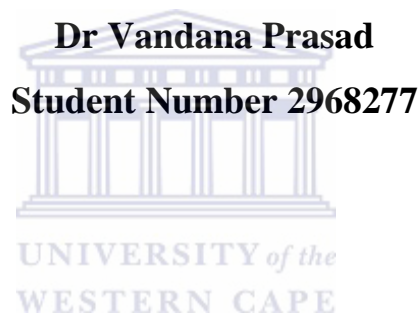


**A Study to Understand the Barriers and Facilitating
Factors for Accessing Health Care amongst Adult Street
Dwellers in New Delhi, India.**



A mini-thesis submitted in partial fulfilment of the requirements for the degree of
Masters in Public Health in the School of Public Health, Faculty of Community and
Health Sciences, University of the Western Cape.

Supervisor: Ms Nichola Schaay

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KEYWORDS

- Street dwellers
- Urban Poor
- Urban Homeless
- Health care services
- Barriers
- Facilitating Factors
- Access
- Qualitative study
- New Delhi
- India



ABSTRACT

Urban health policy has remained a neglected area in India. The homeless remain the most deprived, neglected and stigmatized group amongst the urban poor. While they suffer from a large burden of disease, there are a variety of reasons that prevent them from accessing the available health care services – particularly in the public health sector. Some interventions by concerned non-governmental organisations have attempted to circumvent the barriers to health care access faced by the homeless but these have not been well documented or assessed. This study seeks to establish both the barriers and facilitating factors for access to health care and health care seeking amongst adult street dwellers in an area of New Delhi which is known for a high concentration of homeless persons.

Using a qