital, unemployment, income, Gini coefficient, unemployment rate and headcount poverty rate on self-reported household TB prevalence showed that social capital, overcrowding and leaky roof ($p \leq .01$) were the only significant predictors of TB prevalence at the household level (results not shown).

The full multilevel regression model simultaneously evaluated the influence of household-level indicators leaky roof, overcrowding, social capital, unemployment, income, marital status, and neighbourhood-level indicators Gini coefficient, unemployment rate and headcount poverty rate on self-reported household TB prevalence at the household level. We present crude and adjusted odds ratios of TB in Table 3. These analyses revealed that overcrowding ($p \leq 0.05$) and roof leakage ($p \leq 0.1$) significantly contributed to the probability of a household TB experience, whereas higher social capital ($p \leq 0.01$) significantly reduced this probability. No significant multilevel correlations were found between the neighbourhood-level indicators unemployment rate, Gini coefficients, head count poverty rate and the household-level indicators unemployment, income, and household TB experience (Table 3). The OR for overcrowding was 1.13, indicating a 1.13-fold increase in the odds for household TB experience with each extra person per room, assuming that all other factors in the model remained constant. Similarly, a leaky roof increased the odds for household TB experience by a factor of 0.28, compared to housing without a leaking roof. Social capital was related to a decrease in the probability of household TB experience, as indicated by the OR of 0.69. The ORs for the standardised variables were 1.13 for leaky roof, 1.16 for overcrowding, and 0.82 for social capital. These results show the similarity in the relative strengths of these factors.

Table 3. Crude and adjusted log odds ratios of tuberculosis experience based on multilevel logistic regression analyses.

	Odds Ratio (Crude)	Confidence Interval			Odds Ratio (Adjusted)	Confidence Interval		
Gini Coefficient	0.00	0.00	3.74		0.86	0.71	1.03	
Unemployment rate	1.01	0.99	1.03		1.11	0.89	1.39	
Head poverty count rate	1.00	0.99	1.02		1.03	0.86	1.25	
Overcrowding (number of persons per room)	1.13	1.01	1.27	**	1.16	1.01	1.34	**
Leaky roof	1.28	0.96	1.72	*	1.13	0.98	1.31	*
Social capital	0.69	0.53	0.90	***	0.82	0.71	0.94	***
Unemployment								
Income	1.03	0.95	1.11		1.06	0.90	1.25	
Marital status	1.13	0.85	1.52		1.06	0.93	1.22	

Notes: * $p \leq 0.1$; ** $p \leq 0.05$; *** $p \leq 0.01$.

Discussion

This research used multilevel logistic regression analysis of self-reported TB experience to identify socioeconomic status risk factors at the household and neighbourhood levels for household-level experience with TB in South Africa. The multilevel analytical approach allowed us to differentiate between household- and neighbourhood-level mechanisms affecting the relationship between socioeconomic status and TB prevalence.

Poor housing quality (leaking roof) and overcrowding were significantly correlated with the increased prevalence of TB within the household. These results are consistent with those of earlier studies, which found that the differential prevalence of TB among various population subgroups was explained by the quality of the physical and social environments.[12,13] We also found that higher social capital was associated with significantly lower TB prevalence within a household. Social capital may have promoted the diffusion of TB-related knowledge, since people obtain much of their health information through social connections.[22] Higher levels of social capital may therefore have led to increased knowledge, as well as healthy and TB-preventive behaviours. These results agree with those of earlier research identifying social capital as an important enabling factor for healthy behaviours and individuals' sustained management of their health.[42] Additionally, social capital is an important determinant of health, a relationship that is mediated by healthy behaviour.[23] These studies have reported associations between social capital and health in general; the results of our study more specifically suggest that social capital affected TB prevalence through healthy behaviour and acted as mediator for TB prevention. Lack of social capital may lead to increased feelings of loneliness and stress, which negatively affect health outcomes and lead to increased risks and unhealthy behaviours such as drinking and smoking. These behaviours are high risk factors for TB infection. Furthermore, social capital provides affective support and mutual respect[10,24] that discourage unhealthy behaviours.[23] A recent study confirmed that social capital led to improved awareness, preventive actions, and healthier lifestyles, even for highly stigmatised diseases such as HIV.[26] These findings may be extended to explain the association between social capital and TB outcomes in our study.

Public health practitioners and policy makers have recently turned to more comprehensive and participatory approaches to enhancing social capital, and thereby improving health and TB outcomes.[43] Instead of adopting a top-down approach, policy makers increasingly work with community members to plan and implement health programmes. Farquhar and colleagues[44] found an association between health and social capital, and determined that increased social capital generated through community-based participatory interventions led to significantly improved health outcomes. Our findings also highlighted this effect of social capital. Interventions aimed at strengthening social capital may thus reduce TB prevalence. While other research has uncovered significant associations between low household-level socioeconomic status and TB prevalence, income and unemployment did not emerge as significant indicators for TB experience in our study. The neighbourhood-level socioeconomic status indicators were also not significantly associated with TB prevalence. These differences may be related to the scale of analysis. Previous studies have been conducted at higher geographical levels of aggregation, and have compared people living in economically deprived areas with those living in non-deprived areas. For example, Harling and colleagues[6] found income inequality to be a strong predictor for TB outcomes. They performed a nationwide multilevel analysis in South Africa using a study sample with a Gini coefficient of 0.67. In contrast, our study investigated the relationships of multilevel characteristics with TB prevalence at a lower geographical level of aggregation, within a single South African township. The Gini coefficients of the 20 neighbourhoods in our Eastern Cape suburb ranged from 0.14 to 0.25. Compared to South Africa's national level of inequality (0.67), the residents of Rhini shared equal (low) incomes. Investigation of a larger region with more pronounced neighbourhood income inequalities may produce different results.

The same explanation may be applied to the other socioeconomic status indicators at the household and neighbourhood levels. The association between TB and poverty has long been recognised,[5-7] leading to significantly higher TB prevalence among residents of financially poor areas.[5] Although we did not find a significant association between income and TB within Rhini, the high TB prevalence[3] most likely reflects the low income of the community as a whole. Although people within this small community have similarly low incomes, the apparent disparities in housing conditions led to a statistically significant relationship between housing quality and TB prevalence. Increased risk of TB infection for people of low socioeconomic status incorporates both income and housing characteristics, because overcrowding and poor housing quality facilitate the airborne spread of TB infection.[5-7]

We investigated socioeconomic status indicators of TB risk at only the household and neighbourhood levels. As we did not collect information on host-related indicators (e.g. HIV status, smoking habits, and health status), we could not investigate individual-level health associations. The interactions between such factors and socioeconomic status thus require further investigation. The cross-sectional design of our study constituted another limitation, it reduced our ability to capture neighbourhood dynamics and to draw causal inferences. Furthermore, we investigated TB experience by eliciting subjective verbal reports of past household TB experience. Evidence from South Africa has suggested that reliance on self-reported past TB experience may lead to an underreporting of lifetime TB experience.[45] If such underreporting is not correlated with explanatory variables in the analysis, any introduced bias may lead to the coincident underestimation of associations between variables. A further reporting bias might arise if stigma caused individuals to conceal household TB experience.

International organisations and national TB programmes must acknowledge that risk factors may differ among communities. To effectively combat TB, programmes must target specific populations. Local governments and municipalities should adopt plans that address the needs of the local community, especially in poor communities where TB is exceptionally prevalent.

In conclusion, the present study demonstrated that social capital, overcrowding, and poor housing quality are associated with TB prevalence within the low-income South African township of Rhini. While other multilevel analyses have identified socioeconomic indicators of TB at higher levels of aggregation,[2,6,7] we investigated household- and neighbourhood-level indicators in one small community. While existing TB prevention policies in South Africa emphasise disease treatment, our findings suggest that a greater emphasis on social, economic, and housing policies focused on assisting township residents would also be beneficial. We urge the designers of TB-related interventions to consider the many effects of socioeconomic status, especially social capital, on disease. We trust that these findings will be useful for policymakers, governments, municipalities, and organisations faced with the task of developing and implementing TB programmes and interventions that effectively reduce the spread of the disease within townships. The improvement of housing quality and reduction of overcrowding in low-income townships are advisable policy goals. In addition, the strengthening of social capital could decrease TB risk in poor communities with high TB and HIV/AIDS prevalence rates. Social capital may be strengthened through the creation of meeting opportunities among neighbourhood residents.[46] In addition to reducing TB prevalence in the long term, such policies may also improve a wide range of health issues by promoting healthy behaviour, disease awareness, and disease preventive behaviour.

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JM Cramm, HJM Finkenflügel, V Møller, AP Nieboer

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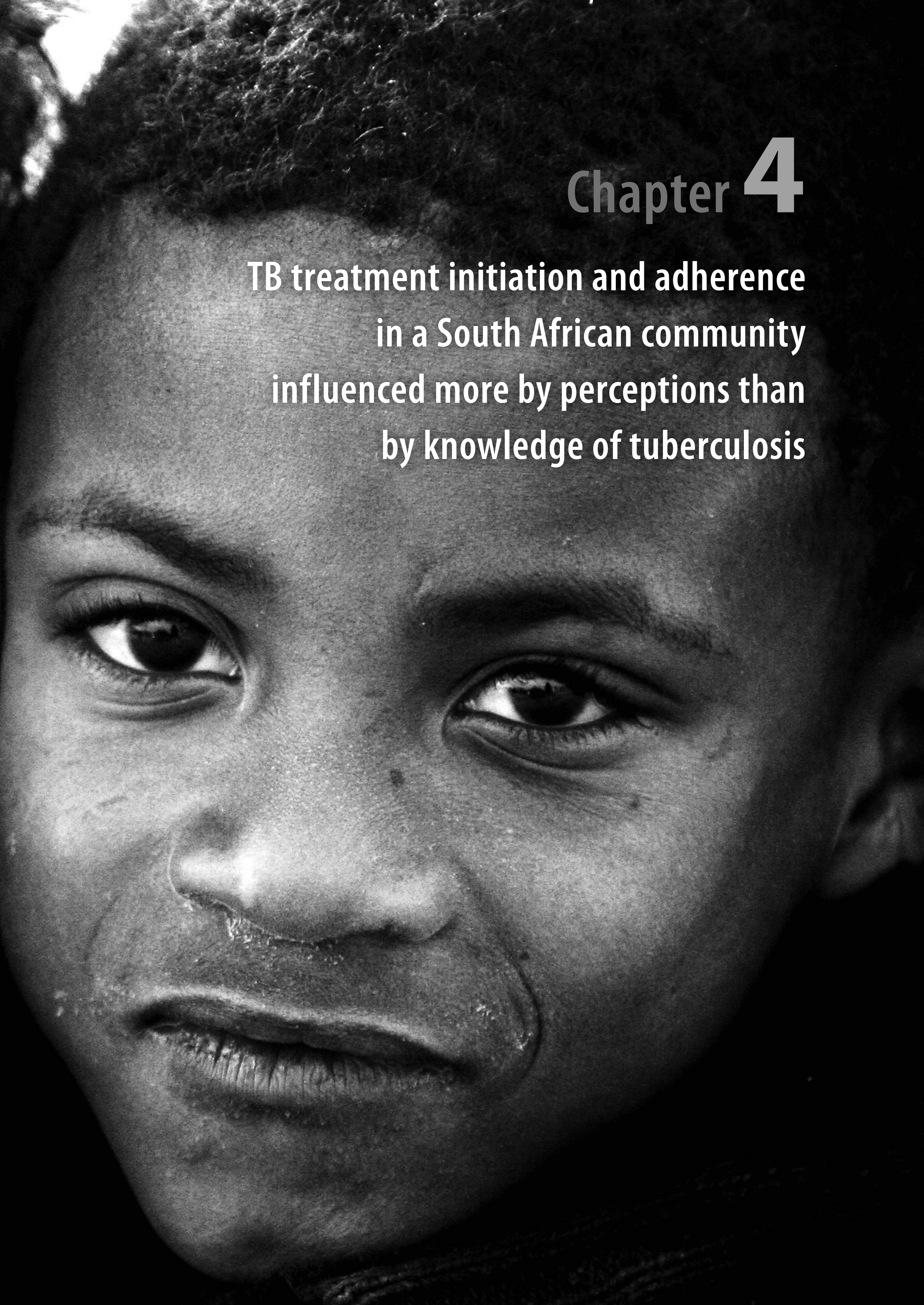
Chapter 4

TB treatment initiation and adherence in a South African community influenced more by perceptions than by knowledge of tuberculosis



Abstract

Background Tuberculosis (TB) is a global health concern. Inadequate case finding and case holding has been cited as major barrier to the control of TB. The TB literature is written almost entirely from a biomedical perspective, while recent studies show that it is imperative to understand lay perception to determine why people seek treatment and may stop taking treatment. The Eastern Cape is known as a province with high TB incidence, prevalence and with one of the worst cure rates of South Africa. Its inhabitants can be considered lay experts when it comes to TB. Therefore, we investigated knowledge, perceptions of (access to) TB treatment and adherence to treatment among an Eastern Cape population.

Methods An area-stratified sampling design was applied. A total of 1020 households were selected randomly in proportion to the total number of households in each neighbourhood.

Results TB knowledge can be considered fairly good among this community. Respondents' perceptions suggest that stigma may influence TB patients' decision in health seeking behavior and adherence to TB treatment. A full 95% of those interviewed believe people with TB tend to hide their TB status out of fear of what others may say. Regression analyses revealed that in this population young and old, men and women and the lower and higher educated share the same attitudes and perceptions. Our findings are therefore likely to reflect the actual situation of TB patients in this population.

Conclusions The lay experts' perceptions suggests that stigma appears to effect case holding and case finding. Future interventions should be directed at improving attitudes and perceptions to potentially reduce stigma. This requires a patient-centered approach to empower TB patients and active involvement in the development and implementation of stigma reduction programs.

Background

Tuberculosis (TB) is a global health concern. It is a major cause of illness and death worldwide, especially in low- and middle-income countries where it is fuelled by human immunodeficiency virus / acquired immune deficiency syndrome (HIV/AIDS), by population increase where TB is most prevalent and by increased poverty.[1]

TB is the most common infection for the estimated 5.5 million South Africans living with HIV/AIDS (in a national population of some 48 million). The co-infection rate of HIV is estimated at 73 per cent in all TB cases. The estimated incidence of TB in South Africa is 692 per 100,000 people,[2] a rate the WHO classifies as a serious epidemic. Even though the DOTS program has been active since 1995, TB remains a major health problem in South Africa and especially in the Eastern Cape.[3] Cure rate of 65% remains well below the 85% rate recommended by the WHO.[2] At 41%, The Eastern Cape's cure rate lags even further behind the national average.[4]

Health seeking behaviour and non-adherence to therapy has been cited as major barrier to the control of TB.[5-18] Non-adherence is a complex, dynamic phenomenon with a wide range of interacting factors impacting treatment taking behaviour.[10] It poses a significant threat to both the individual patient and public health and is associated with higher transmission rates, morbidity, and costs of TB control programs.[6] Furthermore, it leads to persistence and resurgence of TB and is regarded as a major cause of relapse and drug resistance.[7]

The TB literature is written almost entirely from a biomedical perspective. Recent studies show, however, that lay perceptions may explain why people seek and may stop taking treatment.[10] Research that acknowledges social, economic and geographical context is necessary to understand the impact of traditional beliefs and perceptions of illness and wellness on adherence.[11]

Such research is still scarce. From the perspective of public health promotion, (cost-) effective treatment provision, individual wellbeing, and social welfare it is important to gain insight into the views of people regarding TB, especially among high risk populations such as the Eastern Cape.[19,20] Achieving a high level of TB awareness is crucial for the success of prevention and treatment efforts in high risk populations and represents a key challenge for public health initiatives.[20] Since the Eastern Cape is known as a province with high incidence, prevalence,[21] and with one of the worst cure rates of South Africa,[4] its inhabitants can be considered lay experts when it comes to TB. Therefore, we investigated perceptions among an Eastern Cape population. The aim of this study was to gain better insight into what influences health seeking behavior and adherence to TB treatment via investigating knowledge and perceptions regarding TB patients, health seeking behavior and adherence to TB treatment among an Eastern Cape community.

Methods

The Eastern Cape is a South African province characterised by high levels of poverty and unemployment. TB is endemic in the Eastern Cape,[2,21] and the cure rate of 41% lags far behind the 85% rate recommended by the WHO.[4] Data from a survey of 1020 Grahamstown East/Rhini households, conducted in November 2007, were used for this study.

Ethical approval

The Rhodes University Ethical Standards Committee approved this research project. All personal identifiers have been removed or disguised so the person(s) described are not identifiable and cannot be identified through the details of the story.

Sample design

An area-stratified sampling design was applied. Households were selected randomly in proportion to the total number of households in each neighbourhood. Within each of the 23 neighbourhoods, a random starting point was selected. Moving systematically through the neighbourhood, every tenth household was selected for inclusion. This method ensured that all households in all areas of Rhini stood an equal chance of being included in the survey. In each target household eligible respondents were identified. Eligibility criteria included adults over the age of 18 years with 6 months or more of residence in Rhini in the past year. One respondent per household was then selected using a Kish grid. The Kish grid provides a selection procedure by which eligible persons within the household stood an equal chance of being included in the survey.[22] If present at the time, the person selected was then interviewed. If the person was not available, arrangements were made to conduct the interview at a later time. Up to four visits were made to the household to interview the respondent.

Administering questionnaires among households was carried out by Development Research Africa, a well-known organization experienced in undertaking national probability based samples in deep rural and urban areas. With few exceptions, all questions were closed-ended items for which a set of response options was supplied. The full list of options is given in the respective tables.

Instruments

Results from a focus group discussion held in 2006 with people living in the community under study identified several beliefs, perceptions and attitudes toward TB, people with TB, adherence with TB treatment, health seeking behavior and TB treatment types.[21] It appeared that the inhabitants are well informed on TB, Multi-Drug Resistant TB (MDR-TB) and Extensively-Drug Resistant TB (XDR-TB). Since numbers of MDR-TB and XDR-TB are increasing and these types require more extensive and toxic treatment, three questions related to knowledge on these TB types were included. The first question involves knowledge on TB in general; "TB can easily be cured if you take the right treatment". The second, "If you have MDR-TB it takes many months to be cured" assessed knowledge on MDR-TB. The third question " There is no cure at present for extremely drug resistant TB" concerned knowledge on XDR-TB, instigated by recent findings that XDR-TB can be treated through the use of aggressive regimens.[1] During the interview it was made clear to respondents which question addressed TB, MDR-TB and MDR-TB, respectively. Results from the focus groups reveal that there seems to be some misunderstanding about TB and the relation with HIV. Some people believe all TB patients will also develop HIV. Others mention TB to be a typical African disease and think that only poor people may get infected with TB.[21] We incorporated these issues in the TB knowledge test. In total, eight agree/disagree questions were presented to the respondent (correct = score 1, incorrect = score 0). The total score therefore ranges from 0 to 8, with higher scores indicative of greater knowledge.

The focus group results also revealed specific perceptions and attitudes toward TB within this community. People think that irresponsible individuals who do not take their treatment are mainly to blame for spreading TB. Besides blaming those individuals, they accuse them of hiding their TB status for fear of what others might say. They also think that people who acquire TB through drinking and smoking are getting what they deserve and that TB patients are less respected within the community.[21] This suggests that people might be subjected to a high level of stigmatization. These items were included in the questionnaire to investigate the extent to which people in this community share these attitudes and perceptions.

Data analysis

Statistical analyses of attitudes and perceptions toward TB, adherence to TB treatment, health seeking behavior and TB treatment types consisted of frequency counts and percentages. Regression analysis and logistic regression analysis were performed to test whether differences in age, gender and education level led to different knowledge scores and different attitudes and preferences toward TB, adherence to TB treatment, health seeking behavior and TB treatment types. We performed listwise deletion of missing cases in the regression analyses. All statistical analyses were performed using SPSS 16.0.

Results

Respondent profile

An interview was obtained in 97.9 % of the 1042 households targeted. Main reasons for not achieving an interview included non-availability of the respondent after four visits to the household, inability to give an interview for age or health reasons, and refusal due to disinterest or unwillingness.

In the 1020 households included in the final sample the majority (73%) of respondents were women. The median age of respondents was 38 years. Forty percent had completed some secondary education and 18% had matriculated. Approximately 7% had received post-matriculation education and training. Only 8% had no formal schooling.

These 1020 households counted 4245 persons. Just over a quarter (26%) were under 14 years of age. Some 43% were in the 15-59 years age group and 9.6% were over 60 years. The mean age was 30 years. The households included more women (56%) than men (44%).[21] A detailed description of the study population can be found in the Institute of Social and Economic Research, Research Report Series No. 14 & No. 15.[23,24]

Knowledge

The mean score on the TB knowledge test is 5.66 (with 8 being the highest score). 54% of the respondents believe TB to be an African disease and 60% believe that all TB patients will also develop HIV (Table 1). Most respondents correctly answered the other items. The score on the efficacy of treatment item "TB can easily be cured these days if you take your treatment" was high; 98% of the respondents gave the correct answer.

Table 1. Knowledge of TB

Knowledge items	Correct score	
	Frequency	Percent
TB is an African disease	469	46 %
Only people who live in poverty get infected with TB	907	89 %
Only people who are HIV positive get TB	907	89 %
Anyone can get infected with TB because the germs are in the air	938	92 %
TB can easily be cured these days if you take your treatment	1000	98 %
If you have multi-drug resistant TB, it takes many months to be cured	836	82 %
There is no cure at present for extremely drug resistant TB	643	63 %
All people with TB develop HIV/AIDS	408	40%

Lay experts' perceptions

To comprehend lay conceptualisations it is important to know the community's attitudes toward TB. Table 2 reflects this information in the studied population. Results show that 95% believe people with TB tend to hide their TB status because they are afraid of what others may say, 90% believe it is mainly the irresponsible patients who do not take their treatment that are to blame for spreading TB, 74% believes that people who get TB through drinking or smoking get what they deserve and 51% believe that if you have TB people do not respect you.

Table 2. Attitudes toward TB

	Frequency	Percent
Respondent believes people tend to hide when they have TB because they are afraid of what people say about them	967	95%
Respondent believes it is mainly irresponsible people who do not take their treatment who are to blame for spreading TB	918	90%
Respondent believes that people who get TB through drinking or smoking get what they deserve	724	71 %
Respondent believes that if you have TB people do not respect you	520	51 %

Table 3 shows the perceptions of respondents regarding (non) adherence to TB treatment. Thirty-two percent believe "they stick to the rules of treatment" is the most important thing that helps TB patients stay on treatment for 6 months, followed by "they want to show others that TB is like any other curable disease" (16%) and "they don't drink or smoke while on treatment" (15%). As first main reason why TB patients stop taking their treatment before they are cured, 54% of the respondents feel this is caused by "patients feel better and think they are cured", followed by "they are afraid people will talk badly about them when they go to the clinic to collect their pills" (28%). As the second main reason, respondents believe this is due to "they forget to take their medicine because they drink and smoke" (41%), followed by "they are irresponsible and cannot be bothered to take their medicine" (24%).

The perceptions regarding TB treatment seeking behaviors are presented in Table 4. As most important reason why some people delay going to the clinic, 63% of respondents believe that is because "they are afraid they will be told they are HIV positive", followed by "they are afraid that people will talk about their visit to the clinic" (12%). The locations where respondents think TB patients prefer to take their daily treatment are the TB hospital (39%) and the clinic (33%).

Regression analyses were performed to test for different knowledge scores and different attitudes and preferences toward people with TB, TB treatment adherence, case finding and TB treatment types among men and women, young and old, lower and higher educated. We found very few differences in outcomes and do not pres-

Table 3. Perceptions toward adherence

Adherence items		**Frequency**	**Percent**
Most important thing that helps TB patients stay on treatment for 6 months	They stick to the rules of treatment	323	31.8
	They want to show others that TB is like any other curable disease	159	15.6
	They don't drink or smoke while on treatment	147	14.5
	They want to be cured so they can get on with their lives	124	12.2
	They have a sympathetic DOTS volunteer who helps them stay on treatment	87	8.6
	They have support from family and friends	72	7.1
	They have enough food to eat	43	4.2
	They don't listen when people gossip about them	38	3.7
	They are strong willed	23	2.3
	Total	**1016**	**100**
First main reason TB patients stop taking their treatment before they are cured	They feel better and think they are cured	547	53.8
	They are afraid people will talk badly about them when they go to the clinic to collect their pills	289	28.4
	They do not want to be seen standing in the same queue as people collecting Antiretroviral drugs (ARVs)	94	9.2
	They forget to take their medicine because they drink and smoke	64	6.3
	They are irresponsible and cannot be bothered to take their medicine	21	2.1
	Their families and friends are not supportive	2	0.2
	Total	**1017**	**100**
Second main reason TB patients stop taking their treatment before they are cured	They forget to take their medicine because they drink and smoke	414	41.2
	They are irresponsible and cannot be bothered to take their medicine	244	24.3
	They do not want to be seen standing in the same queue as people collecting ARVs	128	12.7
	Their families and friends are not supportive	122	12.1
	They are afraid people will talk badly about them when they go to the clinic to collect their pills	75	7.5
	They feel better and think they are cured	22	2.2
	Total	**1005**	**100**

ent these (tabulated information is available on request). Regression analysis of the TB knowledge test showed no significant differences in age, gender and education. Logistic regression analysis of age, gender and education with attitudes toward people with TB, perceptions regarding first and second main reason why TB patients stop taking their treatment before they are cured and beliefs of the population on TB treatment preferences of TB patients also showed no significant differences between respondents. Logistic regression analyses of perception of the lay public regarding the most important thing that helps TB patients stay on treatment for 6 months, showed that men and women slightly disagree on the item that "they stick to the rules of treatment" is the most important reason for TB patients to stay on treatment (mentioned less by women). Younger people more often mention "they have support from family

Table 4. Perceptions toward treatment

TB treatment items		**Frequency**	**Percent**
Most important reason why some people delay going to the clinic	They are afraid they will be told they are HIV positive	640	63.0
	They are afraid that people will talk about their visit to the clinic	124	12.2
	They don't want to cough into the specimen bottle	64	6.3
	They are afraid that TB treatment will interfere with their social lives	64	6.3
	There are long queues at the clinics	40	3.9
	They are afraid they will lose their job / income	35	3.4
	They are afraid that TB treatment will be unpleasant and difficult	29	2.9
	They first wish to consult a traditional healer	20	2.0
	Total	**1016**	**100**
Location where most TB patients prefer to take their daily treatment	In the TB hospital where the nurses care of them	400	39.4
	In the clinic - they visit the clinic every morning to take their medicine	339	33.4
	At home and a DOTS volunteer visits them every day to bring the medicine	167	16.5
	At home / work and a family collects their medicine for them	108	10.7
	Total	**1014**	**100**

and friends" than do the older respondents. As to the most important reason why some people delay going to the clinic, the higher educated more often mention "there are long queues at the clinics" and slightly more women mention "they are afraid people will talk about their visit to the clinic".

Discussion

Regression analyses revealed similar attitudes and perceptions for the young and the old, for men and women, and for the lower and higher educated -- suggesting that people in this population share the same attitudes and perceptions. Our findings are likely to reflect the actual situation of TB patients in this population. The more so because most respondents know people with TB in their immediate environment.

TB knowledge can be considered fairly good among this community. The perception on "respondent believes it is mainly irresponsible people who do not take their treatment who are to blame for spreading TB" did not imply stigma only. Since some level of the treatment failure is due to irresponsible people this is also an indicator of knowledge.

However, respondents mainly considered TB to be an African disease and were under the misconception that all TB patients will also develop HIV. This perceived link can be explained by the fact that TB is main cause of death among the estimated 5.5 million South Africans living with HIV/AIDS (>10% of the country's population). Indeed, the co-infection rate approaches 73% in TB patients among all age groups.[2] Future publicly released information should emphasize that having active TB disease in an individual who is also infected with HIV leads to a worsening of the HIV illness, but having TB does not lead to becoming infected with HIV. Scores on the other items were fairly good, which contradicts prior findings suggesting that people in developing countries lack TB knowledge.[8,16,19,20,25-27] The population in the current study appears to be better informed in this regard.

The results are suggestive of a high level of stigmatization: a full 95% of respondents believe people with TB tend to hide their TB status because they are afraid of what others may say. People think that irresponsible individuals who do not take their treatment are mainly to blame for spreading TB. Besides blaming those individuals, they accuse them of hiding their TB status for fear of what others might say. They also think that people who acquire TB through drinking and smoking are getting what they deserve and that TB patients are less respected within the community. While research shows that the increased TB incidence and prevalence during the last decade is mainly due to population increase where TB is most prevalent, increase of HIV and increased poverty,[28] most people within this community believe it is mainly the irresponsible patients who do not take their treatment that are to blame for spreading TB. Also the finding that respondents believe people who drink and smoke "get what they deserve" indicates blame and potential stigmatization.

More than half of the respondents believe that TB patients interrupt treatment because they think they are cured. This finding is interesting and justifies the need for improved communication and mutual understanding between care providers and patients. Implementing of interventions aimed at improving communication and mutual understanding between care providers and patients into this matter by the national tuberculosis program would improve TB treatment outcomes nationally. The second most important perception of respondents as main reason for non-adherence (they are afraid people will talk bad about them when they go to the clinic) is suggestive of stigma within the community. The fact that respondents mention this in their top 2 of most important reasons for default from treatment shows that people within this community believe stigma to be a real problem for adherence to TB treatment.[7,8,29-33] This is in line with prior findings indicating that stigma plays a significant role in adherence. If the perceptions of the respondents represent the actual situation for TB patients in the Eastern Cape, stigma causes people to reject the diagnosis, leading to the infection of more people and potential drug resistance.

Furthermore, it is interesting that most respondents believe TB patients prefer active involvement by travelling to the hospital and clinics themselves, compared to having a family member or DOTS volunteer daily delivering the medicine at home.

The major limitation of our study is that we studied perception of the lay public only, not actual behavior. Since attitudes of the lay public play a central role in the patient's decision-making process it is important to gain insight into what actually influences an individual's decision to seek treatment and adherence to that treatment instead of looking at behavior only. However, after learning how these mechanisms work it is important to investigate whether changes in attitudes and perceptions also lead to actual behavior change. Therefore, it would be interesting to conduct a follow-up study amongst TB suspects, adherent and non-adherent TB patients to document actual behavior.

The reason why the majority of respondents were women and older people were overrepresented in comparison to general population figures could be related to the inherent limitation of the conventional Kish grid.[22] Use of this instrument often leads to a higher proportion of women and older people. Regression analyses of age, gender and education show that there are very few significant differences in knowledge, attitudes and perception among these subgroups. Therefore, the higher proportion of women and older people does not appear to have affected our study findings.

Conclusions

The results of this study show that while TB "lay experts" knowledge seems fairly good, their perceptions suggest that stigma may play a significant role in case finding and case holding. Findings from this study are important in improving the societal supports to TB patients. It would seem, therefore, that community education should focus on improving attitudes and perceptions, thus potentially reducing stigma. It requires a patient centered approach, which starts with interventions targeting the intrapersonal level (empowerment, self help, advocacy and support group) to empower TB patients. The next step is involvement of TB patients in the development of stigma reduction programs at other levels.[18] TB patients' experiences are helpful at organizational/institutional and community level in developing training programs and new interventions that should contribute to stigma reduction rather than unintentionally enhance stigmatization. A shift of power relation and an active role of TB patients in this process could lead to more patient centered programs, empowerment of TB patients and stigma reduction. Furthermore, studying the actual situation in TB suspects and patients is necessary to confirm our study findings.

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JM Cramm & AP Nieboer.

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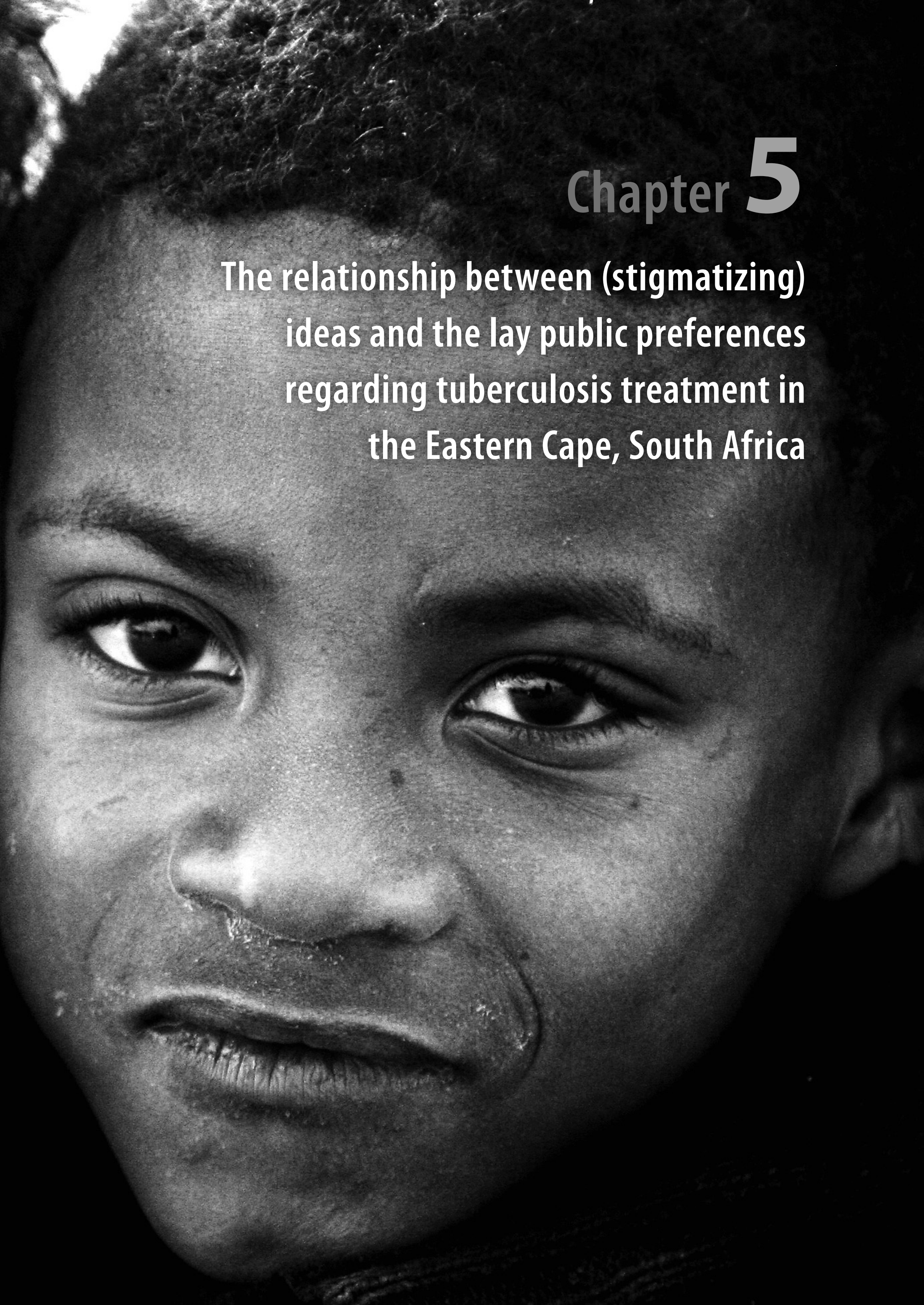
Chapter 5

The relationship between (stigmatizing) ideas and the lay public preferences regarding tuberculosis treatment in the Eastern Cape, South Africa



Abstract

Tuberculosis (TB) and human immune virus/acquired immune deficiency syndrome (HIV/AIDS) stigmas affect public attitudes toward TB treatment and policy. This study examined attitudes toward TB treatment in the Eastern Cape of South Africa, where TB is endemic. Belief systems, which frame attitudes toward TB and affect access and treatment outcomes, were examined in relation to stigmatization. Data were gathered through a survey administered to respondents from 1,020 households in Grahamstown. The survey measured stigmatization surrounding TB and HIV/AIDS, and determined perceptions of respondents whether TB patients should queue with other chronically ill patients. Respondents selected support and treatment options they felt would benefit TB patients. Statistical analysis identified the prevalence of TB stigma, and sought associations between treatment preferences and belief systems. Pearson correlation and logistic regression analyses explored associations between stigmatizing ideas, views regarding TB patients in the chronic illness queue, and attitudes toward support and treatment. Respondents with TB stigmatizing ideas held positive attitudes toward volunteer support, special TB queues, and treatment at clinics; they held negative attitudes toward temporary disability grants, provision of information at work or school, and treatment at the TB hospital. Respondents who felt it beneficial for TB patients to queue with other chronically ill patients conversely held positive attitudes toward provision of porridge and disability grants, and treatment at the TB hospital; they held negative attitudes toward volunteer support, special TB queues, information provision at work or school, and treatment at clinics. These results predict two belief systems, one characterized by TB stigma, the other by the view that TB patients should queue with other chronically ill patients. They are related to visibility factors that expose patients to stigmatization. These belief systems complicate treatment outcomes, and suggest that complex behaviors must be taken into account when designing health policy.

Introduction

Tuberculosis (TB) is a major cause of illness and death worldwide, particularly in low- and middle-income countries where it is fueled by human immune virus/acquired immune deficiency syndrome (HIV/AIDS). Tuberculosis is the most common secondary infection for the approximately 5.5 million South Africans living with HIV/AIDS. Among the national population of approximately 48 million, about 700 per 100,000 inhabitants are infected with TB, classifying it as a serious epidemic.[1] In particular, TB is endemic in the Eastern Cape, a South African province characterized by high levels of poverty and unemployment. The TB cure rates in South Africa (74%) and the Eastern Cape (41%) are well below the 85% rate recommended by the World Health Organization.[1,2] In response to the 9.2 million new cases and 1.7 million TB-related deaths worldwide in 2006, the WHO launched its "Stop TB" strategy.[1] This strategy builds on the successes of the Directly Observed Treatment Short Course (DOTS), earlier launched in 1995. Since then, more than 22 million patients have been treated under DOTS-based services.[3] Though DOTS aims to improve case finding and case holding, real life results seem to be lagging behind.[1,2,4]

Medication adherence is problematic and an estimated 20% to 50% of patients do not take their medications as prescribed and are said to be non-adherent or non-compliant with therapy.[5] Non-adherence with TB treatment poses a significant public health threat, as it is associated with increases in transmission rates, morbidity, and costs to TB control programs.[6] Moreover, non-adherence leads to persistence and resurgence of TB and is regarded as the chief cause of relapse and drug resistance.[7] While drug-resistant TB is generally treatable, it requires extensive chemotherapy of up to two years that is more toxic to patients and prohibitively expensive.[8] Non-adherence is known to be associated with higher perceived stigma and disease visibility complicates treatment adherence.[8-10]

Just as AIDS-related stigmas have shaped public attitudes toward HIV/AIDS treatments and policies,[11,12] TB-related stigmas have also negatively influenced attitudes toward TB treatment.[6,8,9,13-16] Stigmatization towards TB sufferers has an interesting history: they used to be shunned socially, but this stigma was largely eliminated when a cure for TB became available. However, TB-associated stigmas emerged again when TB became a marker for HIV/AIDS.[10,17] The effect became even stronger when the combination of TB and HIV/AIDS treatments was designated the recommended strategy.[3,18]

Disease-related stigmas not only pose negative consequences for the infected individuals and their households, but also affect public attitudes toward prevention, service provision, and health-related policies. A comparison of the stigmas associated with HIV/AIDS, severe acute respiratory syndrome (SARS), and TB in Hong

Kong indicated that participants with less stigmatizing views had significantly more favorable attitudes toward disease-related governmental policies.[14] Availability of a treatment does not necessarily mean that individuals will seek it or adhere to it; behavior is much more complex and is influenced by salient beliefs. For example, the Botswanan government recently began offering free antiretroviral (ARV) treatment to all citizens with AIDS. Although the program was widely publicized and treatment was easily accessible, only 15% of citizens with AIDS participated.[19] Thus, TB- and HIV/AIDS-associated stigmas influence both attitudes and treatment behavior and assumptions that disease-related stigmas will decrease as soon as treatment is provided should not be automatically transferred to expectations about the effect of a particular intervention on stigmatization. Instead, the increases in HIV- and TB-related stigmas, despite antiretroviral medications and TB treatment programs, highlight that renewed efforts to reduce stigma are imperative. Such efforts include interventions that recast TB and HIV as chronic manageable conditions.[20]

Research indicates that public attitudes and health-care policy responses are strongly influenced by perceptions of illness and attitudes and belief systems influence how individuals define and act upon symptoms and life crises.[21]

It remains unclear how HIV/AIDS and TB stigmas affect public attitudes toward TB treatment, and consequently affect access and treatment outcomes. Since the Eastern Cape is characterized as a province with high incidence, prevalence and with one of the worst cure rates of South Africa, people living in this area can be considered experts when it comes to dealing with TB. Therefore, we investigated perceptions among an Eastern Cape population. In this study, we thus sought to identify the pervasiveness of these stigmas and explore how these belief systems work. Furthermore, purpose of this study is to investigate whether these views are related to visibility factors that expose patients to stigmatization via answering the following question: does the idea that TB treatment should be integrated with chronic illnesses lead to different TB treatment preferences compared to having stigmatising ideas? Increased understanding of the relationship between (stigmatizing) ideas and lay public TB treatment preferences is helpful for facilitating TB program design and improving treatment outcomes.

Methods

The Eastern Cape is a South African province characterized by high levels of poverty and unemployment. TB is endemic here.[10] Data from a survey among 1,020 Grahamstown East/Rhini households, conducted in November 2007, were used for this study. Almost three quarters of respondents (73%) were women. The median age of respondents was 38 years. Just over half were single (52%), a third were married

(33%) and the others widowed (9%) or separated/divorced (6%). Forty percent had completed some secondary education and 18% had matriculated. Approximately 7% had received post-matriculation education and training. Only 8% had no formal schooling.

Ethical approval

This study was approved by the Rhodes University Ethical Standards Committee. All personal identifiers have been removed or disguised such that the person(s) described are not identifiable.

Subjects and sampling design

An area-stratified sampling design was applied. Households in the 23 neighborhoods of Rhini, a suburb of Grahamstown, South Africa, were randomly selected in proportion to the total number of households in each neighborhood. In each neighborhood, a starting point was chosen at random. Moving systematically through the neighborhood, every tenth household was included in the sample. All households in all areas of Rhini thus had an equal probability of survey inclusion.

Eligible respondents were those who were over 17 years of age and had resided in Rhini for at least 6 months in the past year. One respondent per household was chosen using a Kish grid, to ensure that all eligible persons in the household had an equal probability of survey inclusion. When present, identified respondents were interviewed immediately if they consented to this. Alternatively, arrangements were made to conduct the interview later. When potential respondents were not present, up to four visits to the house were made. Eventually, an interview was obtained in 1,020 of the 1,042 households (97.9%). The 22 potential respondents that were missed could either still not be contacted upon the fourth visit to the house, or were too old, too ill to be interviewed or just unwilling.

Trained Development Research Africa and local interviewers conducted the interviews. Nearly all questions were closed-ended items for which a set of response options was supplied. A detailed description of the study population can be found in the Institute of Social and Economic Research, Research Report Series No. 14 & No. 15.[23,24]

Instruments

A brief nine-item scale to measure AIDS-related stigma has been developed and tested in several South African communities. The scale is internally consistent and reliable, with a Cronbach's alpha of 0.75.[13] One item exhibiting a low correlation with the total score that reduced the internal consistency of the scale was discarded for the purpose of this study. The resulting eight-item AIDS-related stigma scale (Cronbach's alpha of 0.77) was also used to assess the stigmatizing ideas of respondents regarding TB. Respondents could either agree or disagree on these eight items (Appendix). In addition, respondents were asked to agree or disagree with a statement on a visibility issue: would TB patients stay on treatment if they could queue together with high blood pressure patients?

In the Eastern Cape, TB treatment can be obtained at a TB hospital, clinic, or at home. In the case of home care, either a family member or a DOTS volunteer will daily provide the medicine. The survey asked respondents to state preferences on treatment location and mode of medicine home delivery.

Most surveys of lay public attitudes use a rating approach.[22] Within this approach, all items are equally important and therefore lack the prioritizing that would facilitate treatment decisions.[25] In this study, therefore, we opted for the more realistic priority setting with a ranking approach.[22,26]

A 2006 focus group identified five TB treatment support types available in the Rhini area.[10] TB patients can be paired with a DOTS volunteer to support them; porridge can be provided to ensure that medicines are not taken on an empty stomach; special queues or rooms are made available at some clinics to reduce waiting time for TB patients who collect medication themselves; TB patients are provided a

AIDS-related Stigma Scale

Please answer whether you agree or disagree with the following statements.		
People who have AIDS are dirty.	I agree	I disagree
People who have AIDS are cursed.	I agree	I disagree
People who have AIDS should be ashamed.	I agree	I disagree
People with AIDS must expect some restrictions on their freedom.	I agree	I disagree
A person with AIDS must have done something wrong and deserves to be punished.	I agree	I disagree
People who have AIDS should be isolated.	I agree	I disagree
I do not want to be friends with someone who has AIDS.	I agree	I disagree
People who have AIDS should not be allowed to work.	I agree	I disagree

TB-related Stigma Scale

Please answer whether you agree or disagree with the following statements.		
People who have TB are dirty.	I agree	I disagree
People who have TB are cursed.	I agree	I disagree
People who have TB should be ashamed.	I agree	I disagree
People with TB must expect some restrictions on their freedom.	I agree	I disagree
A person with TB must have done something wrong and deserves to be punished.	I agree	I disagree
People who have TB should be isolated.	I agree	I disagree
I do not want to be friends with someone who has TB.	I agree	I disagree
People who have TB should not be allowed to work.	I agree	I disagree

temporary disability grant, ensuring their financial independence while on treatment; and volunteers will inform TB patients' employers or schools that the disease is not infectious when it is being treated. The survey asked respondents to select up to two support types felt to be the most helpful to patients and their families.

Data analysis

The analysis consisted of four parts. We investigated perceptions among an Eastern Cape population and sought to identify the pervasiveness of these stigmas and explore how these belief systems work. To determine the level of stigmatizing ideas within this community and the notion that TB treatment should be integrated with chronic illnesses we first report descriptive analysis to characterized the prevalence of these beliefs. Secondly, to investigate the correlation between stigmatizing ideas within this community and the notion that TB treatment should be integrated with chronic illnesses and TB treatment preferences Pearson correlation analysis are explored. Thirdly, logistic regression analysis was performed to test whether stigmatizing ideas and the view of queuing TB patients together with other chronically ill patients led to different attitudes and preferences toward TB treatment and support types.

Finally, logistic regression analyses were performed to test whether differences in TB experience led to different attitudes and preferences toward TB treatment and treatment assistance types.

For correlational analyses, statistical r values and p values are reported. P values less than .05 were considered significant. For regression analyses, B, standard error (S. E.), t and odd ratio (OR) values are reported.

Results

The prevalence of stigmatizing ideas regarding HIV/AIDS in this community was higher (mean 0.93) than that of stigmatizing ideas surrounding TB (mean 0.52). Of the 1,020 respondents, 70% believed it would be beneficial to have TB patients queuing together with other chronically ill patients.

Table 1 shows Pearson correlations for stigmatizing ideas, the belief that TB patients would benefit from queuing with other chronically ill patients, and preferences regarding TB treatment and support. With regard to the latter, TB stigmatizing ideas were positively associated with support from DOTS volunteers and special queues for TB patients only. Negative relations were found between TB stigmatizing ideas, disability grants for TB patients, and provision of information to employer or school. HIV/AIDS stigmatizing ideas correlated positively with support from DOTS volunteers and negatively with disability grants. The view that TB patients should be queuing

Table 1. Correlational analyses between stigmatizing ideas and TB patients in the chronic illness queue with TB assistance and treatment preferences.

	Assistance Preferences										Treatment Preferences							
	DOTS volunteer		**Porridge**		**Special TB queue**		**Disability grant**		**Providing information at work or school**		**TB hospital**		**Clinic**		**Family member collecting medicine**		**DOTS volunteer collecting medicine**	
	r	*p*	*r*	*p*	*R*	*p*	*r*	*p*	*r*	*p*	*r*	*P*	*r*	*p*	*r*	*p*	*r*	*p*
TB stigma n = 1020	0.120	0.000	0.022	0.485	0.066	0.034	-0.157	0.000	-0.055	0.077	-0.096	0.002	0.132	0.000	0.008	0.797	-0.064	0.410
HIV/AIDS stigma n = 1020	0.091	0.004	-0.006	0.858	0.010	0.749	-0.065	0.038	-0.037	0.234	0.012	0.700	0.029	0.353	-0.005	0.877	-0.064	0.420
Queued with chronically ill n = 1017	-0.085	0.006	0.072	0.022	-0.048	0.126	0.124	0.000	-0.078	0.012	0.123	0.000	-0.071	0.023	-0.052	0.096	-0.030	0.333

with other chronically ill patients showed positive associations with providing porridge and giving disability grants. Negative associations were found with support from DOTS volunteers, assigning TB patients to a special queue and information provision to employer or school.

With regard to treatment preferences and TB stigmatizing ideas, a negative association was found with the TB hospital and a positive relation with the clinics. No significant association was found between HIV/AIDS stigmatizing ideas and treatment preferences. The view that TB patients should be in the same queue as patients with other chronic illnesses was positively associated with the TB hospital and negatively with the clinics (Table 1).

Logistic regression analysis examined whether stigmatizing ideas and/or the view that TB patients should be queuing with other chronically ill patients affected attitudes toward support and treatment preferences. Except that HIV stigma predicted no significant attitudes, results of this analysis were similar to those obtained with Pearson correlation analysis. TB stigmatizing ideas significantly predict a negative attitude toward disability grants for TB patients and information provision to employer or school, and a positive attitude toward DOTS volunteers and special queues for TB patients at the clinics. The view that TB patients would benefit from queuing with other chronically ill predicted a positive attitude toward providing porridge and disability grants. It predicted a negative attitude toward support from DOTS volunteers and information provision to employer or school (Table 2). Lay public attitudes toward treatment preferences indicated that TB stigmatizing ideas predicted a positive attitude toward treatment at clinics and a negative attitude toward treatment at the TB hospital. The view that TB patients should be queuing with the chronically ill predicted a positive attitude toward TB treatment at the hospital and a negative attitude toward treatment at the clinics (Table 3). Logistic regression analyses were performed to test for different attitudes and preferences toward TB treatment and treatment assistance types between household with and without TB experience. We found no significant differences in outcomes and therefore do not present these (tabulated information is available on request).

Discussion

We investigated lay perceptions and tried to identify the pervasiveness of stigmas and explored how attitudes and belief systems affect rates at which medical treatment is sought and complied with. As this area is characterized as a province with high TB incidence, prevalence and with one of the worst cure rates of South Africa,[1,2] people living in this area can be considered experts when it comes to dealing with TB.

Table 2. Logistic regression analyses of TB treatment assistance preferences and TB stigmatizing ideas, HIV/AIDS stigmatizing ideas and the view that TB patients should be queued with other chronically ill patients.

	Assigning a DOTS volunteer to support them while on treatment				**Providing porridge so TB patients do not take their medicine on an empty stomach**				**Assigning special queues or a special room at clinics**				**Giving TB patients a temporary disability grant so they can be financially independent while on treatment**				**Contacting people at work or school to inform them that the patient is not infectious because he/she is on treatment**			
	B	**S. E.**	**t**	**OR**	**B**	**S. E.**	**t**	**OR**	**B**	**S. E.**	**t**	**OR**	**B**	**S. E.**	**t**	**OR**	**B**	**S. E.**	**t**	**OR**
* TB stigma	0.207‡	0.072	2.875	1.230	0.073	0.074	0.986	1.075	0.156†	0.076	2.053	1.169	-0.346‡	0.080	-0.433	0.708	-0.160*	0.100	-1.600	0.852
* HIV/AIDS Stigma	0.115	0.071	1.620	1.122	-0.025	0.073	-0.342	0.975	-0.041	0.080	-0.513	0.960	-0.018	0.073	-0.247	0.982	-0.065	0.092	-0.707	0.937
TB patients queued with chronically ill	-0.280†	0.131	-2.137	0.756	0.366‡	0.138	2.652	1.442	-0.135	0.147	-0.198	0.873	0.511‡	0.135	3.785	1.667	-0.342†	0.161	-2.124	0.710
Constant	-0.052	0.195	-0.267	0.950	0.150	0.203	0.739	1.161	-1.011‡	0.218	-4.638	0.364	-0.678‡	0.203	-3.340	0.508	-0.880‡	0.234	-3.761	0.415
Model χ^2	$\chi^2 = 22.443^{\ddagger}$				$\chi^2 = 8.062^{\dagger}$				$\chi^2 = 5.295$				$\chi^2 = 42.181^{\ddagger}$				$\chi^2 = 8.475^{\dagger}$			
-2 log likelihood	1381,757				1308.976				1126.231				1361.622				984.000			
Nagelkerke R^2	0.029				0.011				0.008				0.054				0.013			

Notes: $^{\dagger}p < 0.05$; $^{\ddagger}p < 0.01$.

Not stigmatizing ideas = 0; stigmatizing ideas = 1.

It does not help to put TB patients in a queue with other chronically ill patients = 0; it does help to put TB patients in a queue with other chronically ill patients = 1.

Table 3. Logistic regression analyses of TB treatment preferences and TB stigmatizing ideas, HIV/AIDS stigmatizing ideas and the view that TB patients should be queued up with other chronically ill patients.

	TB hospital				**Clinic**				**Family member collecting medicine**				**DOTS volunteer collecting medicine**			
	B	**S. E.**	**t**	**OR**	**B**	**S. E.**	**t**	**OR**	**B**	**S. E.**	**t**	**OR**	**B**	**S. E.**	**t**	**OR**
* TB stigma	$-0.244^{\ddagger}$	0.078	-3.218	0.784	$0.282^{\ddagger}$	0.072	3.917	1.326	0.029	0.110	2.053	1.030	-0.174	0.110	-1.582	0.841
* HIV/AIDS stigma	0.127	0.072	1.764	1.122	-0.051	0.074	-0.689	0.975	-0.035	0.113	-1.310	0.966	-0.152	0.101	-1.505	0.859
TB patients queued with chronically ill	$0.495^{\ddagger}$	0.136	3.640	1.135	$-0.285^{\dagger}$	0.138	-2.065	0.950	-0.259	0.197	-1.315	0.772	-0.140	0.166	-0.843	0.869
Constant	$-1.080^{\ddagger}$	0.207	-5.217	0.339	$-0.442^{\dagger}$	0.203	-2.177	0.643	$-1.789^{\ddagger}$	0.288	-6.212	0.167	$-1.240^{\ddagger}$	0.247	-5.020	0.289
Model χ^2	$\chi^2 = 26.003^{\ddagger}$				$\chi^2 = 21.687^{\ddagger}$				$\chi^2 = 1.817$				$\chi^2 = 7.646^{\dagger}$			
-2 log likelihood	1340.191				1275.412				687.333				901.778			
Nagelkerke R^2	0.034				0.029				0.004				0.013			

Notes: $^{\dagger}p < 0.05$; $^{\ddagger}p < 0.01$.

Not stigmatizing ideas = 0; stigmatizing ideas = 1.

It does not help to put TB patients in a queue with other chronically ill patients = 0; it does help to put TB patients in a queue with other chronically ill patients = 1.

Therefore, our study results are relevant to improve treatment outcomes. The most salient aspect of this study is that our study findings predict two belief systems, one characterized by TB stigma, the other by the view that TB patients should queue with other chronically ill patients. Both belief systems clearly led to opposing TB treatment attitudes and preferences.

In this study HIV stigmatizing ideas predicted no significant attitudes above TB stigmatizing ideas, probably because these stigmas are highly related to each other. Other research also shows how visible signs of TB trigger HIV stigma and even claim that a new disease stigma has unfolded, namely the TB-HIV stigma.[17]

TB stigmatizing ideas were associated with positive attitudes toward treatment at the clinic and negative attitudes toward treatment at the hospital, the converse was associated with the preference for lining TB patients with other chronically ill individuals.

Theoretically, all TB patients are assigned a treatment supervisor. This supervisor's role at the hospital and clinics is minimal, however, compared to that of family members or volunteers who collects medicine. It would seem that the belief system prefers the less supervised treatment types requiring active involvement of TB patients. TB patients who actively take responsibility by collecting medication personally may fall prey to stigma by being identified as TB- or HIV/AIDS-infected, especially when TB and HIV/AIDS treatments are combined. Home visits from a DOTS volunteer also bring the disease to light in the neighborhood and consequently may lead to stigma. These belief systems lead to other attitudes toward TB treatment. Our results show that a belief system incorporating TB stigmatizing ideas or the view that TB patients should queue with other chronically ill patients indeed led to different attitudes toward TB treatment. There seems to be no single solution, therefore, and perhaps it would be better to differentiate programs by belief systems. Combined TB and HIV/AIDS treatment presents another problem. Some belief systems of the lay public (e.g., views regarding combined or separate TB queues) might lead to negative attitudes toward combined TB and HIV/AIDS treatment. This will result in the undesired behavior of not seeking treatment.[27] Such belief systems could explain the Botswanan example, where only 15% of citizens with AIDS participated in the free ARV treatment program.[19]

For other assistance types, the belief systems predicted contrasting attitudes. While TB stigmatizing ideas led to a positive attitude toward assigning DOTS volunteers, the view that TB patients should queue with the chronically ill predicted a negative attitude toward DOTS volunteers. Only the view that TB patients should queue with the chronically ill predicted a positive attitude toward providing porridge. TB stigmatizing ideas led to a positive attitude only regarding special queues for TB patients. Mixed results are shown for predictors of attitudes toward disability grants. TB stigmatizing ideas led to a negative attitude toward disability grants, while the view that TB patients should queue with the chronically ill predicted a positive attitude.

The assistance options for TB patients on treatment vary with widely differing social and financial dimensions. Other factors, such as the disease visibility in many treatment types, also seem to influence attitudes. In the present study, different belief systems primarily led to different attitudes on helpful assistance types for TB patients on treatment. There is unanimity of opinion on only one item; negative attitudes toward information provision at work or school were associated with both TB stigmatizing ideas and the view that TB patients should queue with the chronically ill. The belief system that TB patients benefit from being included with the chronically ill led to positive attitudes toward financially supporting assistance types. Porridge provision is a less obvious form of financial assistance than disability grants, but it alleviates a burden for both the TB patient and the family. Food for the family is an immediate benefit and saves money normally spent on food, which can be used for other purposes. People participating in this belief system preferred financial assistance through porridge or a grant to more controlled assistance types such as DOTS volunteers, whose home visits may identify an individual as a TB or possibly an HIV/AIDS patient. This may also be the main reason for preferring that TB patients be in the same line as the chronically ill. Chronic diseases are usually not associated with stigma; the visibility of seeking treatment for a chronic illness therefore does not lead to negative attitudes among respondents with this belief system.

The TB stigmatizing belief system also led to contrasting attitudes toward assistance for TB patients on treatment. While those who favor combined queues for TB and other chronically ill patients found financial assistance types helpful, TB stigmatizing ideas led to negative attitudes toward disability grants. Blame is a component of stigma, and people with stigmatizing ideas might blame TB patients for their illness and therefore think they do not deserve financial support. A positive attitude was found between TB stigmatizing ideas and the controlled observation of treatment by a DOTS volunteer. This belief system led to preferences for visible-stigma-sensitive assistance types and negative attitudes toward financial assistance. Visibility of TB patients and exposure to stigma were not important factors for people with TB stigmatizing ideas. They preferred separate queues for TB patients and direct observation of treatment by a DOTS volunteer. Results from a recent evaluation on effectiveness on the TB treatment in the priority facilities of four other TB crises areas in South Africa show that the fewer the number of patients allocated to a DOTS volunteer the higher the cure rates.[28] The same belief systems might apply for these communities. They are related to visibility factors that expose patients to stigmatization. Visits from a DOTS volunteer leads to visible exposure within the neighbourhood. These belief systems could explain the lower cure rates of the DOTS volunteer and suggest that complex behaviors must be taken into account when designing health policy.

Given the cross-sectional nature of the results, the interpretation of study results is restricted. Future research with a longitudinal approach would be valuable. A major limitation of the study is that this research investigated perceptions of the lay public only, actual behavior when faced with TB in family or friend might be different. However, given the nature of our study with random selection and inclusion of every tenth household which led to equal probability of survey inclusion of lay perceptions within all households in all areas within this community and the fact that households with and without TB experience share the same views indicates that our study findings might represent the actual situation. Since attitudes of the lay public play a central role in the patient's decision-making process it would be interesting to conduct a follow-up study to gain insight into whether and how disease stigma's actually influences an individual's attitudes and preferences toward TB treatment and treatment assistance types.

Conclusions

The two belief systems are associated with opposing attitudes toward assistance for TB patients on treatment. This in its turn poses a significant public health threat on account of higher transmission rates, morbidity, and costs to TB control programs.[6] Moreover, non-adherence leads to persistence and resurgence of TB and is regarded as the chief cause of relapse and drug-resistant or multi-drug resistant strains.[3] Although combination of TB and HIV/AIDS treatments is promoted as the most cost-effective strategy,[18] some groups would still be overlooked and that this may be more generally applicable to other populations. Further research that examines whether treatment outcomes are improved by different organization of access to treatment (e.g., separate queues for TB patients, queuing TB patients with other chronically ill patients, combining TB and HIV/AIDS patients) would provide additional guidance for the development of these strategies. The contribution of this study is also of interest to the HIV/AIDS field and other stigmatized diseases. Visibility factors and disease markers related to the organization and delivery of treatment are also likely to affect health seeking behavior and some groups may seek treatment at an earlier stage if it were differently organized. Solutions are not easy and clear-cut, especially when considering highly stigma-sensitive diseases associated with complex behaviors. Various strategies are probably necessary to improve access and adherence numbers and, thereby, treatment outcomes.

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JM Cramm, J van Exel, V Møller, HJM Finkenflügel

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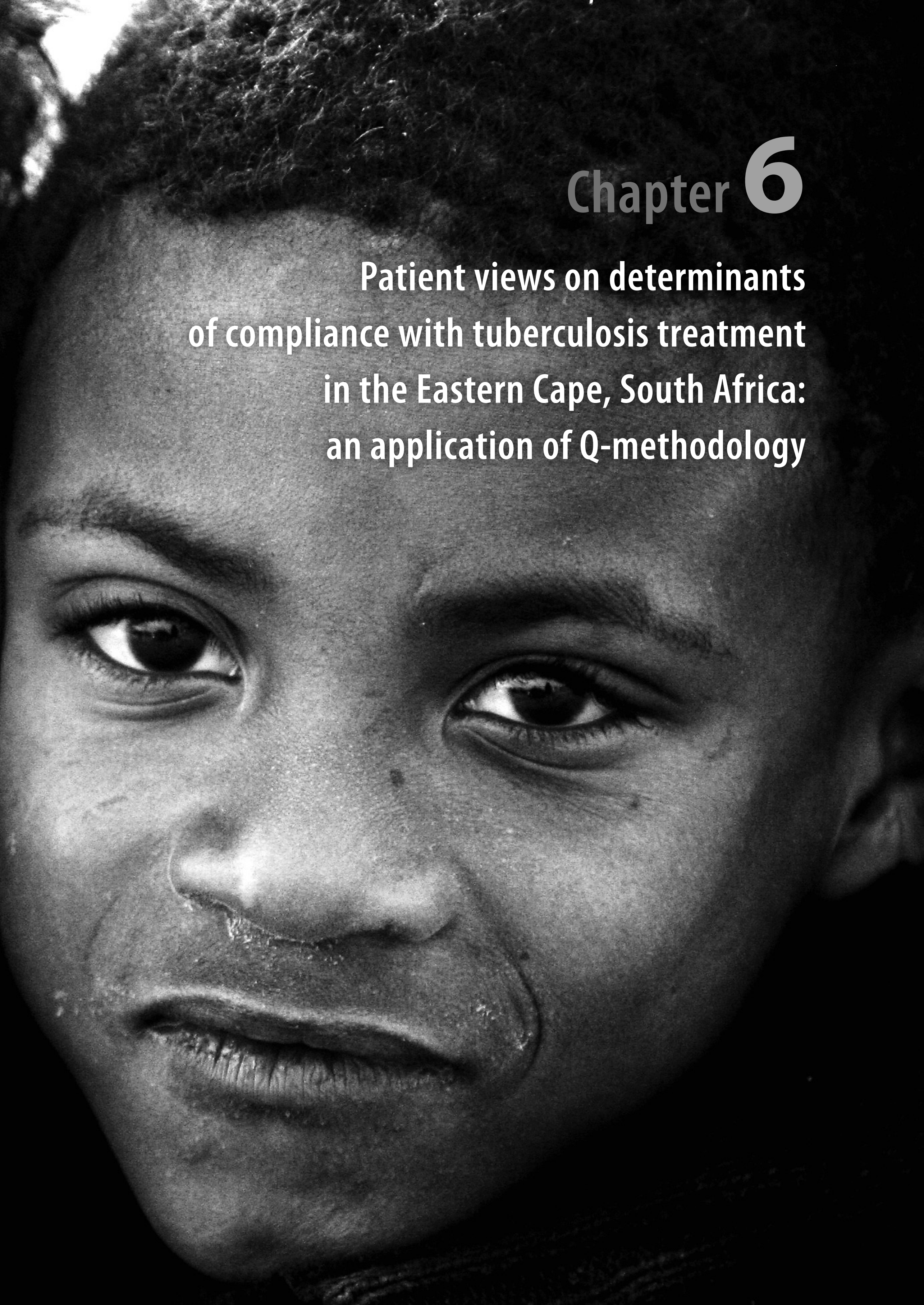

Chapter 6

Patient views on determinants of compliance with tuberculosis treatment in the Eastern Cape, South Africa: an application of Q-methodology

Abstract

Background Tuberculosis (TB) constitutes one quarter of all avoidable deaths in developing countries. In the Eastern Cape, South Africa, TB is a public health problem of epidemic proportion. Poor compliance and frequent interruption to treatment are associated with increased transmission rates, morbidity, and costs to TB control programs. This study explored determinants of (non-)compliance from the patients' perspective.

Methods Semi-structured interviews were conducted with patients (33 treatment compliers and 34 treatment non-compliers) and 14 community health workers from local community clinics and the hospital in the township of Grahamstown, Eastern Cape, South Africa. Q-methodology was used. Patients rank ordered 32 opinion statements describing determinants of treatment compliance from the TB adherence model. By-person factor analysis was used to explore patterns in the rankings of statements by compliers and non-compliers. These patterns were interpreted and described as patient views on determinants of compliance with treatment. Patients and community health workers selected the top five determinants of compliance and non-compliance.

Results Compliers believed that completing treatment would cure them of TB. Economic prospects were crucial for compliance. Compliers felt that the support of the government disability grant helped with compliance. Non-compliers believed that stigmatization had the greatest impact on non-compliance, together with the burden of disease, the arrangements involved with receiving treatment, restrictions accompanying treatment, and the association of TB with HIV/AIDS infection.

Conclusion Stigmatization makes TB a 'social disease'. Individual motivation and self-efficacy appear to have a considerable effect on compliance, but, for non-compliers, the general lack of job prospects and being able to provide for themselves or their family also makes TB very much an 'economic disease'.

Introduction

According to the WHO, tuberculosis (TB) is the most important resurgent disease worldwide, with the highest morbidity and mortality rates of any single pathogen.[1] Despite the availability of potent chemotherapeutic agents, about 2 million people in developing countries die from this curable disease annually. This constitutes one quarter of all avoidable deaths in these countries.[2] In South Africa generally and the Eastern Cape in particular, TB is a health problem of epidemic proportion.[3] While according to the WHO, the mortality rate of new sputum smear-positive cases should be less than 5%, South Africa reported a mortality rate of 7%,[2] mainly as a consequence of poor compliance with, and frequent interruption of, treatment.[4]

Non-compliance with TB treatment poses a significant public health threat, as it is associated with increases in transmission rates, morbidity, and costs to TB control programs.[5] Moreover, non-compliance leads to persistence and resurgence of TB and is regarded as the chief cause of relapse and drug resistance.[6] While drug-resistant TB is generally treatable, it requires extensive use, for up to 2 years, of chemotherapy that is toxic to patients and prohibitively expensive.[1]

In the Eastern Cape, people with TB are treated with 6-months' multiple drug therapy, in accordance with the Directly Observed Treatment, Short-course (DOTS) control strategy. DOTS has been recommended by the WHO since 1996, and aims at improving case finding and case holding (i.e. identifying patients and monitoring their treatment) by integrating TB control into primary healthcare. Compliance with treatment is supposed to improve as a result of constant and direct observation of TB patients' drug intake by a community health worker. Although DOTS is potentially one of the most cost-effective health interventions available for TB control,[7] real-life results lag behind.[8]

The greatest problem facing TB control programs in the Eastern Cape is ensuring that patients comply with and complete their 6-month treatment. From the perspectives of public health promotion, (cost) effectiveness of healthcare provision, and individual and social welfare, it is therefore important to gain insight into patient-level determinants of compliance with TB treatment. Here we present the results of a study investigating determinants of compliance with TB treatment from the patients' perspective, conducted among people with TB in the Eastern Cape, South Africa.

Methods

Compliers' and non-compliers' views on determinants of compliance with TB treatment were explored using Q-methodology, a method that combines characteristics of qualitative and quantitative methods and provides a scientific foundation for investigating subjectivity (e.g. peoples' attitudes, preferences, and opinions). Q-methodology is a fairly novel method in the field of health services research, but has been well established in other fields in the past 70 years;[9-13] a number of studies using Q-methodology were published in the field of health more recently.[14-20]

The aim of Q-methodology is to access the principal views existing on a certain topic. Typically, participants are presented with a sample of opinion statements about the topic and are asked to rank order these statements according to importance or agreement from their individual perspective. By ordering them, respondents give their subjective meaning to the sample of statements and reveal their subjective viewpoint.[10,11] Stephenson[9] presented Q-methodology as an inversion of conventional by-item factor analysis, in the sense that Q correlates individuals instead of items (i.e. by-person factor analysis). Correlation between individual rankings of statements indicates similar viewpoints on the topic; if significant clusters of correlations exist, they could be identified through factor analysis and described as common viewpoints, and respondents could be mapped to these viewpoints.

Q-methodology can thus be used to describe a population of viewpoints, but not a population of people.[16] Because the purpose is to reveal the principal viewpoints and not the proportion of any population that adheres to these viewpoints, a small sample of respondents is sufficient.[15,16]

The study was conducted in three steps: development of the statement set, administration of the interviews, and analysis. These steps are described in the following sections.

Development of the Statement Set

The research instrument was developed as a set of opinion statements representative of the variety of issues associated with (non-)compliance with TB treatment in developing countries. Consultation of recent literature showed that the main determinants of (non-)compliance included the following: (i) lack of information and awareness of the disease and its treatment; (ii) patients' perceptions of the disease and its treatment; (iii) social stigma; (iv) social support; (v) access and costs (financial and non-financial) of treatment; (vi) alternative healthcare providers; and (vii) the patient-care provider relationship.[8,21-37]

The TB Compliance Model[21] (figure 1) was used to structure the statement set. According to this theoretical framework for examining compliance behavior, treatment compliance is directly determined by health beliefs, and support mechanisms and barriers, and indirectly determined by socioeconomic and demographic factors.[21,37] The health beliefs are influenced by enabling factors, predisposing factors, and internal (e.g. symptoms and health status) and external (e.g. empathy of the staff) reinforcing

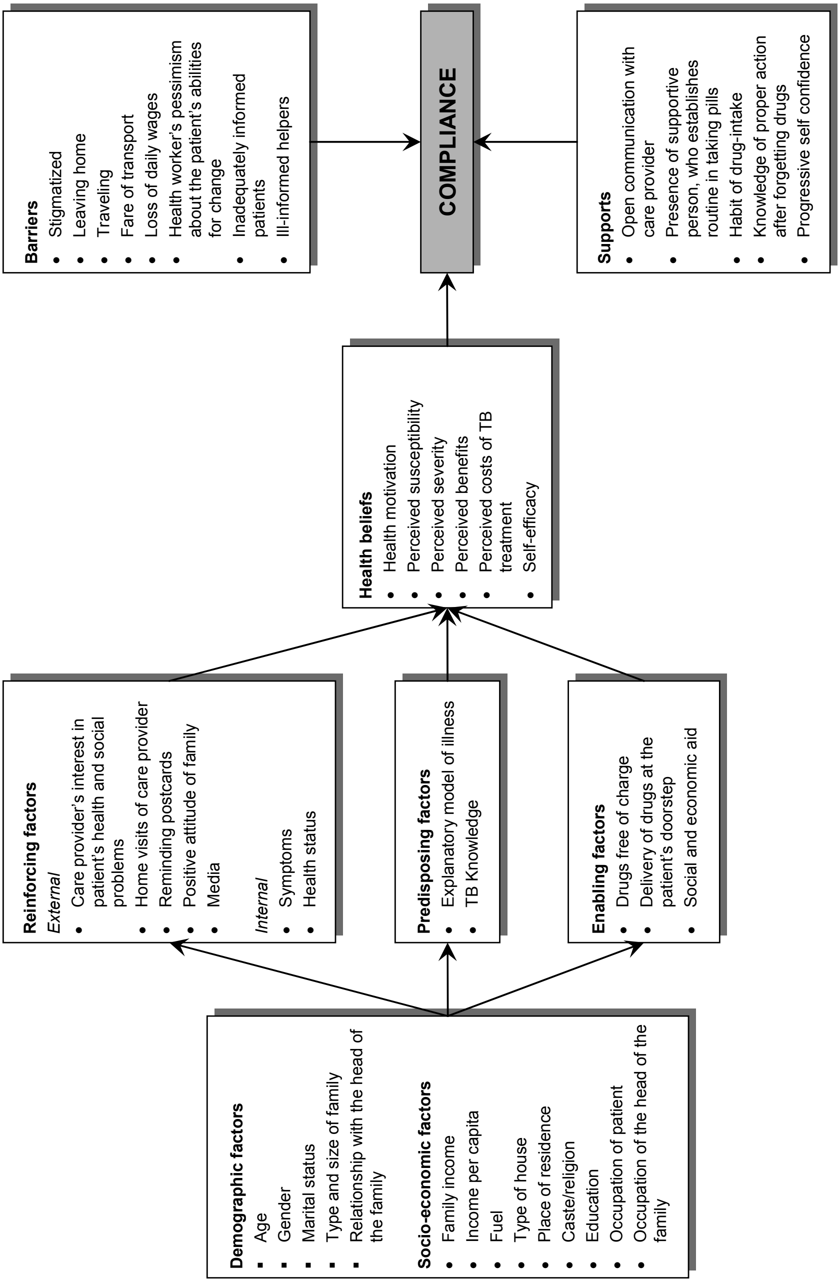

Figure 1. TB Compliance Model

factors, which in turn are associated with personal and environmental characteristics of the TB patient. As the statement set should consist of self-referent statements (i.e. opinions, not facts), it was restricted to the external reinforcing factors, enabling factors, health beliefs, barriers, and supports. Relevant factual data, such as personal and environmental characteristics, were collected at the end of the interview.

Together with local experts from Rhodes University of Grahamstown (who had previously conducted focus groups with TB patients on the subject of compliance with treatment), the items in the TB Compliance Model were examined for their applicability to the actual situation in the Eastern Cape. Based on transcripts from these focus groups and the experience of the local experts with the subject and the context, a number of adjustments were made. Reminder postcards are not used in the Eastern Cape so this item was excluded from the final statement set. For 'social and economic aid', two separate statements were used: one addressing the support and help from support groups (statement 8; table I), the other referring to the support of a government disability grant that TB patients receive for a period of 6 months (the duration of treatment; statement 9). In addition, there is a strong association between TB and the rapid growth of the HIV/AIDS epidemic in South Africa. Although TB is a leading killer among HIV-infected people with weakened immune systems, these patients are usually more concerned with HIV than with TB. This was therefore added as an item. In addition, stigmatization was split into two separate statements, addressing the public association of TB with HIV/AIDS (statement 18) and the associated fear among TB patients of disclosing their TB status (statement 19).

Additional items for the Q-sample were generated through focus groups with community health workers on the subject of compliance with treatment and through examination of the transcripts of the focus groups with TB patients as previously mentioned. Patients in the Eastern Cape mentioned experiencing difficulties with the number of pills they have to take, the rules and restrictions that accompany the therapy (e.g. abstinence from smoking and drinking), and clinic waiting times. These may be considered as barriers to compliance with TB treatment, and, as such, were added to the statement set.

The final statement set comprised 32 items. The statements were translated by an official translator into Xhosa, the primary language in the Eastern Cape, and printed on cards. A small pilot study was conducted to test whether the statements (in English and Xhosa) were clear and understandable for the study population. No changes were necessary.

Interviews

Semi-structured interviews were conducted with purposive samples of compliers and non-compliers in the Eastern Cape. Because no unambiguous sampling criteria were

Table 1. Composite rankings of statements

Determinant	Nr	Statement	Compliers	Non-compliers
Reinforcing factors	1	Community health worker's support and interest in me	+1	0
	2	Home visits by the community health worker	-2	-1
	3	Other people's opinion of TB treatment	0	+1
	4	My family's opinion of TB	+1	+1
	5	Media attention for the consequences of TB	+1	-1
Enabling factors	6	Receiving TB drugs free of charge	+1	-2
	7	Delivery of TB drugs at my doorstep	-1	-2
	8	The support and help from support groups	0	-1
	9	The support of a government disability grant which is paid for six months	+2	+1
Health beliefs	10	I take my treatment because I really want to get healthy again	+2	0
	11	The main thing is to improve my life situation, so I take my treatment	+3	0
	12	The chance that TB makes me sick	+1	0
	13	The chance of dying of TB	-2	-1
	14	I think this treatment will really help me so I'm prepared to take the medicine	+1	-1
	15	Having to think about TB and the drugs all the time is burdensome	-2	+2
	16	Trust that I can take the drugs for the whole six months	+2	0
	17	My expectations of life after TB treatment	+3	0
Barriers	18	The public association of TB with HIV/AIDS	-3	+3
	19	Fear of telling others that I have TB	-1	+3
	20	The number of pills that I have to take	0	+1
	21	The treatment of an other disease (e.g. HIV/AIDS) is more important	-1	0
	22	Having to leave home	-1	0
	23	Travel time to the TB clinic	0	-2
	24	The rules and restriction that come along with the therapy	-1	+2
	25	Abstinence from smoking and drinking	0	+2
	26	Waiting time in clinics	0	+1
	27	Money to buy fare for transport to the TB clinic	-1	-3
	28	Loss of daily wages	-3	-3
	29	Treatment by the staff	0	0
Supports	30	The communication with the community health worker	0	-1
	31	Presence of supportive person, who establishes routine in taking pills	0	0
	32	Difficulties in keeping routine in taking the drugs	0	+1

available for this population either from theory or from former empirical studies, participants were recruited in consultation with local experts and community healthcare workers. Based on discussions with them, the sociodemographic characteristics presented in table II were used as the relevant sampling criteria in the region of study. Compliers were recruited by the principal investigator (J.M.C.) at clinics and the hospital in the Grahamstown township, and were interviewed on the spot. Non-compliers were recruited through community health workers and through participating compliers, who were asked if they knew someone who had defaulted on their treatment. In the Eastern Cape, patients who do not take their treatment are followed-up, even after missing a day. If patients have missed ten treatments in a row, they have to be retested and are considered a non-complier. Non-compliers who agreed to participate were interviewed in their homes in the townships of Grahamstown East. A translator was always present during the interviews, so that interviews could be conducted in either Xhosa or English, according to the respondent's preference.

Table 2. socio-demographic characteristic of participants

	Compliers (n=33)	Non-compliers (n=34)
Gender (% female)	52	53
Mean age in years	34	34
Employed (%)	45	6
Mean household size	9	9
Marital status (% single)	55	53
Some formal education (%)	94	88

The statement set was presented to respondents in the form of a pack of cards with the statements in random order. Respondents were asked to rank the cards in order of importance (least-to-most) for their (non-)compliance with treatment using a score sheet (figure 2) and the following instructions:

- compliance group: "What is helping you to stick to your six-month TB treatment? Here are some things that other people have told us. What has helped you?"
- non-compliance group: "What has made you stop your six-month TB treatment? Here are some things that other people have told us. What were the main reasons for you?"

Participants were instructed to read the 32 statements and to divide them into three piles: important, unimportant, neutral. They were then asked to take the 'important' pile, read the statements again, select the two statements they found most important and place these in the two spots at the right end of the score sheet (figure 2). Then they were asked to read the remaining 'important' statements, to select the next three they agreed with most and place them in the next column, and so on.

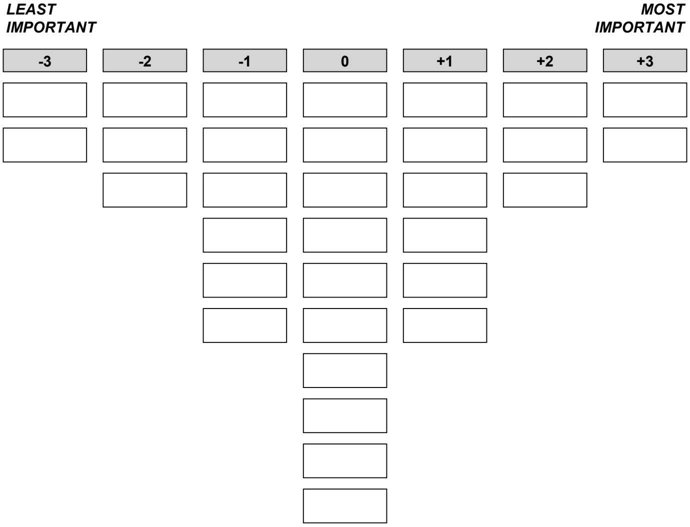

Figure 2. score sheet

A similar procedure was followed for the cards in the ‘unimportant’ pile (working from left to right on the score sheet), and finally the statements from the ‘neutral’ pile. After finishing the Q-sort, respondents were asked to explain their ranking, particularly the items they regarded as least and most important for their (non-) compliance with TB treatment. These explanations were recorded, transcribed, and used as supplementary information for interpretation and description of the results.

Next, in order to assess how well participants were informed about TB, they were asked the following structured questions about their knowledge and beliefs related to TB and its treatment:

- What are the most common TB symptoms?
- How is TB mainly transmitted?
- What are the main causes of TB?
- What are the main risk factors for TB?
- What can you do to prevent getting TB?
- Can TB be cured?
- What is the duration of TB treatment?
- In your community, how is a person who has TB regarded/treated?
- How do you feel towards people who have TB?

These responses were analyzed separately by one of the researchers (J.M.C.) and resulted in a judgment of their level of knowledge (bad, medium, or good).

Finally, compliers were asked to read the 32 statements once again and to select the top five items they felt were most important for *non*-compliers to default on treatment (and non-compliers, vice versa). Likewise, community healthcare workers were also asked to read the 32 statements and to select the top five items they felt were most important for compliers to complete treatment and for non-compliers to default on treatment.

Analysis

The individual Q-sorts were factor analyzed using PQMethod 2.11[38] (extraction method = centroid factor analysis; rotation method = varimax) in order to reveal a limited number of distinct patterns in which the statements were ranked (i.e. factors), which were then interpreted and described as views on determinants of compliance with TB treatment.[10] Q-sorts of compliers and non-compliers were analyzed independently, as they ranked the 32 statements under different instructions.

For each distinct pattern in which the statements were sorted (i.e. each view on determinants of compliance) resulting from the factor analysis, a composite sort was computed. This composite sort, also called an idealized Q-sort, represents the way in which an individual person holding exactly this view on compliance (i.e. with a 1.00 correlation coefficient with that factor) would have ranked the statements on the score sheet (figure 2), and is computed as the weighted average ranking of statements by the respondents defining this pattern (i.e. those respondents loading statistically significantly on that factor ($p < 0.05$), with their correlation coefficient with the factor as weight). The composite sort is used to interpret and describe the specific view on determinants of compliance, supplemented with the explanations that respondents defining the view gave to their ranking of the statements. Some of these explanations are cited in the results section so that the descriptions reflect, as closely as possible, the actual views and corresponding language use of TB patients in the Eastern Cape. The statement numbers in parentheses correspond with those in table I.

The top five statement selections for completing or defaulting treatment by community healthcare workers, compliers, and non-compliers are presented and discussed separately.

Results

A total of 33 compliers, 34 non-compliers, and 14 community health workers participated in the study. Table II presents the sociodemographic characteristics of the TB patients. The community health workers comprised 11 females (78.6%) and three males (21.4%), and their mean age was 33 years (range 26–45).

Response to the questions about knowledge and beliefs related to TB and its treatment showed that both compliers and non-compliers were well informed about TB, were aware of the main TB symptoms (coughing, lost of appetite, coughing up blood, and weight loss), knew that TB is curable, and also that compliance with treatment is crucial to being cured. However, many believed that TB would always develop into HIV/AIDS, and most considered people with or cured from TB to be weak.

The results for compliers and non-compliers are presented consecutively. In both groups, the focus is on the most important determinants for (non-)compliance.

Compliance Group

After examining a range of factor solutions, a one-factor solution emerged as dominant, with 32 of the 33 compliers participating in the study defining this view on determinants of compliance with TB treatment ($p<0.01$; mean correlation coefficient/agreement of respondents with factor was high [0.73; range = 0.62–0.85]). See table I for the composite sort of items.

The view of compliers on the most important determinants of compliance with TB treatment appears fairly clear, as a small number of statements stand out on the 'most important' side of the distribution (figure 2), with relatively high average Z-scores (not presented here), indicating high consensus about what is most important for adhering to their TB treatment. These compliers point to self-efficacy and motivation as key factors, by their belief that they can complete treatment and that it will work, and their optimistic expectations of life after TB. In addition, the support of a government disability grant during the treatment period seems to be an important external trigger. Regarding their motivation (statements 10, 11, 17), respondents added:

"*I don't like feeling sick. The pills from the clinic make me healthy, so I take them.*"

"*TB made me really sick. After I took the pills, I felt better again. When I take my pills for a few months, I am cured from TB. That is why I am going to finish my treatment.*"

"*I don't want to spread the disease to my family. If I take my medicine I will be cured from TB and will no longer be contagious, which is why I take my medicine.*"

Health is considered an important aspect of life and a way to improve and secure economic prospects and one's general life situation.

"*I want to get a job soon; therefore I need to be healthy.*"

The importance of self-efficacy in this account was evident in the score of item 16; patients appear to be confident that they will complete their treatment, and mostly relate this to their motivation.

"*My boss does not like his employees to be sick, so I go to the clinic every day to collect my pills.*"

"*I do not want to stay sick for too long because I don't want to lose my job. Last year somebody got fired because of TB that is why I go to the clinic every day to collect my pills.*"

And not unimportant, in this context, compliers really believe treatment will be effective (statement 14). That the support of the government disability grant helps with compliance (statement 9) was explained as follows:

"*Now that I have my own money I can buy food again. Because of the money, my neighbors and my family respect me.*"

"*The grant made me feel less troubled. I could totally focus on getting healthy again.*"

Contrary to the 'most important' factors, there was much less consensus among compliers regarding the 'least important' factors. Compliers indicate that the possible loss of wages (statement 28), the social stigma (18), home visits by the community health worker (2), the chance of dying of TB (13), and the burden of taking medication (15) were least important for them. They do not experience or pay much attention to these barriers and supports, apparently because treatment is going well. This aligns with their beliefs about the effectiveness of treatment and their self-efficacy, and their motivation related to their expectations of life after treatment.

Non-Compliance Group

In this group, a dominant one-factor solution also emerged, with all 34 non-compliers defining this view on determinants of compliance with TB treatment ($p<0.01$; mean agreement = 0.76; range = 0.58–0.87). See table I for the composite sort of items.

Non-compliers indicated that stigmatization and the burden of the requirements that come with the treatment strategy as principal barriers to treatment compliance. The stigma-related items 'the public association of TB with HIV/AIDS' (statement 18) and 'fear of telling others that I have TB' (statement 19) were ranked as the most important, but other statements referring to social aspects (statements 3 and 4) also gained high scores.

"*People saw me at the clinic and thought I had HIV, so I stopped going.*"

"*After I told my family I had TB, they didn't want to see me anymore. I explained to them that treatment would cure me from TB, but they were afraid that I soon would also have HIV, so it does not matter to them even if I am cured from TB.*"

Furthermore, non-adherent patients indicated that the perceived burden of TB treatment has a great impact (statements 15, 20, 24, 25).

"*After weeks of following the rules I wanted to have fun again, so I stopped the treatment.*"

"*It was difficult for me to remember the rules of the treatment. I often forgot to go to the clinic for my medicine.*"

Some hospitalized patients added boredom to this list:

"*If only I had something to do, to keep my mind off things.*"

"*My hospital stay felt like being in prison, I wanted to go out and enjoy life again.*"

"*… weeks of just sitting around and doing nothing all day made me want to leave the hospital.*"

More so than in the compliers group, there was little consensus on the 'least important' aspects; four statements stand out. The threat of 'loss of daily wages' (statement 28) was most prominent, and probably reflects that the vast majority of non-compliers were not employed. ‘Money to buy the fare to the TB clinic’ (statement 27) did not apply to this group; with six clinics in the township, most TB patients lived close enough to walk. A considerable number of non-compliers found ‘receiving TB drugs free of charge’ (statement 6) of little importance for defaulting, which – as respondents indicated – needs no further explanation. Finally, non-compliers indicated that ‘delivery of TB drugs at my doorstep’ (statement 7) was not important for them. More importantly, they firmly declined this possibility because family or neighbors could notice and be faced with the fact that they have TB, with significant social repercussions. This point was clearly related to the social stigma of TB and its association with HIV/AIDS, which this group accentuated as an important factor for not complying with their treatment.

Top Five Determinants of (Non-)Compliance

Community health workers and compliers both indicated that the rules and restrictions that accompany therapy, particularly abstinence from smoking and drinking, are key barriers to compliance among non-compliers (table III). Community health workers, in addition, recognized the effect of stigma on defaulting; however, compliers thought lack of motivation was more important for defaulting.

Community health workers and non-compliers largely agreed that intrinsic motivation and self-efficacy are the primary determinants of compliance with TB treatment (table III). In addition, community health workers highlighted their personal contribution to compliance success of compliers, while non-compliers suggested the presence of a supporting person to be important for compliance.

Discussion

This article presents the results of an investigation of determinants of compliance with TB treatment conducted among people with TB in the Eastern Cape, South Africa. Looking at the factors from the TB Compliance Model, our results clearly suggest that patients’ health beliefs –particularly their motivation and self-efficacy – are crucial for compliance, while barriers to TB treatment have the greatest impact on non-compliance. The compliant group largely believe that compliance with their TB treatment will cure them of TB. The 6-month government disability grant was apparently an important supporting factor for compliance. The non-compliance group was most bothered by the social stigma, the burden of disease, and the rules and restrictions that accompany therapy. In addition, boredom was an important aspect for hospitalized TB patients; non-compliers indicated that the main reason for their escape from hospital was that they had nothing to do for months.

Table 3. Primary determinants of adherence and non-adherence based on top-5 selection by compliers, non-compliers and community health care workers

	Statement		Non-compliers (n = 34)		Compliers (n = 33)		Community health workers (n = 14)		Total	
Adherence	16	Trust that I can take the drugs for the whole six months	31	(91%)			14	(100%)	45	(94%)
	10	I take my treatment because I really want to get healthy again	29	(85%)			12	(86%)	41	(85%)
	11	The main thing is to improve my life situation, so I take my treatment	28	(82%)			7	(50%)	35	(73%)
	17	My expectations of life after TB treatment	21	(62%)			11	(79%)	32	(67%)
	31	Presence of an important person who establishes routine in taking pills	31	(91%)			-	(0%)	31	(65%)
	14	I think this treatment will help me, so I'm prepared to take my medicine	17	(50%)			7	(50%)	24	(50%)
	30	The communication with the community health worker	8	(24%)			13	(93%)	21	(44%)
	5	Media attention	-	(0%)			6	(43%)	6	(13%)
Non-adherence	25	Abstinence from smoking and drinking			28	(85%)	13	(93%)	41	(87%)
	24	The rules and restrictions that come along with the therapy			21	(64%)	13	(93%)	33	(70%)
	11	The main thing is to improve my life situation, so I take my treatment			24	(73%)	8	(57%)	32	(68%)
	10	I take my treatment because I really want to get healthy again			25	(76%)	5	(36%)	30	(64%)
	15	Having to think about TB is burdensome			20	(61%)	9	(64%)	29	(62%)
	18	The public association of TB with HIV/AIDS			16	(48%)	12	(86%)	28	(60%)
	19	The fear of telling other about TB			19	(58%)	7	(50%)	26	(55%)
	9	The support of a government disability grant			17	(52%)	4	(29%)	21	(45%)

After examining a range of factor solutions, a one-factor solution emerged as dominant among compliers and non-compliers. Rarely, other studies have found a single view on their subject matter (i.e. a one-factor solution). [19] We did not anticipate finding only a single view among both compliers and non-compliers. An important reason for choosing Q-methodology was the desire to explore differences in viewpoint within these groups. In the course of the analysis, all factor solutions supported by the data were inspected; however, the general finding in both groups was that, in solutions with more than one factor, the same statements dominated the 'most important' side of the composite sorts (figure 2), while a limited number of statements distinguished the 'least important' side of the ranking of statements. Therefore, within these two subgroups we found that these small distinctions at the 'least important' side only were not sufficiently interesting to suggest different views about determinants of compliance with TB treatment among compliers and non-compliers.

When we compare the rankings of statements between the compliance and non-compliance groups (table I), some issues are clear. The largest difference in rank score between the groups is obviously in the statements that are descriptive for both groups at the 'most important' end of the score sheet (figure 2), that is, those addressing stigmatization, burden of disease, rules and restrictions, and health beliefs. Another notable difference was found with the ranking of statements concerning TB medication. Compliers largely trusted that they would take their medication for the full treatment period and attached more importance to receiving the drugs free of charge. However, non-compliers put more emphasis on the number of pills they have to take and difficulties in continuing the drug-taking routine. Therefore, the willingness to take the medication appears to be connected to the differences in health beliefs between compliers and non-compliers.

An alternative way to compare the results would be to combine the complier and non-complier data and to analyze these data simultaneously. In principle, the use of different instructions for compliers and non-compliers impedes this procedure, as different subjectivities are measured, but because the instructions were more or less mirror images, we conducted the analysis out of general interest and it led to exactly the same result. The combined data thus led to a two-factor solution, all compliers joining on one factor, all non-compliers on the other. The correlation coefficient between the views of compliers and non-compliers (i.e. the factor scores) was −0.1 and, with the exception of three statements with 0 and −1 scores (statements 7, 8, and 31), all statements distinguished between the views of compliers and non-compliers in this combined analysis. This further indicates that compliers did not associate at all with the view on determinants of compliance with TB treatment elicited from non-compliers (and vice versa), which supports the notion that the interaction between social and economic factors works differently for compliance and non-compliance with treatment.

Another interesting comparison is between the rankings of statements and the 'top five' lists. Regarding compliance, community health workers and non-compliers recognize the importance of health beliefs and self-efficacy, but both hint at the importance of an extrinsic motivator (table III); 13 of 14 community health workers felt that the communication between them and the patient was of crucial importance for compliance, while 31 of 34 non-compliers indicated that the presence of an important person who establishes routine in taking pills was probably important. However, compliers ranked these statements in the middle (table I).

Regarding non-compliance, community health workers and compliers recognized that the stigmatization and the burden of disease may hinder compliance, but the four statements regarded as most important all relate to the patient's motivation: rules and restrictions win over health beliefs (table III). Thus, while compliers feel their intrinsic motivation is most important for their success, non-compliers and community health workers hint at the important role of extrinsic motivators such as 'Presence of an important person who establishes routine in taking pills' and 'The communication with the community health worker' (table III); and while non-compliers hint at all sorts of barriers for compliance, compliers and community health workers tend to attribute their failure largely to lack of willpower (table III). During the interviews, compliers frequently mentioned lack of motivation as important for defaulting. They saw non-compliers mostly as people who just do not want to deal with the disease, who do not want to change their lifestyle, especially their drinking habits, and who care little about their health. Many of the TB patients held non-compliers responsible for their TB infection, for putting society in general at risk of infection, and for the stigmatization of TB patients.

As described in the introduction section, there is a general lack of knowledge about TB among people in developing countries. The people involved in this study were fairly well informed, but certain beliefs appeared to play an important role. People with or cured from TB were still considered to be weak and less respected members of the community. A trip to the clinic and/or home visit from a DOTS volunteer increases the risk of bringing the disease to light, causing rejection and stigmatization in the local community. Moreover, many believe that TB will develop into HIV/AIDS. TB may therefore still be considered a 'social' disease.

A few limitations of this study need mentioning. First, the sampling of respondents was not easy, in part because of the stigma of TB. Respondents were approached in various ways; however, because there were no clear sampling criteria for this population and we therefore relied on consultation with local experts for the selection of criteria in the region of study (see sociodemographic characteristics in table II), it is difficult to be sure that all theoretically relevant patient groups were included. We believe the cooperation with local clinics and a hospital helped us recruit a variety of respondents. In addition, by asking respondents to help recruit an additional participant, we gained access to TB patients who – for whatever reason – were not, or were less, in contact with health services.

Second, an interpreter was present at all times, which may have influenced the exchange of information, again in relation to stigmatization. For the interviews conducted in English, participants may have felt limited in their ability to say all they wanted to say. For those conducted in Xhosa, the indirect communication and translation issues may have been of additional influence. Nonetheless, our impression was that people were very engaged with the study, spoke extensively, and felt free to touch upon all sorts of issues. Patients in hospital seemed particularly keen to participate (see also final paragraph of this section).

Third, as a result of our choice to use a single statement set with different instructions for compliers and non-compliers, some of the statements may seem a bit at odds with the instruction they received for ranking the statements. During the interviews we checked whether respondents understood the task by observing and encouraging them to think aloud while sorting the statements and by asking them to explain their Q-sort when they had finished. Although respondents commented on only a limited number of statements, their explanations indicated they generally understood the task and experienced no difficulties sorting the statements.

Finally, Q-sorting is generally a cognitively demanding task. Although almost all participants had some formal education, rank ordering 32 written statements will have been challenging for some participants. We attempted to make the task more feasible by introducing an intermediate step (first sorting into three piles and then working further pile by pile), and by encouraging them to think aloud, ask questions when something was not clear, and discussing their results with them. We believe all respondents included in the analysis understood the task and were able to communicate their views during the interview.

The influence of these limitations on our results is not clear. One of the principal reasons for choosing Q-methodology was that we anticipated finding more than a single view in each group. Based on the interviews and both the statistical results from the Q-sorts and the explanations of participants to their Q-sorts, we believe that this was not as a result of these limitations of our study. However, replications of this study are needed to confirm our findings (both in the Eastern Cape, South Africa, and in other places in which compliance with TB treatment is a public health problem).

Although the study sample is of sufficient size for the purpose of Q-methodology (which is to reveal the principal viewpoints on a subject), it is rather small for investigating statistical associations between groups and individual background characteristics. However, the relation with employment really stands out: employment was substantially higher among compliers (45%) than among non-compliers (6%) [table II]. Community health workers indicated that unemployment (and therefore the inability to provide food and other necessities for oneself or the family, and the failure to be a respected member of the community) often leads to low morale and low self-esteem. Other studies have also found that a patient's financial situation has a large effect on compliance behavior.[5,17] Patients' inability to deal with their TB appears to be strongly linked to a lack of economic prospects. Many patients with TB drink excessively to try and forget their troubles (living in a township, infection with HIV/AIDS, stigmatization, frequent confrontation with people dying in the same situation they are in) and, subsequently, also default from their TB treatment. This highlights that TB is not only a 'social' disease but also very much an 'economic' disease in the sense that economic development, leading to better work prospects and being able to provide for themselves or their family, will contribute to declining incidence and prevalence rates of TB.

In the period between developing the research instrument and writing up our findings, the results of two related studies were published. Munro et al.[39] conducted a systematic review of qualitative studies addressing factors contributing to TB medication compliance considered important by patients, caregivers, and healthcare providers, and developed a model depicting four main factors influencing compliance: (i) structural (e.g. poverty and social marginalization); (ii) personal (e.g. motivation, knowledge, and beliefs); (iii) health service (i.e. the influence of the organization of TB treatment); and (iv) social context.

Sagbakken et al.[40] conducted 50 in-depth interviews and two focus groups with TB patients, their relatives, and health personnel in Addis Ababa, Ethiopia, to explore how symptoms of TB are perceived and managed and to discover the principal enablers and barriers in the management of TB treatment.[41] Patients' perceptions and lack of knowledge about TB and the social stigma associated with TB were found to cause delays in diagnosis and to affect patients' abilities to manage TB. The authors argued that compliance with TB treatment is the result of a dynamic interplay between social and economic costs and other burdens. The organization of treatment (time-consuming and physically demanding daily treatment, rigid routines at health clinics) and the effect on employment can be an important barrier to compliance. Social and practical support from the community (e.g. providing food, money for transportation, or encouragement) can be crucial for patients to maintain their health and social status and continue treatment.

It was encouraging that the factors identified in the two studies[39,40] as potentially contributing to treatment compliance were also represented in our research instrument, and that largely the same factors were found to be important for compliance with TB treatment. However, and more importantly, the authors of both studies[39,40] emphasized that all these factors interact – making TB a social and an economic disease – and therefore cannot be taken in isolation when trying to understand treatment compliance or when developing community-based TB treatment programs.

One of the contributions of our study is that we specifically addressed this interaction from the patients' perspective. Our study shows how compliers and non-compliers value these social and economic factors relative to each other, and that this interaction works differently for compliance and non-compliance with treatment. As a result, this study contributes to a better understanding of TB patients' choices regarding their treatment, and provides directions for refining TB treatment programs and improving compliance.

Another contribution is that our findings support and reinforce those of previous studies, albeit using a different method. This is particularly relevant because previous studies were qualitative in nature, while the method used in this study, Q-methodology, combines the richness of these qualitative studies with the rigor of quantitative methods.

Finally, a positive aspect of this study was that many respondents spontaneously indicated that they enjoyed participating. Respondents described having fun reading the cards and sorting them on the score sheet. Hospital-based patients, in particular, stated that they enjoyed participating (see earlier remarks on boredom). Some also mentioned they had become more aware of their own thoughts and behaviors through the interview. For these reasons, Q-methodology may be considered a useful research method to investigate TB patients' perspectives on determinants of compliance with TB treatment, but also to raise awareness among patients and the community about this subject.

Conclusion

The stigmatization of patients by the community makes TB a 'social disease'. Our study indicated that individual motivation and self-efficacy appear to be important determinants for compliance with treatment. For non-compliers, the general lack of job prospects and being able to provide for themselves or their family makes TB very much an 'economic disease'.

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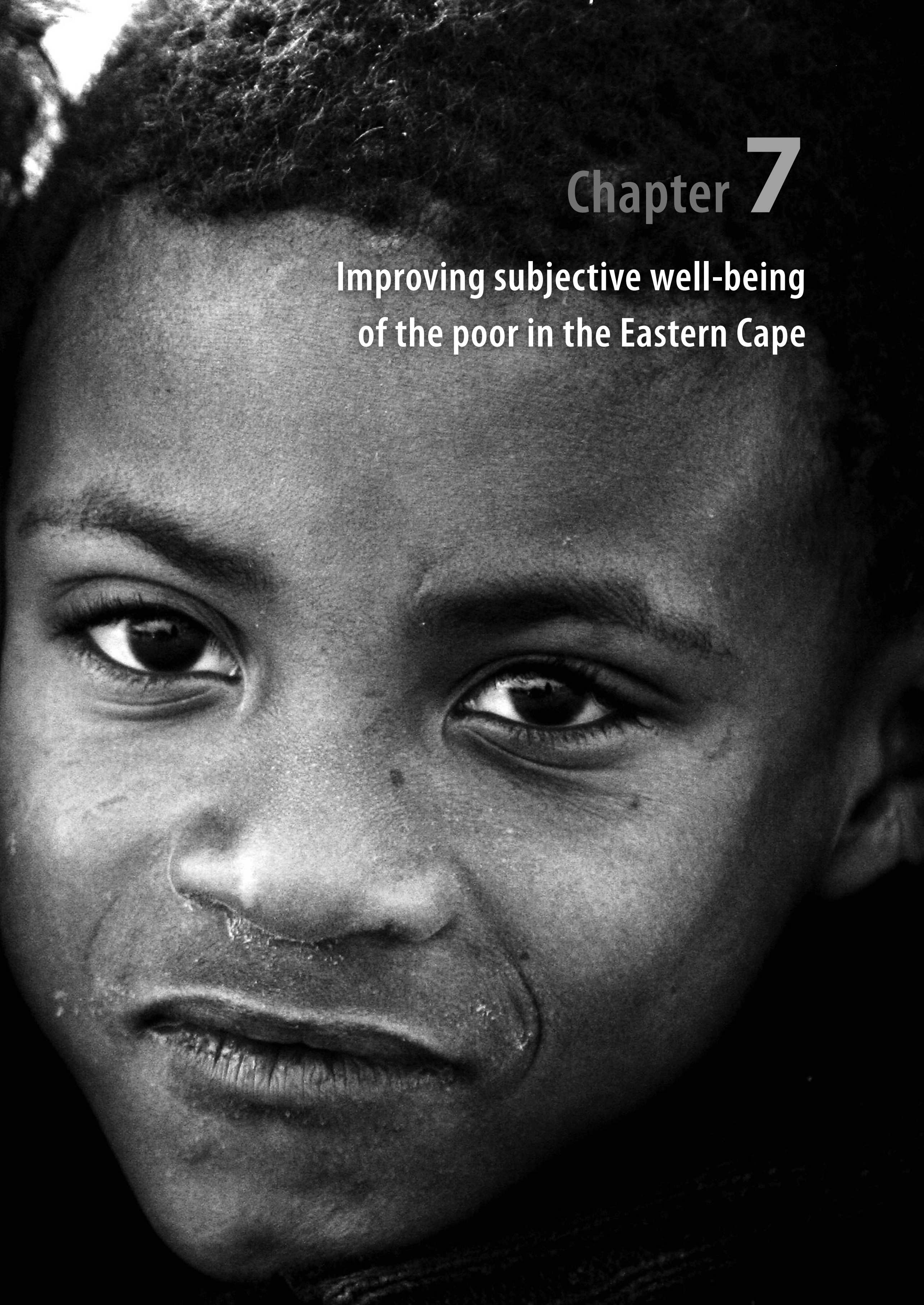

Chapter 7

Improving subjective well-being of the poor in the Eastern Cape

Abstract

This study investigated the effects of income, health, social capital, marital status, employment, education and crime experience on subjective well-being within a poor community in the Eastern Cape of South Africa. It appeared that higher income is associated with higher subjective well-being and that social capital serves as an important subjective well-being predictor in all income groups. Efforts must be made to ensure that countries do not develop economically at the expense of other aspects of life important for well-being in the very poor, such as social capital.

Introduction

Researchers from a wide range of countries have produced a large body of literature pertinent to happiness or subjective well-being. It would appear that happiness cannot be measured directly, but several measures of subjective well-being have been shown to be valid and reliable (Pavot & Diener, 1993). These measures revealed that subjective well-being outcomes for high-income individuals are better than those for poor people (Keck & Krause, 2007; Fahey, Whelan & Maitre, 2005). In fact, a meta-analysis of global subjective well-being (Marks, Abdallah, Simms, Thompson, 2006) showed a general trend of greater subjective well-being levels in countries that enjoy a high gross domestic product (GDP) – North America, North-western Europe, Yemen, United Arab Emirates, Australia and New Zealand. Lower subjective well-being levels predominate in poorer geographical regions – e.g. most of Africa, Eastern Europe, India and Pakistan.

Linking these subjective well-being data to data on health, wealth, and access to education, White (2007) found that subjective well-being correlated most strongly with health, followed closely by wealth and access to basic education. Hence, it is evident that wealth and variables associated with wealth are strongly linked to subjective well-being worldwide.

Easterlin, a pioneer of the economics of subjective well-being (Easterlin 1974, 1995, 2000), has provided solid evidence for the purported link between financial status and subjective well-being. In a study using 30 surveys from 19 countries, including developing countries, wealthy people in all countries report higher levels of subjective well-being than poorer people (Easterlin, 1995).Others found that wealth-subjective well-being correlations are more pronounced in poor countries than in developed nations, with a much higher risk of low subjective well-being outcomes for poor people (Lipovcan, Brkljaclc & Sakic, 2007; Diener & Robert Biswas-Diener, 2002; Blanchflower & Oswald, 2004; Frey and Stutzer, 2003; Diener, 1984). Also in South Africa researchers consistently found a strong link between income and subjective well-being (Møller, 2007; Møller & Devey, 2003; Devey & Møller, 2002; Møller, 1998).

Not only the absolute level of income plays a role in this respect: Wilkinson and Pickett (2006) from a literature review conclude that subjective well-being tends to be poorer in societies where relative income differences are larger. The proportion of supportive findings substantially differed according to whether inequality was measured in large or small areas. The authors therefore suggest that the studies of income inequality are more supportive in large areas because in that context income inequality serves as a measure of the scale of social stratification, or how hierarchical a society is (Wilkinson and Pickett, 2006).

In the light of these findings, improving the subjective well-being of the poorest of the poor is often framed as a goal of human development programs. In 2000, 189 countries signed the United Nations Millennium Declaration, which set eight Millennium Development Goals (MDGs) to be achieved by 2015. These MDGs should decrease poverty and inequality and improve subjective well-being (MDG steering group, 2008). International experts have redefined subjective well-being as follows: "An umbrella term for different valuations that people make regarding their lives, the events happening to them, their body and minds, and circumstances in which they live (Diener, 2006; p2). Since non-monetary measures of well-being are critical, the wider issue of human development is also important. Income is important for subjective well-being, but what other aspects buffer subjective well-being among the poor? Apart from income, employment, health and education, social capital is increasingly acknowledged as an important determinant of subjective well-being (Wilkinson and Pickett, 2006; Yip, Sybramanian, Mitchell, Lee, Wang & Kawachi, 2007; Bjørnskov, 2005; Bjørnskov, 2003; Grootaert, 2002; Easterlin, 2000). A widely-used definition of social capital is the following: "the set of cooperative relationships between social actors that facilitate collective actions" (Requena, 2003; p331). Social capital may shelter people from the harmful effects of unemployment and poverty (Winkelman, 2008, Camfield & Skevington, 2008). In this regard, it would be helpful to identify factors other than income that predict subjective well-being within poor communities. Such knowledge will enable to set up programs and interventions aimed at helping communities achieve greater subjective well-being for a greater number of people. Subjective well-being research among the poorest of the poor is still scarce, however. Research on this topic so far mainly concerned populations in developed economies (Snyder, 2002), where data tend to be better available (Graham & Pettinato, 2001).

The question is: What efforts must be made to achieve higher subjective well-being amongst the poorest of the poor? The present study investigated the effect of income, social capital, health and crime experience on subjective well-being in a community in the Eastern Cape province of South Africa, characterised by much poverty and unemployment (Møller & Erstad, 2007). It also addressed the question whether social capital may act as a buffer. The mean well-being score (0-10) for this community is 4.6 (Møller, 2007), which is substantially lower than that reported for the whole nation of South Africa (5.7) (Marks et al., 2006). This community, therefore, represents an interesting population for the purpose of the study reported here.

Methods

Participants and sampling

An area-stratified sampling design was applied. Households in Rhini, a suburb of the city of Grahamstown, South Africa, were selected randomly in proportion to the total number of households in each neighbourhood. In each of the 23 neighbourhoods of Rhini, a starting point was taken at random. Moving systematically through the neighbourhood, the researchers selected every tenth household for inclusion in the sample. This method ensured that all households in all areas of Rhini stood an equal chance of being included in the survey. Eligible respondents were identified in each target household.

Eligible respondents needed to be 18 years of age or older and should have been residing in Rhini for at least 6 months of the past year. One respondent per randomly selected household was then selected using a Kish grid to ensure all eligible persons in the household stood an equal chance of being included in the survey. The person selected was then interviewed. If this person was not available, arrangements were made to conduct the interview at a later time. Up to four attempts were made to interview selected respondents. An interview was obtained in 1020 of the 1042 households (97.9%) targeted. Reasons for not achieving an interview included not finding the respondent at home after four visits to the household, old age or poor health, and disinterest or unwillingness.

Staff from Development Research Africa, a well-known organization experienced in undertaking national probability based samples in deep rural and urban areas, administered the questionnaires. Almost all questions were closed-ended items for which a set of response options was supplied. The interviewers gathered demographic information, such as gender, age, health status, education level, living arrangements, and employment. On the basis of the average monthly household income the respondents were assigned to one of three groups: low income (<R1000), middle income (R1001-2000), or high income (>R2000). A detailed description of this study population can be found in Møller (2008) and Møller (2007).

Instruments

Diener's Satisfaction with Life Scale (SWLS) was used to assess respondents' satisfaction with life as a whole. It consists of five items (statements) for which respondents rate their level of agreement on a 5-point scale (In most ways my life is close to my ideal; The conditions of my life are excellent; I am satisfied with my life; So far I have gotten the important things I want in life; If I could live my life over, I would change almost nothing). This scale was used to investigate significant correlations and predictors of happiness per income group. The SWLS's Cronbach's alpha in the present study was 0.88, indicating that the scale was reliable. Social capital was assessed with three statements for which respondents rate their level of agreement on a four point scale: people in this area are friendly; people in this area help each other without having to be asked; people in this area trust their neighbours. This scale's Cronbach's alpha was 0.87.The questionnaire further probed factors previously implicated as potential predictors of subjective well-being, such as income, health, education, marital status, full-time employment, part-time or casual employment and crime experience (Ahuvia & Friedman 1998; Clark & Oswald 1994, Diener, Sandvik, Seidlitz, & Diener 1993; Diener, Horwitz, & Emmons 1985; Larson 1978; Andrews & Withey 1976; Campbell, Converse, & Rodgers, 1976). Crime experience was assessed with the following statements: there is not a lot of crime in this area; household has experienced a housebreaking or burglary in the past year; a member of the household has experienced a serious personal violent crime in the past year.

Data analysis

Mean values are reported with standard deviations (SD). A one-way analysis of variance (ANOVA) was performed to detect whether there was significant variability of SWLS scores among the three income groups. Regression analyses using listwise deletion of missing values were performed to determine subjective well-being predictors for the whole study cohort and for each income group. The Statistical Package for the Social Sciences (SPSS) version 16.0 software was used for all statistical analyses.

Results

Response and sample characteristics

The majority (73%) of respondents were women. The median age of respondents was 38 years. Just over half were single (52%), a third were married (33%) and the others widowed (9%) or separated/divorced (6%). Forty percent had completed some secondary education and 18% had matriculated. Approximately 7% had received post-matriculation education and training. Only 8% had no formal schooling. These 1020 households counted 4245 persons. Their mean age was 30 years. Just over a quarter of household members (26%) were under 14 years of age. Some 43% were in the 15-59 years age group and 9.6% were over 60 years. The households included more women (56%) than men (44%) (Møller, 2007).

Subjective well-being scores

The overall mean SWLS score (SD) was 2.62 ± 0.87 (N = 1011; 9 respondents left items unanswered), with scores ranging from 1 to 5. A one-way ANOVA revealed that mean SWLS scores differed among the three income groups ($F_{2,1008}$ = 12,782; $p < 0.0001$). The differences between the high-income group and the other two groups were statistically significant ($p = < 0.001$). The mean scores in the low-income group (N = 481) was lowest (2.523 ± 0.84), that in the middle-income group (N = 365) intermediate (2.617 ± 0.87), and that in the high-income group (N = 165) was highest (2.913 ± 0.87).

Predictors of subjective well-being

Table 1 presents associations between income, health, social capital, marital status, full-time employment, part-time or casual employment, education, crime experience and subjective well-being. Income, health, social capital, marital status, employed in a full-time job and education all significantly correlated with subjective well-being.

Table 1. Correlations between independent variables and subjective well-being

	r	*p*	N
Household's average monthly income	.174	P<.0001	1011
Health status	.169	P<.0001	1014
Social Capital	.161	P<.0001	1011
Marital status	-.127	P<.0001	1019
Household members employed in a full-time job	.147	P<.0001	1019
Household members employed in a part-time or casual job	.003	.920	1016
Education completed by respondent	.127	P<.0001	1013
There is not a lot of crime in this area	.002	.952	1010
Household has experienced a housebreaking or burglary in the past year	-.024	.451	1011
Household member has experienced a serious personal violent crime in the past year	.024	.448	1008

Regression analysis was performed to identify predictors of subjective well-being. As shown in Table 2, for the entire study cohort income ($\beta = 0.129$, $p = < 0.000$), health status ($\beta = 0.122$, $p = < 0.000$), social capital ($\beta = 0.154$, $p = < 0.000$) and marital status ($\beta = -0.121$, $p = < 0.000$) were all predictors for subjective well-being. Total explained variance was 9.5%.

Regression analyses per income group served to identify whether subjective well-being predictors vary among different income groups. For the low-income group (Table 2) social capital ($\beta = 0.145$, $p = < 0.001$) and marital status ($\beta = -0.154$, $p = < 0.001$) were subjective well-being predictors. Together, these factors explained 6.7% of the variance in the low-income group. For the middle-income group (Table 2) social capital ($\beta = 0.117$ p, $= < 0.032$), health status ($\beta = 0.145$, $p = < 0.010$) and a low crime rate within the neighbourhood ($\beta = -0.114$, $p = < 0.040$) were subjective well-being predictors. Together, these factors explained 6.5% of the variance of the middle-income group. For the high-income group (Table 2) social capital ($\beta = 0.241$, $p = < 0.005$) and education completed by respondent ($\beta = -0.161$, $p = < 0.041$) predicted higher levels of subjective well-being. Total explained variance was 20% in the high-income group.

Table 2. Regression analyses of independent variables on subjective well-being

	All respondents		Low-income		Middle-income		High-income	
	$F_{(9,924)} = 10.245$ p<.0001 $R^2 = 9.5$		$F_{(8,426)} = 3.703$ p<.0001 $R^2 = 6.7$		$F_{(8,328)} = 2.612$ p = .006 $R^2 = 6.4$		$F_{(8,143)} = 4.182$ p<.0001 $R^2 = 20$	
	Beta	P	Beta	P	Beta	P	Beta	P
Household's average monthly income	.129	.000						
Health status	.122	.000	.068	.160	.158	.010	.104	.216
Social Capital	.154	.000	.148	.001	.117	.032	.214	.005
Marital status	-.121	.000	-.154	.001	-.071	.189	-.126	.103
Household members employed in a full-time job	.030	.425	.029	.535	.012	.831	.049	.530
Household members employed in a part-time or casual job	.005	.864	.023	.614	-.068	.211	.074	.322
Education completed by respondent	.051	.130	.047	.326	-.007	.911	.161	.041
There is not a lot of crime in this area	-.009	.775	.052	.261	-.144	.040	.012	.879
Household has experienced a housebreaking or burglary in the past year	-.041	.205	-.076	.109	-.018	.750	.026	.739
A member of the household has experienced a serious personal violent crime in the past year	.008	.815	.068	.149	-.042	.454	-.062	.415

Discussion and Conclusions

This study explored the effect of income on subjective well-being within a poor South African community. Considering three income groups separately, the lowest income group had the lowest subjective well-being outcomes, the middle-income group reported an intermediate level, and the highest income group reported the highest level of subjective well-being. Hence within this relatively poor region, even modest differences in income had notable effects on subjective well-being. These findings are consistent with prior studies indicating a positive association between income and subjective well-being (Møller, 2007; Lipovcan, Brkljaclc & Sakic, 2007; Møller & Devey, 2003; Devey & Møller, 2002; Diener & Robert Biswas-Diener, 2002; Blanchflower & Oswald, 2004; Frey and Stutzer, 2003; Møller, 1998; Ahuvia & Friedman, 1998; Diener, 1984).

The regression analyses indicated that, in addition to income, social capital, marital status and health status were predictors of subjective well-being for the study group as a whole. These results are consistent with the literature (White, 2007; Lipovcan, Brkljaclc & Sakic, 2007; Marks et. al, 2006; Diener & Robert Biswas-Diener, 2002; Easterlin 1974, 1995, 2000). A prior meta-analysis found that subjective well-being correlated most strongly with health, closely followed by wealth and education (Marks et al., 2006). Within a poor community, such as that examined here, predictors of subjective well-being may differ from those observed in wealthier communities. While the importance of health as a predictor of subjective well-being persisted, education did not emerge as a strong predictor of subjective well-being in the present study.

Social capital served as an important subjective well-being predictor in all three income groups. But interestingly, these three groups differed on other predictors of subjective well-being; for example help within the neighbourhood. This notion is consistent with the traditional norms of mutual assistance among neighbours in low-income areas of South Africa. As to this matter, Haggerty et al. (2001) cite social participation and community as important domains of subjective well-being. Likewise, Marks and colleagues' (2006) investigation of the correlation between social capital and subjective well-being also indicated a strong relationship between greater social capital and higher life satisfaction. In the low-income group, marital status is a significant well-being indicator next to social capital. Marital status is also a social capital indicator making social capital even more important for subjective well-being of the most vulnerable group.

The most important predictors of subjective well-being for the middle-income group respondents besides social capital were health status and having a low crime rate within their neighbourhoods. Hence, modest increases in financial resources went together with a shift toward conservation of property and low crime. This is consistent with earlier study findings indicating that better-off South African households tended to be targeted more often by housebreaking. Income-mediated victimisation is known to harm subjective well-being (Møller, 2005).

The fact that higher income is generally associated with better access to good nutrition and health care may have reduced health concerns and variability in the high-income group – with education as main predictor of subjective well-being besides social capital. High-income households protect themselves from crime using so-called target-hardening security measures (e.g. locks and fencing). This could explain why crime experience becomes less important for their subjective well-being.

There are some limitations associated with the study. One is the relatively low explained variance of the low and middle-income groups. Their low incomes probably effect other variables as well. Respondents from the high-income group are more homogenous on health, full-time employment and part-time employment. While, earlier research indicated six broad groups of determinants of subjective well-being (personality factors; contextual and situational factors; demographic factors; institutional factors; environmental factors; and economic factors) (Hoorn, 2007), we only included the amendable determinants of subjective well-being. Since the aim of our study was to investigate efforts that must be made to improve subjective well-being we choose not to research the non-amendable personality factors. The institutional factors (welfare state, ideological complexion of governments) and macro level determinants (environmental factors and economic factors) are also less influential for our study population. Exclusion of these determinants may have caused the relatively low explained variance. A second limitation is the relatively low proportion of males in the sample. However, the study design with random selection and inclusion of every tenth household led to equal probability of survey inclusion. We expect this to be of minor importance to the findings of the study, seeing that subjective well-being is affected more by income inequality than by gender.

In conclusion, the present study demonstrated a weak positive relationship between higher income and subjective well-being in a relatively poor community. The fact that we explored the amendable determinants of subjective well-being only probably accounts for the rather low explained variance. The similar macro level determinants of well-being for the three income groups suggests higher level of variance and thus a stronger relationship between income and subjective well-being. The findings also corroborate the view that economic factors are important predictors of subjective well-being. Local economic development strategies should be designed to meet the specific needs of each community. Policy makers must realize that stimulating local economic development and household businesses in poor communities should also enhance social capital and be based on the neighborhoods' social structure. A possible solution is group lending, a microcredit scheme which refers to the practice of working with clients in small groups (typically comprised of three to seven neighbors). Loans are made to individuals, but the group as a whole is held jointly liable should repayment difficulties arise. This intervention stimulates social group ties via frequent meetings and joint liability, reducing the social distance between group members in the short run and enhancing their social capital and economic development in the long run. If enhancing well-being of people is a goal of development, efforts must be made to ensure that countries do not develop economically at the expense of other aspects of life that are particularly important predictors of subjective well-being of the poor, such as social capital.

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JM Cramm, V Møller, AP Nieboer.

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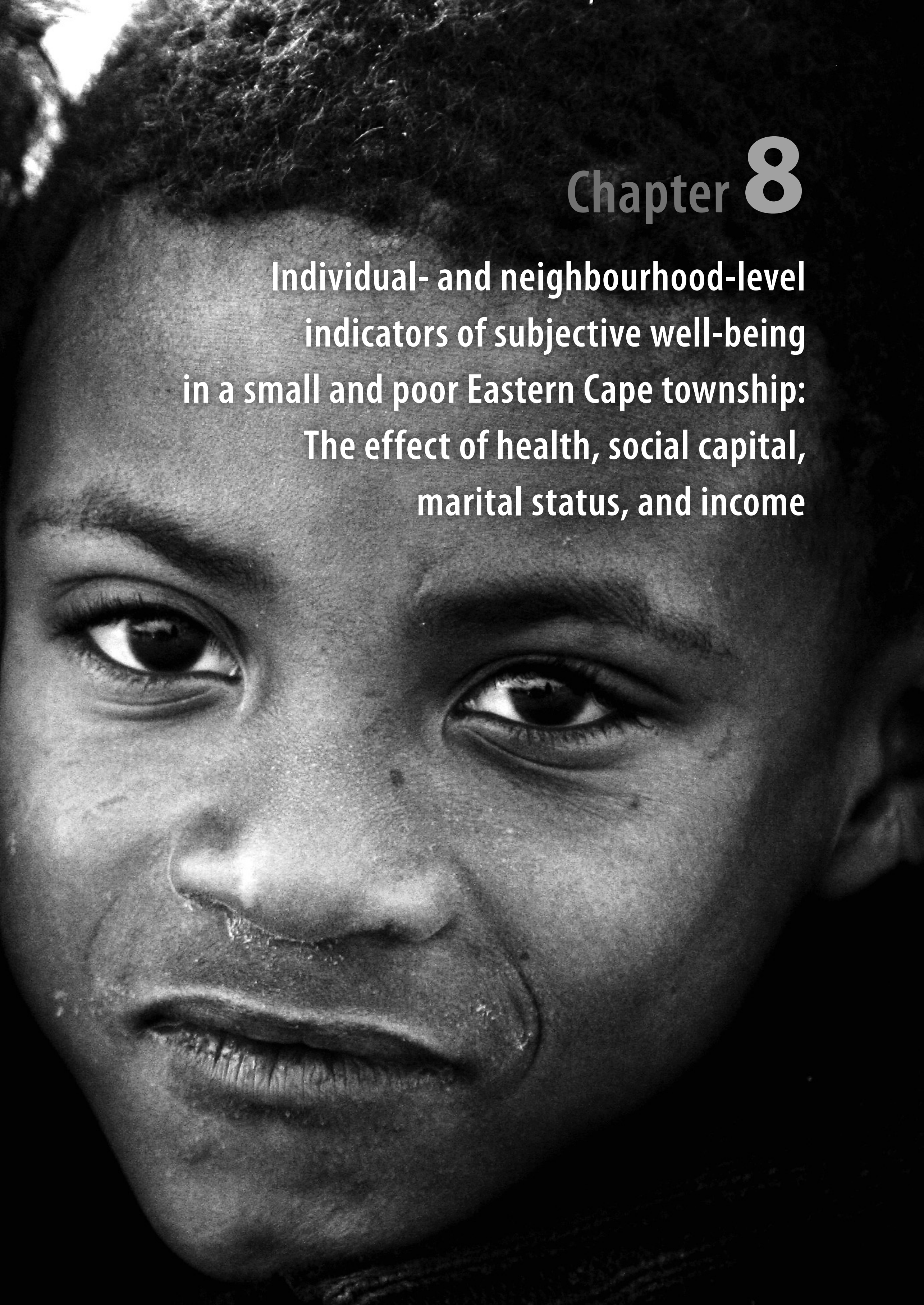

Chapter 8

Individual- and neighbourhood-level indicators of subjective well-being in a small and poor Eastern Cape township: The effect of health, social capital, marital status, and income

Abstract

Our study used multilevel regression analysis to identify individual- and neighbourhood-level factors that determine individual-level subjective well-being in Rhini, a deprived suburb of Grahamstown in the Eastern Cape province of South Africa. The Townsend index and Gini coefficient were used to investigate whether contextual neighbourhood-level differences in socioeconomic status determined individual-level subjective well-being. Crime experience, health status, social capital, and demographic variables were assessed at the individual level. The indicators of subjective well-being were estimated with a two-level random-intercepts and fixed slopes model. Social capital, health and marital status (all $p < .001$), followed by income level ($p < .01$) and the Townsend score ($p < .05$) were significantly related to individual-level subjective well-being outcomes. Our findings showed that individual-level subjective well-being is influenced by neighbourhood-level socioeconomic status as measured by the Townsend deprivation score. Individuals reported higher levels of subjective well-being in less deprived neighbourhoods. Here we wish to highlight the role of context for subjective well-being, and to suggest that subjective well-being outcomes may also be defined in ecological terms. We hope the findings are useful for implementing programs and interventions designed to achieve greater subjective well-being for people living in deprived areas.

Introduction

In recent years, scholars in a wide range of disciplines have attempted to define, measure and analyze well-being in various contexts (Hoorn 2007). A recent study defines subjective well-being as "an umbrella term for different valuations that people make regarding their lives, the events happening to them, their body and minds, and circumstances in which they live" (Diener 2006; p2). While happiness cannot be directly measured, the validity and reliability of several measures of subjective well-being have been demonstrated (Pavot and Diener 1993). Questions concerning well-being are increasingly used in population surveys, reflecting the emergence of a new science of well-being. This pursuit aims to identify the main factors affecting well-being and to quantify their relative importance. There is a rapidly growing body of interdisciplinary research on subjective well-being (Dolan et al. 2007; Frey and Stutzer 2003).

Evidence suggests that subjective well-being may fuel individual differences in resilience over time (Fredrickson 2001; Fredrickson and Joiner 2002; Lyubomirsky et al. 2005). The positive effects of enhanced subjective well-being on resilience can be explained by an individual's personal resources such as physical health, economic activity, and social contacts. (Isen 1990; Aspinwall 1998, 2001; Fredrickson 2004). Importantly, these resources function as buffers, enabling individuals to achieve well-being in multiple ways because they can substitute one resource for another (Nieboer and Lindenberg 2002; Nieboer et al. 2005). The risk of low subjective well-being is much higher for poor people (Diener and Biswas-Diener 2002; Cramm et al. 2010). Better-off individuals can substitute one subjective well-being resource for another; small changes for poor people who lack these resources often negatively impact their well-being levels (Diener and Lucas 2000; Nieboer and Lindenberg 2002; Nieboer et al. 2005). In this regard, it would be helpful to identify indicators for subjective well-being within poor communities. Such knowledge may enable to set up programs and interventions aimed at helping communities achieve greater subjective well-being for a greater number of people.

Most quantitative studies have used single-level regression models to infer relationships between well-being and a wide range of socioeconomic and demographic characteristics (Blanchflower and Oswald 2004) or to compare aggregate well-being levels between countries (Farid and Lazarus 2008; Marks et al. 2006; Veenhoven 1993, 2000). The influence of grouping factors like neighbourhoods, however, should also be taken into account. A systematic review of multilevel regression analyses (MLRA) of health outcomes has demonstrated consistent evidence for neighbourhood effects on health (Pickett and Pearl 2001). Socioeconomic neighbourhood characteristics may also affect well-being between individuals (Deneulin and Townsend 2007). If individual well-being correlates with a shared environment, single-level regression analyses will underestimate the standard errors for contextual effects and produce biased results (Merlo et al. 2005). MLRA, however, can be used to identify the distribution of disparities in well-being at both individual and neighbourhood levels.

The influence of neighbourhood-level effects on individual well-being is probably greater among people living in socioeconomically deprived neighbourhoods. Spatial variations in economic and social conditions that produce concentrated deprivation are not merely reducible to "compositional effects" (i.e., the personal and family characteristics of the neighbourhood's population) and can involve a contextual neighbourhood-related effect (e.g., income inequality within neighbourhoods and the neighbourhood's socioeconomic status) resulting from concentrated disadvantage. The already disadvantaged people living in deprived neighbourhoods and dealing with poverty, (infectious) diseases, and the like are even more burdened with negative neighbourhood effects that compound problems of concentrated disadvantage and social exclusion. The effects of multilevel characteristics on individual well-being and the extent to which each indicator at each level affects individual well-being are currently unknown. Identifying multilevel factors that affect subjective well-being would help toward finding the most effective level of intervention and enable policymakers to design programs that achieve greater subjective well-being for a greater number of people.

This study seeks to identify indicators of subjective well-being at the individual and neighbourhood levels in a community in the Eastern Cape province of South Africa characterized by high levels of poverty and unemployment (Møller and Erstad 2007) and multiple deprivation domains, such as income, employment, health, and education (Noble et al. 2009). Subjective well-being has not been thoroughly examined at lower levels of aggregation, such as neighbourhoods. A smaller spatial unit of analysis and consistent economic deprivation may dramatically affect the variables that contribute to subjective well-being. It remains unclear whether contextual factors will continue to account for differences in subjective well-being at smaller spatial units of analysis characterised by consistent deprivation.

South Africa's historical pattern of racial segregation may have led to low levels of subjective well-being in some settings (mostly townships). The mean well-being score (0-10) for the community under study is 4.6 (Møller 2007b), which is substantially lower than found in South Africa as a whole (5.7) (Marks et al. 2006). Since enhanced subjective well-being shows positive effects on health as well as social and economic activity, the population suits the purposes of our study.

Contextual neighbourhood-level indicators of individual subjective well-being

Absolute level of income is not the only relevant economic variable. Wilkinson and Pickett (2006) have concluded that subjective well-being tends to be lower in societies where relative income differences are larger. The degree of correlation substantially differed whether measured in large or small communities. The authors therefore have suggested that studies of income inequality will find that subjective well-being is explained by greater variance in large neighbourhoods, where the variable measures the scale of social stratification or extent of hierarchy (Wilkinson and Pickett 2006). A variant on the argument that relative income influences well-being stems from the long-established literature on relative deprivation; individuals feel deprived if they are doing less well than their comparator (Knight and Song 2006). Relative poverty is likely to be more important in countries with pronounced economic inequality, but most research has reported results at high geographical levels of aggregation. Studies on communities within the same city are scarce (Wong et al. 2009).

The valid and reliable (Kawachi et al. 2003) Townsend deprivation index (Townsend et al. 1988) is widely used in academic health research (Galobardes et al. 2007). Since socioeconomic status affects health at the individual level, it may also affect subjective well-being. This has not been investigated, however, and further research is necessary to establish the association (Oswald 2007).

Compositional individual-level indicators of subjective well-being

Factors of demography, income, unemployment, health, and social capital are potential indicators of subjective well-being (Ahuvia and Friedman 1998; Andrews and Withey 1976; Campbell et al. 1976; Clark and Oswald 1994; Cramm et al. 2010; Diener et al. 1985; Diener et al. 1993; Larson 1978). Early research in this field tended to focus primarily on the relation of subjective well-being to demographic factors such as age, gender, education, and marital status. Such factors, however, have been shown to account for only a small amount of variance (Diener and Biswas-Diener 2002). Although some trends linking subjective well-being and age have been observed, the findings have not been consistently replicated and the effect appears to be small (Diener and Scollon 2003). Some researchers have identified a "u-shaped" relationship between age and well-being, suggesting that individuals are happier in youth and old age (Blanchflower and Oswald 2004; Gerdtham and Johanneson 2001; Hoorn 2007). Some studies examining gender differences in well-being have reported slightly higher subjective well-being in females than in males (Frey and Stutzer 2003; Gerdtham and Johanneson 2001; Hoorn 2007). Other studies, however, have found no gender differences (Diener and Scollon 2003) or argue that they have disappeared in recent decades (Frey and Stutzer 2002). Research has found that married people, on average, are happier than unmarried people (Diener and Scollon 2003; Frey and Stutzer 2002; Hoorn 2007). Evidence for the impact of education on subjective well-being has been mixed. Some studies suggest a positive relationship (Diener and Scollon 2003; Frey and Stutzer 2003), while others (Clark and Oswald 1994) have observed a negative impact that may be due to changing aspirations and the creation of expectations for a higher income.

Extensive research has been conducted on the relationship between economic variables and well-being, revealing that subjective well-being correlates positively with income (Cramm et al. 2010; Fahey et al. 2005; Keck and Krause 2007). Most studies report a positive but relatively weak relationship between absolute income and happiness (Cramm et al. 2010; Diener and Biswas-Diener 2002; Easterlin 1974). Unemployment shows a consistently negative association with well-being and may have severe long-term impacts (Clark and Oswald 1994; Hoorn 2007).

Studies consistently report a high positive correlation between well-being and health (Diener 2002; Diener and Scollon 2003; Dolan et al. 2007; Frey and Stutzer 2002; Hoorn 2007). Research indicates that individuals reporting higher levels of subjective well-being live longer than their counterparts. Good health is probably both a cause and an effect of high levels of well-being (Diener and Biswas-Diener 2002).

Social capital is also increasingly acknowledged to be an important indicator of subjective well-being (Bjørnskov 2003, 2005; Cramm et al. 2010; Easterlin 2000; Grootaert 2002; Wilkinson and Pickett 2006; Yip et al. 2007, Haggerty et al. 2001). It is defined as "the set of cooperative relationships between social actors that facilitate collective actions" (Requena 2003; p331) and its core components are civic engagement and mutual trust among community members. Social capital shelters people from the harmful effects of unemployment and poverty (Camfield and Skevington 2008; Cramm et al. 2010; Winkelman 2009). Various studies have proposed that people with friendly, helpful, and trustworthy neighbours report higher levels of subjective well-being than those who are more solitary (Wilkinson and Pickett 2006). Marks and colleagues (2006) have indicated a strong relationship between greater social capital and higher life satisfaction. Socio-cultural features such as crime have also been found to be associated with well-being (Borooah 2006; Chan and Lee 2006).

Methods

Participants and sampling

This study applied a neighbourhood-stratified sampling design. Households in Rhini, a suburb of Grahamstown, South Africa, were randomly selected in proportion to the total number of households in each neighbourhood. In each of the 20 neighbourhoods of Rhini, a random starting point was taken. Moving systematically through the neighbourhood, the researchers selected every tenth household for inclusion in the sample. This method ensured that all households in all neighbourhoods of Rhini stood an equal chance of being included in the survey.

Eligible respondents identified in each target household were at least 18 years old and had resided in Rhini for at least 6 months of the past year. One respondent per randomly-selected household was selected using a Kish grid (to ensure all eligible persons in the household stood an equal chance of being included in the survey) and interviewed. If this person was not available, up to four attempts were made to conduct the interview at a later time. The interview rate was 1020 of 1042 targeted households (97.9%). Reasons for forgoing the interview included not finding the respondent at home after four visits, old age or poor health, and disinterest or unwillingness.

Staff from Development Research Africa, a well-known organization experienced in undertaking national probability-based samples in deep rural and urban areas, administered the questionnaires. Almost all questions were closed-ended and a set of response options was supplied. The interviewers gathered demographic information about the participants, such as gender, age, health status, education level, living arrangements, and employment. A detailed description of this study population can be found in Møller (2007a, 2008).

Areas

Housing, infrastructure, and access to services in Grahamstown East/Rhini are historically grounded. The period of development is telling in terms of housing and neighbourhood conditions (Møller 2007a). Each neighbourhood has had its own wave of solutions to modernization, which may have contributed to differences in individual subjective well-being outcomes.

Measurements

Diener's Satisfaction with Life Scale (SWLS) was used to assess respondents' satisfaction with life as a whole. This instrument consists of five items rated on a 5-point scale: (1) in most ways my life is close to my ideal; (2) the conditions of my life are excellent; (3) I am satisfied with my life; (4) so far I have gotten the important things I want in life; and (5) if I could live my life over, I would change almost nothing (Pavot and Diener 1993). Cronbach's alpha for the SWLS in the present study was 0.88, indicating that the scale was reliable.

The Townsend index was used to investigate neighbourhood-level socioeconomic status effects on individual-level subjective well-being. It includes four variables: unemployment (lack of material resources and insecurity); overcrowding (material living conditions); lack of owner-occupied accommodation (a proxy indicator of wealth); and lack of car ownership (a proxy indicator of income). The four variables combine to form an overall score, which is a summation of the standardized scores (z scores) for each variable (scores > 0 indicate greater levels of material deprivation). A higher Townsend index score indicates a more deprived and disadvantaged neighbourhood. Since the score is considered the most reliable and viable indicator of material deprivation available, we used it to investigate neighbourhood-level differences in socioeconomic status and individual-level subjective well-being (Galobardes et al. 2007; Townsend et al. 1988).

The Gini coefficient of inequality was used to measure income inequality. The coefficient ranges from 0 (complete equality) to 1 (complete inequality) and has been shown to be valid and reliable (Kawachi et al. 1997).

Crime experience was assessed with the statement, "There is not a lot of crime in this neighbourhood". Respondents rated their level of agreement on a four-point scale.

Health status was measured via self-rated health, which is considered a valid and robust measure (Wen et al. 2003). A large body of evidence has demonstrated that self-reported health assessment has high predictive validity for mortality, physical disability, and chronic disease status. Furthermore, self-assessed health is a stronger predictor of mortality than physician-assessed health (Idler and Benyamanini 1997; Idler and Kasl 1995; Mossey and Shapiro 1982). As a subjective measure of health status, this measure captures the personally experienced problems of physical well-being that may impair subjective well-being (Wen et al. 2003).

Social capital was assessed with three items: "People in this neighbourhood are (1) friendly; (2) help each other without having to be asked; (3) trust their neighbours", to which respondents rated their level of agreement on a four-point scale. Cronbach's alpha was 0.87.The questionnaire further probed factors previously implicated as potential indicators of subjective well-being, such as income, education, unemployment, marital status, gender and age.

Data analysis

Our data analysis sought to verify the impact of contextual neighbourhood- and compositional individual-level effects on individual subjective well-being. We generated descriptive summary statistics and used Spearman's rank correlations to explore univariate associations between the independent variables and subjective well-being. To account for the hierarchical structure of the study design we fitted a hierarchical random-effects model. The hierarchical structure comprises 1020 individuals (level 1) nested in 20 neighbourhoods (level 2) of Rhini. Individuals were excluded if observations were missing for any outcome, leading to a total of 957 individuals in the MLRA. The independent variables were all standardized. The indicators of subjective well-being were estimated with a two-level random-intercepts and fixed slopes model structure. The resulting estimated parameters in the fixed part were tested by dividing the regression coefficient by its standard error. All regression models were employed using SPSS (Version 17.0) software.

We report our results in the sequence of analysis. To estimate the relative contributions of independent variables, we calculated the reduction in model deviance from the null (intercept only) to models containing the intercept and each individual variable. To estimate the strength of associations we obtained explained variance at both individual and neighbourhood levels. First we described the estimates of the empty model (1), which reflects variation in the intercept. Second, we estimated the adjusted coefficients of the different independent variables in two series of models (models 2 and 3). In model 2 we added the two contextual indicators at neighbourhood-level (the Townsend score and Gini coefficient). Because it is unclear whether contextual factors will continue to account for differences in subjective well-being at smaller spatial units of analysis characterised by consistent deprivation, we first added the contextual indicators (gini coefficient and Townsend score) in model 2. Model 3 contained the adjusted compositional coefficients of crime experience, social capital and health, the economic indicators of unemployment and income, and demographic data (age, gender, marital status and education).

Results

Respondents had a median age of 38 (range = 18-98) and the majority was female (73%). Just over half were single (52%), a third married (33%), and the others widowed (9%) or separated/divorced (6%). Forty percent had completed some secondary education and 18% had matriculated. Approximately 7% had received post-matriculation education and training. Only 8% had no formal schooling. Respondents' unemployment rate was 62%. Tables 1 and 2 provide descriptive statistics for the other individual-level independent variables and neighbourhood-level information, respectively.

Table 1. Descriptive statistics for the variables used in the regression analyses (N=1020).

Model	Mean	SD	Min	Max
Diener subjective well-being	2.62	0.87	1.00	5.00
Crime in the area	2.98	0.89	1.00	4.00
Social capital	2.04	0.54	1.00	4.00
Health status	5.00	3.55	1.00	5.00
Income	5713	1863	0.00	>7001

Univariate analyses of the associations between the neighbourhood- and individual-level indicators and subjective well-being are presented in table 3. The Townsend score, social capital, health, unemployment, income, marital status and education were all significantly correlated with subjective well-being in our sample.

Table 2. Summary descriptive statistics for neighbourhood-level indicators.

Neighbourhood	Townsend score	Gini coefficient
1	2.29	0.20
2	-0.66	0.17
3	-4.67	0.19
4	0.39	0.19
5	-0.47	0.19
6	-2.94	0.18
7	-2.24	0.16
8	-8.27	0.16
9	-0.09	0.17
10	-0.08	0.21
11	0.12	0.23
12	0.74	0.18
13	3.44	0.25
14	1.29	0.19
15	1.97	0.22
16	1.21	0.21
17	1.40	0.14
18	1.42	0.24
19	2.53	0.24
20	0.47	0.20

Table 3. Correlations between independent variables and subjective well-being.

N= 1020 in 20 neighbourhoods	*r*	*p*
Townsend score	-.112	<.0001
Gini coefficient	-.029	.360
Crime in the area	.003	.919
Social capital	.153	<.0001
Health status	.163	<.0001
Unemployment	-.147	<.0001
Income	.172	<.0001
Age	-.030	.337
Gender	-.039	.221
Marital status	.125	<.0001
Education level	.116	<.0001

The MLRA simultaneously evaluated the effects of neighbourhood-level indicators (Townsend score and Gini coefficient) and individual-level indicators (crime experience, social capital, health status, unemployment, income, and demographics) on subjective well-being at the individual level. Table 4 presents the results of MLRA.

Table 4. Multilevel regression analyses on subjective well-being.

Model	1		2		3	
	β	se	β	se	β	se
Constant	3.373	.059	3.362	.052	2.612	.052
Townsend score			-.118†	.059	-.110†	.060
Gini coefficient			-.002	.058	.019	.058
Age					.039	.033
Gender					.005	.026
Marital status					.093‡	.026
Education level					.030	.031
Social capital					.138‡	.027
Unemployment					-.031	.031
Income					.075*	.031
Health status					.138‡	.031
Crime in the area					-.004	.027
- 2 log likelihood	2542		2537		2274	
Variance level 1 individual	.700‡	.031	.700‡	.032	.614‡	.028
Variance level 2 area	.050†	.023	.035†	.018	.036†	.017
Explained variance level 1			0%		8.3%	
Explained variance level 2			30.0%		40.0%	

Notes: $^{\ddagger}p \leq .001$; * $p \leq .01$; $^{\dagger}p \leq 0.05$.

The first set of contextual indicators documents the influences of neighbourhood-level socioeconomic status (Townsend score) and neighbourhood-level income inequality (Gini coefficient) on individuals' subjective well-being. They were tested by regressing subjective well-being on possible indicators of subjective well-being (model 2 of table 4). Neighbourhood-level socioeconomic status appears to be a significant indicator of subjective well-being (Townsend score: β -.118; p < .05), while neighbourhood-level income inequality is not. In sum, individuals appear to have higher reported levels of subjective well-being when their neighbourhood is less deprived when measured with the Townsend deprivation score. Income inequality within the neighbourhood was less influential for subjective well-being outcomes in our population. The explained neighbourhood-level variance is 30%. The second set of indicators measured the association between crime experience, social capital, health, unemployment, income, demographics and subjective well-being by regressing subjective well-being on the indicators (model 3 of table 4). The Townsend score remains an indicator of subjective well-being (β -.110; p < .05). Social capital is associated with subjective well-being (β .138; p < .001) as is health status (β .138; p < .001) and income level (β .075; p < .01). Unemployment and neighbourhood crime did not emerge as significant indicators for subjective well-being. Among the demographic variables, only marital status was a strong indicator of subjective well-being (β .092; p < .001). The explained variance is 8.3% at the individual level and 40.0% at the neighbourhood level. The strongest associations with subjective well-being in this population are social capital, health, and marital status (all $p < .001$), followed by income level ($p < .01$) and the Townsend score ($p < .05$).

Discussion

This article has presented cross-sectional evidence for the correlated nature of subjective well-being at the individual and neighbourhood levels. The key findings of this study are as follows. First, the Townsend deprivation score is a statistically significant indicator of subjective well-being. People living in more deprived areas report lower subjective well-being.

Neighbourhood income inequality was not found to be statistically significant indicators of subjective well-being. These differences may be related to the scale of analysis. For example, compared to the national level of inequality in South Africa (0.58; United Nations, 2009) this study investigated income inequality at a lower geographical level of aggregation, within a single South African township. The gini coefficients of the 20 neighbourhoods in our Eastern Cape suburb ranged from 0.14 to 0.25. Compared to South Africa's national level of inequality, the residents of Rhini shared equal (low) incomes. Investigation of a larger region with more pronounced neighbourhood income inequalities may produce different results.

Second, social capital, marital status, health and income were strongly associated with subjective well-being. Third, in contrast with previous single-level subjective well-being studies that have consistently found a negative association with unemployment (Clark and Oswald 1994; Hoorn 2007), the variable did not emerge as a statistically significant indicator in our MLRA. The effect, however, could be minimized by the Townsend deprivation score and the income variable. In our correlation analysis, unemployment did significantly correlate with subjective well-being. Fourth, the demographic indicators of educational level, age, and gender did not statistically significantly affect individual-level subjective well-being in our study. However, univariate regression analysis showed that education correlated with subjective well-being. The effect of education in the MLRA may also be partly minimized by income and the Townsend deprivation score.

Our research is not without limitations. The cross-sectional design hampered our ability to capture neighbourhood dynamics and draw causal inferences. Although it is not possible to determine the direction of the causation, our results establish a significant association, an important step that prompts further study to identify directionality. We were unable to take into account the impact of residential changes and the cumulative effects of the socioeconomic environment over time. Our study was restricted to a single Eastern Cape suburb, perhaps limiting the applicability of our findings, but given the many areas with similar neighbourhood characteristics that exist in African developing countries, our study is likely to be applicable elsewhere. To our knowledge, we are the first to use MLRA in the investigation of subjective well-being. Our results therefore need confirmation, especially using data from similar African areas.

In conclusion, the study demonstrated high degrees of explained variance at neighbourhood level. We highlighted the role of context for subjective well-being, and suggested that subjective well-being outcomes may also be defined in ecological terms. We identified multilevel factors that are associated with subjective well-being for people living in health- and economically-deprived areas and believe the findings are useful for implementing programs and interventions designed to achieve greater subjective well-being. Research shows that subjective well-being fuels individual differences in resilience that affect health outcomes (Fredrickson 2001). The positive effects of enhanced subjective well-being on resilience help build an individual's personal resources. These resources allow people to achieve well-being in multiple ways, as they can substitute one resource for another (Nieboer and Lindenberg 2002; Nieboer et al. 2005). It is therefore important that programs aimed at one resource (e.g., economic development) in deprived areas are not implemented at the expense of another (e.g., social capital) that may ultimately harm overall well-being scores (Cramm et al. 2010). Subjective well-being promotes physical health and longevity and as such the indicators of subjective well-being found in this study need to be protected. Healthy people, in turn, are more productive in economic and social terms and thus contribute to overall economic and social development.

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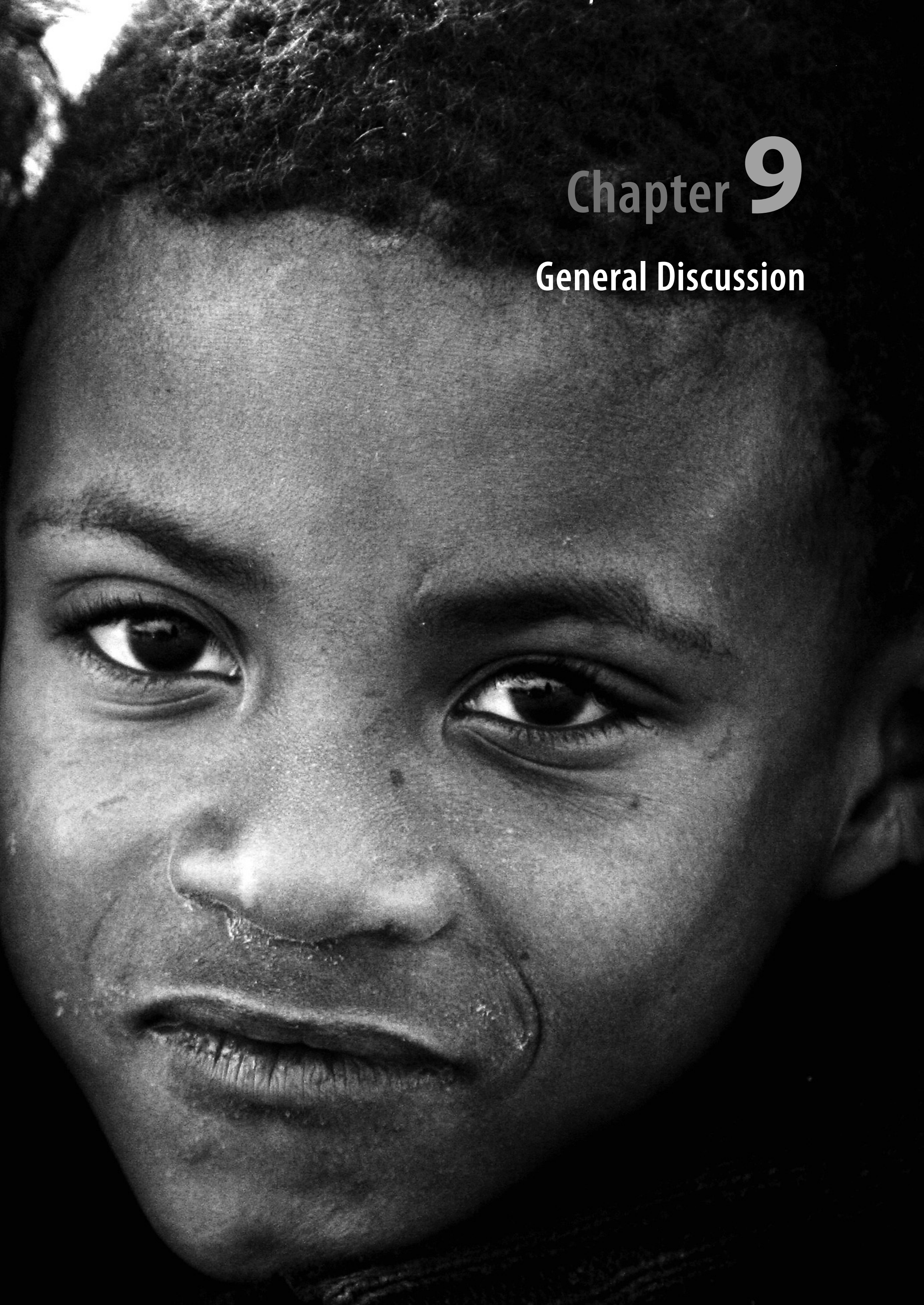
Chapter 9

General Discussion



Introduction

Outcomes of widely implemented top-down disease programs and reaching the MDGs in sub-Saharan Africa falls short of expectations (WHO, 2008; MDG Steering Group, 2008). In-dept understanding of the relationships between individual and environmental social and economic conditions within a local context is necessary to increase our understanding of the specific situation people living in these deprived areas are dealing with (Mitchell & Linsk, 2004). This dissertation aimed to identify the relationships between individual and environmental social and economic conditions and health and subjective well-being within one economically and health-deprived community in Rhini, a small township of Grahamstown, in the Eastern Cape province of South Africa. High levels of poverty and unemployment characterize this community. Furthermore, this region reports one of the worst TB cure rates in South Africa and one of the highest TB incidence and prevalence numbers. Therefore, this community represents an interesting population for the purposes of this dissertation. Increased in-dept understanding of the relationships between individual and environmental social and economic indicators and health and well-being among a community in consistent economic deprivation may enable development agencies, healthcare organization and governments to develop more effective policies and programs. Such programs may enhance health, promote a healthier environment, intensify primary prevention, and influence public policies in all sectors to address the root causes of (environmental) threats to health and subjective well-being. This study is part of a three-year project (2006-2008) on TB Stigma and Quality of Life in the Eastern Cape and build upon earlier held focus group discussion and in-dept interviews with TB patients on treatment. Eight focus group discussions were held with 59 residents from Rhini. Discussants represented a mix of generations, socio-economic backgrounds, and bio-medical and traditional knowledge of TB. Groups participating in the study included high school youth, school leavers, middle-aged and older men and women, TB patients, health workers, and traditional healers" (Møller and Erstad, 2006; 2007).

This chapter first presents and contextualizes the main findings of the study. Next, theoretical and methodological considerations are discussed. Finally, the implications of this research for policy, service delivery and future research are described.

Main Findings on health and social burdens

Health

Our investigation of the relationship between (stigmatising) ideas and TB treatment preferences revealed two belief systems within this community; one characterized by

TB stigma, the other by the view that TB patients should queue with other chronically ill patients. These two belief systems led to opposing attitudes toward assistance for TB patients on treatment. They are related to visibility factors that expose patients to stigmatization. The fact that the two belief systems cause a contradiction in the community complicates treatment outcomes, and suggests that complex behaviors must be taken into account when designing health policy and health services (Chapter 5). In addition, in our community perception study, TB lay experts perceived that stigmas played a significant role in case finding and case holding (Chapter 4). This poses a significant public health threat in the form of higher transmission and morbidity rates, and higher costs for TB control programs (Johansson et al., 1999). Moreover, non-adherence leads to persistence and resurgence of TB and is regarded as the chief cause of relapse and drug-resistant or multi-drug resistant strains (WHO, 2008).

Examination of the views on determinants of (non) adherence among compliers and defaulters indicated that stigmatization makes TB a “social disease”. Individual motivation and self-efficacy appear to have considerable effects on compliance, but the general lack of prospects among non-compliers for finding work and being able to provide for themselves or their family also makes TB very much an “economic disease” (Chapter 6). Other studies have also found that a patient’s financial situation greatly affects adherence behaviour (Johansson, Long, Diwan, & Winkvist, 1999; Van Exel, de Graaf, & Brouwer, 2006). Development programs that improve these social and economic factors may therefore contribute to declining incidence and prevalence rates of TB. Studies of TB treatment outcomes emphasize that social and economic factors interact, and therefore cannot be viewed in isolation when trying to understand treatment adherence or developing community-based TB treatment programs (Munro et al., 2007; Sagbakken et al., 2008a; Sagbakken et al., 2008b).

Our study contributes to this issue by specifically addressing social and economic interactions from the patient perspective. We have detailed the relative values given to these social and economic factors by compliers and defaulters, and have shown that this interaction works differently for compliance and non-compliance with treatment (Chapter 6). Treating visible signs of disease and enabling patients to return to socially and economically productive lives may trigger a virtuous social cycle. More intervention is needed, however, given the persistence of social stigma and the attendant challenges of adherence to pill-taking and appointment follow-ups in the setting of limited social support. Policy makers, healthcare organizations and program implementers may improve treatment outcomes by linking treatment programs with specific interventions to empower patients to cope with the disclosure of their TB status and to maintain participation in or re-integrate into family and community life while on therapy (Mahajan, 2008).

This study investigated relationships between individual- and neighbourhood-level socioeconomic indicators and self-rated health, and revealed that employment and education are associated with better health outcomes within a small economically and health-deprived community (Chapter 2). These results suggest that health outcomes may be improved by interventions that aim to create job opportunities, strengthen education systems and promote educational access for all community members. Our study has also demonstrated that in a single economically disadvantaged community, the quality of housing and the social environment significantly are related to the risk of developing TB (Chapter 3). Therefore when developing programs that aim to reduce the spread of TB in economically poor districts, it may be beneficial to address housing and social environments.

Subjective well-being

We investigated the relations between income, health, social capital, marital status, employment, education and crime experience and subjective well-being within a poor community in the Eastern Cape of South Africa. Higher income was associated with higher subjective well-being, and social capital was related to subjective well-being in all income groups. In the low-income group only social capital factors were linked to subjective well-being (Chapter 7).

This study also identified multilevel factors that are related to subjective well-being among people living in an economically and health-deprived area. The strongest relationship with subjective well-being was found with social capital, health and marital status, followed by income level and the Townsend deprivation score. The Townsend score was demonstrated to be a significant indicator of subjective well-being. Individuals reported higher levels of subjective well-being in less deprived neighbourhoods. Our findings point to the importance of recognizing community-level resources as a primary target for intervention, and for the protection and strengthening of individual-level buffers (Chapter 8).

Theoretical and methodological considerations

Theoretical reflections

One implication of subjective well-being is the variability of conditions across cultures. If subjective well-being is a culture-specific construct, its determinants will also be culturally specific. Empirical studies seeking correlates of subjective well-being should thus show considerable cultural variation and lack of universal patterning. Yet the available data show otherwise. Comparisons of average subjective well-being between and within countries show much similarity. In particular, social capital and health are strong correlates of subjective well-being all over the world (Diener, 2000; Veenhoven, 2006a).

A second implication is the variability of subjective well-being over time. Its dependence on shared notions of the good life should lead to variation in average subjective well-being in different nations. Again, the data contradict this premise. Average subjective well-being has been stable in Western nations over the last 30 years, increasing slightly without much fluctuation (Veenhoven, 2006b). Follow-up studies at the individual level have also shown considerable constancy over time (Ehrhardt, Saris, & Veenhoven, 2000). Why are people still fairly satisfied with their lives even when they lack important resources such as income or employment? One plausible answer to this question is that people are much more active in the production of their own subjective well-being than is generally assumed (Nieboer, 1997). People are resourceful in substituting across different life-domains and different forms of subjective well-being. For example, a loss of status can be compensated by focusing more on behavioral confirmation and affection and even by putting more emphasis on stimulation and comfort. (Nieboer & Lindenberg, 2002). Thus, while overall subjective well-being outcomes are stable over time via substitution processes they can be caused by different domains.

A third implication is that subjective well-being is of little consequence. If subjective well-being is merely cognitive spin based on fashionable ideas, its positive or negative nature will not matter much. Once more, this appears not to be the case. Subjective well-being goes hand in hand with objective thriving, and follow-up studies have shown that it is a strong predictor of physical health and longevity (Danner, Friesen, & Snowdow, 2001).

Some researchers have argued that stigma is context-specific and variable across time. Evidence from a multi-country study conducted from 2001-2004 in several developing African countries shows otherwise (ICRW, 2006). Stigma is far less varied and context-specific than assumed. Rather, its key causes, impact, and consequences have shown many more similarities than differences across contexts.

Study Design

This research is not without limitations. The absence of data on HIV infection, an established risk factor for TB, poor health and subjective well-being, is a principal limitation of these studies. The interaction of HIV and TB, health and well-being outcomes is a crucial consideration when generalizing our results and when designing interventions to reduce health and social burdens. Furthermore, the cross-sectional design of the multilevel and community studies hampered our ability to capture neighbourhood dynamics and to draw causal inferences. We were unable to take into account the impact of residential changes and the cumulative effects of the socio-economic environment over time. It is not possible to determine the direction of demonstrated causations using our study findings. Our results establish a significant association between social and economic conditions and health and subjective well-being, which is an important step that prompts further studies to identify directionality. In addition, the study on TB outcomes at household level used measures based on self-reported data rather than laboratory-confirmed disease. These measures may have diverged if respondents recall was imperfect or if not all household members disclosed their TB status to other household members. Evidence from South Africa suggests that reliance on self-reported past TB experience may lead to underreporting (TeWaterNaude et al., 2006). This research only investigated relationships between social and economic conditions and health and well-being, studies with a quasi experimental design are necessary to identify effects and causality of social and economic conditions on health and well-being outcomes. Furthermore, longitudinal studies including more respondents per household are called for to increase our understanding of the interplay between individual, household and neighbourhood level effects on health and well-being.

Many researchers have recommended that multilevel applications of observational data be grounded in substantive theories that carefully consider what to measure and how to critically evaluate findings. Multilevel analyses can thereby bring extra predictive power that allows the researcher to understand causal effects (Diez Roux, 2004; Oakes, 2004; Subramanian, 2004). We followed these recommendations in our study, and our findings successfully identified important social and economic associations with health and subjective well-being. We were able to increase our understanding of the individual- and neighbourhood-level relationships with health and subjective well-being. In addition, a combination of methods can strengthen research findings (Diez Roux, 2004; Oakes, 2004; Subramanian, 2004). The associations found in our survey studies are measures of conditional associations under certain circumstances. Findings from our Q-study support these associations, and strengthen the notion that the health of people living in a poor region are related to social and economic conditions.

Our study is restricted to a single Eastern Cape suburb, limiting the applicability of our findings to other areas. However, our study findings are theoretically consistent which suggests that the identified mechanisms of health and subjective well-being are relevant to the other areas especially with similar neighbourhood characteristics in developing African countries. To our knowledge, our study is the first to use MLRA in the investigation of subjective well-being and the first MLRA investigating health and TB within a small and poor community. Our results therefore need confirmation, especially from similar African areas.

Implications for research and practice

Our results show that health and social burdens of people living in an economically and health-deprived area are associated with social and economic conditions. To promote health equity within these deprived communities may be achieved with improvement of the social and economic conditions in close collaboration with actors beyond the health sector. To combat stigma and empower patients, a patient-centred approach focused on interventions at the individual level may be beneficial. Multidimensional and multilevel approaches may further reduce stigma and enhance subjective well-being and health (Bos, Schaalma, & Pryor, 2008; Mahajan et al., 2008; Maughan-Brown, 2009; Mutalemwa et al., 2008; Nyblade, Stangl, Weiss, & Ashburn, 2009; Chapter 2; Chapter 3; Chapter 5; Chapter 6; Chapter 7; Chapter 8). Such multidimensionality accounts for the range of conditions and actors within and beyond the health sector that can contribute to enhanced health and subjective well-being outcomes. Multilevel approaches account for individual, and community levels of stigma and individual- and environmental-level that are related to health and subjective well-being. Since neighbourhoods and communities are amendable to intervention, changes at these levels may effectively improve the health of populations.

Social and economic conditions at the individual and environmental levels are associated with the health and subjective well-being of individuals living in deprived areas (Chapter 2; Chapter 3; Chapter 5; Chapter 6; Chapter 7; Chapter 8). Our study findings suggest that health outcomes may be improved by strengthening community-level social capital, employment and education. Social capital is an important enabling factor for health seeking behavior and adherence in a resource-limited setting (Chapter 6), since people who adjust are more likely to sustain the management of their condition (Russell & Seeley, 2010). People need meaningful economic and social lives to live with as well as manage their diseases or illnesses (Chapter 6; Straus, 1990). With guidance and support people can become active self-managers of their condition (Kralik et al., 2004). Guidance and support must, however, take into account people's own perspectives and strategies, looking beyond the perspective of health professionals and simple adherence to medicine, to take into account patients' wider social and economic lives and the family and social contexts in which they are living (Chapter 2; Chapter 3; Chapter 6; Kralik et al., 2004; Mitchell & Linsk, 2004). Growing evidence from many African developing countries supports the concept that community-based approaches can be highly effective in improving the health of populations, especially when these approaches are connected to other community-based activities for social and economic improvement. Such community-based approaches promote empowerment of individuals and communities, social justice, equity, community participation, and inter-sectoral approaches to health improvement. While top-down approaches are necessary to obtain the support of policymakers and donors, these approaches too often fail to give adequate attention to strengthening the health service delivery system at the community level. Professional and lay health workers therefore need to understand the social and economic lives of patients, their quests for order and control, the challenges that they face and the support that they need beyond medicine (Russell & Seeley, 2010). Local economic development strategies and interventions to support livelihood rebuilding strategies should be designed to meet the specific needs of each community. Policies and service delivery programs that stimulate local economic development and support household businesses in poor communities may also need to be designed to enhance social capital and to effectively function within the neighbourhoods' social structure (Chapter 3; Chapter 6; Chapter 7; Chapter 8).

It is of great importance that international development and health organizations and national health promotion programs acknowledge the differences in socioeconomic and environmental health-related risk factors in different settings, and the interactions among these factors. To effectively promote good health, programs need to be targeted at specific populations. It seems essential that governments, health and development agencies develop comprehensive community based approaches adapting their plans to the needs of the local community in order to improve health outcomes, especially within poor and health-deprived communities. Identifying local health and socioeconomic priorities, needs, capacities and implementing appropriate strategies may also promote empowerment of individuals and communities.

Research shows that subjective well-being fuels individual differences in resilience that affect health outcomes (Fredrickson, 2001). Buffers allow people to achieve well-being in multiple ways, as they can substitute one means for another (Nieboer & Lindenberg, 2002; Nieboer et al., 2005). While the better-off individuals can substitute one means of subjective well-being for another, small changes for the most deprived who lack these buffers often negatively impacts their well-being levels (Diener & Lucas, 2000; Nieboer & Lindenberg, 2002; Nieboer et al., 2005). It is therefore important that programs designed to address one buffer (e.g., economic development) in deprived areas are not implemented at the expense of other buffers (e.g., social capital). This process may ultimately harm overall well-being scores.

Social stigmas have important implications for the affected person's subjective well-being, health and for epidemic control (Macq et al., 2005). People with TB are severely affected by stigmas and discrimination. Stigmas are increasingly recognized to have a major impact on public health interventions by delaying diagnosis, prolonging the risk of transmission, leading to poor treatment adherence and increasing the risk of disability and drug resistance. The availability of a treatment does not necessarily mean that individuals will seek it out or adhere to it; behaviour is much more complex and is influenced by belief systems (Azjen, 1991). Disease-related stigmas not only pose negative consequences for the infected individuals and their households, but also affect public attitudes toward prevention, service provision, and health-related policies (Chapter 5; Macq et al., 2005). We suggest that community education should focus on reducing stigma and improving attitudes and perceptions. Stigmas are complex social constructs that are influenced by many factors. Assumptions that disease-related stigmas will decrease as soon as treatment is provided should not be automatically transferred to expectations about the effect of a particular intervention on stigmatization. Instead, a multi-dimensional approach is necessary to monitor stigmas over time and to identify the factors and processes by which stigmas are changed. The increases in HIV- and TB-related stigmas, despite antiretroviral medications and TB treatment programs, highlight that renewed efforts to reduce stigma are imperative. Such efforts include interventions that recast TB and HIV as chronic manageable conditions (Chapter 5; Maughan-Brown, 2009).

Although stigma is considered a major barrier to effective responses to the HIV/AIDS and TB epidemics, stigma reduction efforts are often relegated to the bottom of treatment program strategies (Mahajan et al., 2008). While much work has been carried out to understand stigmatization and develop stigma reduction strategies, far less emphasis has been placed on assessing their effectiveness. A literature review conducted by Heijnders & van der Meij (2006) identified several levels at which stigma reduction strategies and interventions were implemented for HIV/AIDS, mental illness, leprosy, TB and epilepsy. They conclude that single-level and single-target-group approaches are not sufficient to significantly reduce disease-related stigma and discrimination. Meaningful reduction requires a patient-centered approach, beginning with interventions at the individual level (e.g., empowerment, self help, advocacy and support groups). Research shows that patients' internalized stigma is reduced when a package of interventions, including TB or HIV clubs and patient-centred home visits, is successfully implemented (Macq, Solis, Martizes, & Martiny, 2008). The next step is involvement of TB patients in the development of stigma reduction programs at the organizational/institutional and community levels (Heijnders & van der Meij, 2009). The consideration of patients' experiences may help healthcare organizations, care providers and policy makers develop training programs and interventions at these levels that contribute to stigma reduction, rather than unintentionally enhance stigmatization. A shift in power relations and an active role for patients in this process could lead to more patient-centered programs, empowerment of patients, and stigma reduction. For example, training workshops for health workers in governmental TB control programs have been shown to effectively eliminate stigma among those health workers (Wu et al., 2009). A review of stigma in the HIV/AIDS epidemic concluded that roll-out of treatment programs should be linked with community-level stigma reduction interventions (Mahajan et al., 2008). Patients suffer from stigma at both the community and organizational levels (Mutalemwa et al., 2008; Wu et al., 2009). Research shows that stigmatization of persons with TB or HIV by health care workers leads to inadequate treatment, resulting in more patients who decline to disclose their TB or HIV status to friends and family (Mutalemwa et al., 2008). In addition, this stigmatization leads to delays in seeking medical care and problems of adherence (Wu et al., 2009). Stigma reduction in health care facilities has important implications for improving patient-provider interactions, improving quality of care, and creating a safe and supportive environment to help patients deal with or challenge stigma from family and community members (Nyblade, Stangl, Weiss, & Ashburn, 2009). The improvement of communication between health professionals and patients and the reduction of stigma are essential for improving treatment adherence, even with directly observed treatment short course (DOTS) (Mishra et al., 2006).

Although the combination of TB and HIV/AIDS treatments is promoted as the most cost-effective strategy (Karim et al., 2009), some groups within this community would still be overlooked and this may be more generally applicable to other populations (Chapter 5). Solutions are not easy or clear-cut, especially when considering highly stigma-sensitive diseases associated with complex behaviours (Chapter 5; Chapter 6). Various strategies on policy and services delivery levels are probably necessary to improve access and adherence numbers and, thereby, treatment outcomes. Further research that examines whether treatment outcomes are improved by different organization of access to treatment (e.g., separate queues for TB patients, queuing TB patients with other chronically ill patients, combining TB and HIV/AIDS patients) would provide additional guidance for the development of these strategies.

Policy makers, healthcare organizations, care providers and community health workers must realize that disease-related stigma directly harms social capital, the only source of subjective well-being among deprived individuals (Chapter 7). Social capital as a facilitator and stigma as a barrier are diametrically opposed concepts. Disease-related stigmas not only pose negative consequences for the infected individuals and their households, but also affect public attitudes toward prevention, service provision, and health-related policies (Chapter 4, Chapter 5). Programs that aim to enhance health and subjective well-being may be most effective if they simultaneously seek to reduce disease-related stigmas. Through the assurance of a comprehensive approach based on principles of equity, disease prevention, and health promotion governments, policy makers, care providers and community health workers may help alleviate social inequities, reduce exposure to physical and psychosocial hazards, and enhance opportunities for health and subjective well-being. These interventions should be closely monitored and evaluated over time to identify the most effective components and assess the underlying mechanisms affecting stigma, health and subjective well-being. Future programs may thereby substantially improve the health and subjective well-being of populations, and reduce health inequality.

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Summary

To be poor is by definition to have less of the good things in life, including health and longevity. In all countries at all levels of income, health and illness follow a social gradient: the lower one's socioeconomic position, the worse one's health. Socioeconomic determinants of health are responsible for a major part of health inequities between and within countries. Differences of this magnitude simply should not occur since these differences in health are judged to be avoidable. Putting right these inequities is a matter of social justice.

The nature and depth of health inequity are often not well understood on account of lack of adequate data. Good understanding of the relations between socioeconomic conditions and health is essential. Comprehensive data are mostly lacking in countries with the worst health problems, which tend to be economically and healthcare-deprived communities. This dissertation aimed to identify the relationships between individual and environmental social and economic conditions and health, subjective well-being and the burden of stigma within the Eastern Cape South Africa.

Stigma

Social stigmas have important implications for the affected person's subjective well-being and health, as well as for epidemic control. We focused attention on people with tuberculosis (TB), who are severely affected by stigmas and discrimination. Stigmas are thought to have a major impact on public health interventions. They may lead to delayed diagnosis and thus higher risk of transmission; to poor treatment adherence; and to higher risk of disability and drug resistance. The availability of treatment does not necessarily mean that individuals will seek it out or adhere to it; behaviour is much more complex and is influenced by belief systems. Disease-related stigmas not only pose negative consequences for the infected individuals and their households, but also affect public attitudes toward prevention, service provision, and health-related policies. Our investigation of the relation between (stigmatising) ideas and TB treatment preferences revealed two belief systems related to disease visibility factors that expose patients to stigmatization among community members. Consequently we observed opposing attitudes toward assistance for TB patients on treatment. Such a division in the community complicates treatment, and suggests that health policy makers must take these opposing attitudes and complex behaviors into account. In addition, from our community perception study it appeared that TB lay experts see a significant role for stigmas in case finding and case holding. Furthermore, examination of the views on determinants of (non) adherence among compliers and defaulters indicated that stigmatization makes TB a "social disease". Individual motivation and self-efficacy appear to considerably enhance compliance, but the general lack of prospects among non-compliers for finding work and being able to provide for themselves or their family also makes TB very much an “economic disease”. Development programs that improve these social and economic factors may therefore help to bring down the incidence and prevalence rates of TB. Social and economic factors interact, and therefore should not be viewed in isolation when trying to understand treatment adherence or developing community-based TB treatment programs. Treating visible signs of disease and enabling patients to return to socially and economically productive lives may trigger a virtuous social cycle. More intervention is needed, however, given the persistence of social stigma and the attendant challenges of adherence to pill-taking and appointment follow-ups in the setting of limited social support. It may be beneficial to link treatment programs with specific interventions aimed at empowering patients to cope with the disclosure of their TB status and at participation in family and community life while on therapy.

Health

Most human development programs seek as a primary goal to improve the health of those most affected by poverty. Health and health equity may not be the aim of all social and economic policies, but these factors may be fundamentally impacted by nearly every policy implemented. Inequity is evident in the conditions of early childhood and schooling, the nature of employment and working conditions, the physical form of the built environment, and the quality of people’s natural and social environments. The variation in the experiences of material conditions, psychosocial support, and behavioural options results in differential vulnerability to poor health. Social stratification has consequences for the inequitable promotion of health, disease prevention, and illness recovery and survival. Policy actors need to understand the factors affecting a population’s health and the operation of the social gradient. Coherent action at all levels of government is essential to achieve better health equity. This would require good understanding of health inequity and the socioeconomic conditions related to health. We studied these relationships in an economically and health-deprived community in the Eastern Cape of South Africa – characterized by high levels of poverty and unemployment and multiple deprivation domains such as income, education, employment and health. It was found employment and education are related to improved health outcomes. Therefore, it may be beneficial to set up interventions that aim to create job opportunities, strengthen education systems and promote educational access for all community members. Our study has also demonstrated that poor housing quality is associated with higher risk of TB infection and that a solid social environment protected against TB infection. Addressing housing and social environments when developing programs that aim to reduce the spread of TB in economically poor districts may lead to improved outcomes.

Subjective well-being

Research shows that subjective well-being fuels individual differences in resilience that affect health outcomes. Subjective well-being is influenced by different valuations that people make regarding their lives, the events happening to them, and circumstances in which they live. Since non-monetary measures of well-being are critical, the wider issue of human development is also important. Income is important for subjective well-being, but what other aspects would buffer subjective well-being among the poor? Buffers allow people to achieve well-being in multiple ways, as they can substitute one means for another. Apart from income, employment, health and education, social capital is increasingly acknowledged as an important determinant of subjective well-being. We studied relationships like these in a poor community in the Eastern Cape of South Africa. Higher income was associated with higher subjective well-being, and social capital was important for subjective well-being within all income levels. For the poorest, only social capital factors were linked to subjective well-being. It is therefore important that programs designed to address one buffer (e.g., economic development) in deprived areas are not implemented at the expense of other buffers (e.g., social capital). Neglecting this requirement may ultimately harm overall well-being scores.

Implications for future strategies

International organizations and national health promotion programs cannot but acknowledge the differences in socioeconomic and environmental well-being and health-related risk factors in different settings. Programs need to be targeted at specific populations. It is essential that governments adapt their plans to the needs of the local community; this may improve outcomes, especially within poor and health-deprived communities.

Our results show that social and economic conditions are related to health and subjective well-being. Strengthening these socioeconomic conditions may reduce the health and social burdens of people living in an economically and health-deprived area and promote health equity. An essential precondition in this process is close collaboration with actors beyond the health sector. Solutions are not easy or clear-cut, especially when considering highly stigma-sensitive diseases associated with complex behaviours. Various strategies are probably necessary to improve access and adherence to treatment and, thereby, to treatment outcomes. A patient-centred approach is required to combat stigma and to empower patients. Approaches to further reduce stigma and enhance subjective well-being and health probably need to be multidimensional and multilevel. Such multidimensionality accounts for the range of conditions and actors within and beyond the health sector that can contribute to enhanced health and subjective well-being outcomes. Multilevel approaches account for individual, organizational and community levels of stigma as well as for individual- and environmental-level relationships with health and subjective well-being. Since neighbourhoods and communities are amenable to intervention, changes at these levels may effectively improve the health of populations.

Policy makers must realize that disease-related stigma directly harm social capital, the only source of subjective well-being among deprived individuals. Social capital as a facilitator and stigma as a barrier are diametrically opposed concepts. Disease-related stigmas not only pose negative consequences for the infected individuals and their households, but also affect public attitudes toward prevention, service provision, and health-related policies. Programs that aim to enhance health and subjective well-being must therefore simultaneously seek to reduce disease-related stigmas. A comprehensive approach based on principles of equity, disease prevention, stigma reduction and health promotion may help alleviate social inequities, reduce exposure to physical and psychosocial hazards, and enhance opportunities for health and subjective well-being.

Samenvatting

Sociale ongelijkheid veroorzaakt grote verschillen in levensverwachting wereldwijd, wat niet door biologische factoren kan worden verklaard. Overal, ongeacht het inkomensniveau, vertonen gezondheid en ziekte een sociale gradiënt: hoe lager de sociaal economische positie des te slechter de gezondheid. Sociaal-economische determinanten van gezondheid zijn verantwoordelijk voor een groot deel van de ongelijkheid in gezondheid. Deze verschillen zouden simpelweg niet mogen bestaan, omdat ze vermijdbaar zijn. Het bestrijden van deze vermijdbare gezondheidsverschillen is daarmee een kwestie van sociale rechtvaardigheid.

In landen met de grootste gezondheidsproblemen is de minste gezondheidsinformatie informatie beschikbaar. Maar juist daar is het van belang te weten welke relaties er bestaan tussen sociaal-economische omstandigheden en gezondheid.

Deze dissertatie beoogt de onderliggende sociale en economische relaties te achterhalen die gezondheid, welzijn en stigma beïnvloeden in een arme gemeenschap met grote gezondheidsproblemen – en wel op individueel en buurtniveau. De studies in deze dissertatie betroffen een arme gemeenschap met grote gezondheidsproblemen in de Oostkaap van Zuid-Afrika.

Stigma

Sociale stigma's hebben belangrijke implicaties voor het welzijn en de gezondheid van de betrokkenen en epidemiologische beheersbaarheid van ziekte. Deze stigma's vormen een belangrijke barrière voor het succes van gezondheidsinterventies. Bij tuberculose (TBC) resulteert dit in een verlate diagnose en dus groter risico op verspreiding van TBC; problemen met therapietrouw; en uiteindelijk een grotere kans op lichamelijke beperkingen en resistentie tegen medicijnen. Het feit dat behandeling gegeven kan worden betekent niet dat men automatisch hulp zoekt en de behandeling trouw volgt; gedrag is veel complexer en wordt beïnvloed door persoonlijke overtuigingen van mensen. Ziektegerelateerde stigma's hebben niet alleen negatieve consequenties voor de persoon in kwestie en diens omgeving, maar zijn ook van invloed op publieke attitudes ten aanzien van preventie, zorgverlening, en gezondheidsgerelateerd overheidsbeleid. Dit onderzoek naar de relatie tussen (stigmatiserende) ideeën en voorkeuren voor TBC-behandelingen toont aan dat er twee overtuigingen leven in deze gemeenschap, gerelateerd aan de zichtbaarheid van de ziekte. Deze twee overtuigingen gaan gepaard met twee tegengestelde voorkeuren voor behandeling voor TBC patiënten. Dit staat een succesvolle behandeling van TBC patiënten in de weg en wijst er op dat men bij het vaststellen van gezondheidsbeleid rekening moet houden met verschillende voorkeuren en complex gedrag. Daarnaast heeft de studie onder "leken"-experts aangetoond dat stigma een belangrijke rol speelt bij het opsporen van

TBC patiënten en bij therapietrouw. Dat stigma van TBC een “sociale” ziekte maakt bleek uit het onderzoek naar meningen over determinanten van (niet) therapietrouw zijn onder TBC patiënten die óf hun behandeling helemaal hebben afgerond óf eerder zijn gestopt. Individuele motivatie blijkt een enorme invloed te hebben op therapietrouw van TBC patiënten. Gebrek aan goede economische vooruitzichten (zoals een baan) blijkt daarentegen een belangrijke reden voor voortijdig staken van de therapie, wat TBC een “economische” ziekte maakt. Ontwikkelingsprogramma’s gericht op het verbeteren van deze sociale en economische factoren kunnen de incidentie en prevalentie van TBC wellicht helpen verminderen. Sociale en economische factoren hebben een wisselwerking op elkaar, en kunnen niet los van elkaar worden gezien als we therapietrouw echt willen begrijpen. Deze wisselwerking is ook van belang bij het ontwikkelen van behandelprogramma’s. De weg naar een eervol en volwaardig sociaal bestaan ligt open als de TBC-behandeling minder ‘zichtbaar’ wordt gemaakt en de patiënten in staat worden gesteld sociaal en economisch productief te zijn. Gezien het feit dat stigma’s moeilijk uit te bannen zijn en dat het in een omgeving waar men weinig steun krijgt een uitdaging is om gedurende minstens 6 maanden dagelijks medicijnen in te blijven nemen en op controleafspraken te verschijnen, zijn specifieke interventies gewenst. Deze dienen te zijn gericht op het versterken van de positie van TBC patiënten, zodat zij hun TBC status durven te uiten en deel uit kunnen maken van het gezin, de familie en de gemeenschap.

Gezondheid

De meeste hulporganisaties hebben als doelstelling om de gezondheidssituatie te verbeteren van degene die er het slechtste aan toe zijn: de armste bevolkingsgroepen. Gezondheid (en gezondheidsgelijkheid) is wellicht niet de (primaire) doelstelling van alle economische en sociale interventies, maar bijna al deze interventies hebben daar wel invloed op. Ongelijkheid ontstaat al in de vroege jeugd, bij het naar school gaan, in de werkomgeving, en in iemands natuurlijke en sociale omgeving. Er ontstaat daarom een variëteit aan materiële condities, psychosociale steun en gedrag, hetgeen resulteert in verschillende niveaus van kwetsbaarheid in gezondheidsstatus. Sociale stratificatie leidt tot ongelijkheden in gezondheidsbevordering, ziektepreventie en herstel van ziekte. Beleidsmakers dienen te begrijpen welke factoren van invloed zijn op gezondheid en hoe gezondheid zich in verschillende contexten ontwikkelt. Eenduidig beleid op elk niveau is essentieel om gezondheid te bevorderen en ongelijkheden hierin tegen te gaan. Het is van belang om inzicht in de sociale en economische relaties met gezondheid te krijgen, vooral in arme gebieden die te kampen hebben met de grootste gezondheidsproblemen. In de Oostkaap van Zuid-Afrika heerst veel armoede en werkloosheid. Daarnaast heeft deze regio te maken met grote gezondheidsproblemen. Uit ons onderzoek blijkt dat werk en opleiding positief gerelateerd zijn aan gezondheidsuitkomsten. Het stimuleren van werk, het versterken van het opleidingssysteem en het bevorderen van toegang tot (hogere) opleidingen zou kunnen bijdragen aan het verminderen van ongelijkheid in gezondheid. Uit het onderzoek kwam ook naar voren dat er een relatie is tussen de kwaliteit van huisvesting, de sociale omgeving en TBC prevalentie. Interventies gericht op het reduceren van het aantal mensen per kamer en het verbeteren van het materiaal van daken (zodat het dak niet lekt wanneer het regent) zouden daarom waardevol kunnen zijn, evenals het versterken van de sociale omgeving.

Welzijn

Onderzoek heeft aangetoond dat welzijn een sterke invloed heeft op de weerbaarheid van individuen en bijgevolg op hun gezondheid. Welzijn wordt bepaald door de waarde die men geeft aan het leven, de gebeurtenissen die men mee maakt, en de omstandigheden waarin men leeft. Aangezien niet-financiële middelen voor een belangrijke deel het welzijnniveau bepalen is het van belang om de bredere context van ontwikkeling te bekijken. Inkomen speelt uiteraard een rol, maar zijn er ook andere aspecten? Welke aspecten kunnen als buffer fungeren om een gewenst welzijnsniveau te behouden voor degenen die een laag inkomen hebben, of in tijden van inkomensverlies? Bij het wegvallen van een welzijnsbron (zoals werk, inkomen, vriendschap) kunnen de beter bedeelden dit opvangen doordat zij over andere welzijnsbronnen als buffer beschikken. Naast inkomen worden werk, gezondheid, opleiding en sociaal kapitaal steeds vaker gezien als belangrijke factoren voor welzijn. Ons onderzoek heeft zich gericht op de relatie tussen deze en andere factoren en het welzijnniveau van een arme gemeenschap in de Oostkaap van Zuid-Afrika. Een hoger inkomen bleek gepaard te gaan met een hoger welzijnsniveau. Sociaal kapitaal bleek samen te hangen met welzijn ongeacht het inkomensniveau. Voor de allerarmsten bleek sociaal kapitaal zelfs de enige bron voor welzijn. Het is daarom belangrijk dat interventies gericht op de ene bron (b.v. economische ontwikkeling) niet ten koste gaan van andere welzijnsbronnen, en in het bijzonder sociaal kapitaal. Het is aannemelijk dat het algehele welzijnniveau van de allerarmsten omlaag gaat als dit wel het geval is.

Implicaties voor toekomstige strategieën

Internationale organisaties en nationale gezondheidsprogramma's dienen er van uit te gaan dat sociaal-economische verschillen van invloed zijn op welzijn en gezondheid en dat deze per specifieke deelpopulatie anders doorwerken. Programma's dienen daarom afgestemd te worden op specifieke doelpopulaties, vooral in de arme gemeenschappen met grote gezondheidsproblemen.

Uit ons onderzoek bleek dat sociale en economische condities gerelateerd zijn aan gezondheid en welzijn. Interventies gericht op het versterken van deze condities kan bijdragen aan verbeterde gezondheidsuitkomsten. Hiervoor is nauwe samenwerking noodzakelijk met actoren buiten de zorgsector. Oplossingen zijn niet eenvoudig, helemaal niet als het ziektes betreft waarbij stigma en complex gedrag een grote rol spelen. Verschillende strategieën zijn waarschijnlijk nodig om toegang tot zorg en therapietrouw in deze gevallen te verbeteren. Het tegengaan van stigma en versterken van de positie van patiënten vereist een patiëntgerichte aanpak vanuit meerdere dimensies en niveaus. Een aanpak vanuit verschillende dimensies is waarschijnlijk noodzakelijk vanwege de variëteit aan aandoeningen en actoren die een bijdrage kunnen leveren aan verbetering van welzijn en gezondheid in de gemeenschap. Een aanpak op meerdere niveaus is aanbevolen om zowel op individueel, organisatie en gemeenschapsniveau gezondheid en welzijn te verbeteren.

Beleidsmakers en zorgorganisaties moeten zich realiseren dat ziektegerelateerde stigma's een directe aanslag vormen op het sociaal kapitaal van mensen – vaak de enige welzijnsbron van de allerarmsten. Sociaal kapitaal is een bevorderende factor voor welzijn, in tegenstelling tot stigma's; die vormen een barrière. Ziektegerelateerde stigma's vormen niet alleen een bedreiging voor de persoon in kwestie en diens omgeving, maar ook voor publieke attitudes ten aanzien van preventie, zorgaanbod, en gezondheidsbeleid. In de programma's die zich richten op het verbeteren van gezondheid en welzijn dient dus ook plaats te zijn voor het reduceren van stigma. Kortom, een veelomvattende aanpak gebaseerd op ziektepreventie, stigmareductie en gezondheidsbevordering kan overheden en beleidsmakers in staat stellen om iets te doen aan de sociale ongelijkheid in de wereld.

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PhD Portfolio

PhD student : Jane Murray Cramm
Department : Institute of Health Policy and Management
PhD period : 2007-2010
Promotor : Prof. Dr. Joris van de Klundert
Supervisor : Dr. Anna Nieboer

PhD training

Courses

- Multilevel Regression Analysis	2010
- Social Epidemiology Erasmus Summer Programme Johan Mackenbach	2010
- English Presentation Skills	2010
- Q-methodology	2009
- A masterclass on long term conditions by Ed Wagner, London	2008

Conferences

- Global health Congress Washington DC	2010
- Symposium ‘Marketing in de Gezondheidszorg’	2008
- Symposium Klanten ervaring in de zorg	2007
- Consumer Quality Index congress	2007
- International Society for Quality of Life Research Conference Grahamstown, South Africa	2007

Teaching experience

- Supervising Bachelor and Master Theses	2007-2010
- Presenting a BMG seminar on ‘Improving health outcomes of people living in a health and economically deprived region’	2010
- Teacher of a workshop on (systematic) literature review in Uganda	2008
- Supervisor of students during a study tour in Uganda	2007

Fundraising and project experience

- Project leader ‘palliative day care’	2007-2008
- Project leader ZonMw ‘small innovation project’	2007-2008
- Project leader ‘microcredit for people with disabilities’	2007-2010
- Senior researcher ZonMw project Evaluating disease-management programmes in chronic care	2010-2012

Ancillary Activities

- Consultant/Data Analyst Ergonomique BV (period of 6 months in 2008)
- Member of the International Consortium for Research and Action Against health-related Stigma (ICRAAS) consortium
- President and founder of the Credit for Rehabilitation Aimed at the Marginalized Minorities (CRAMM) Foundation

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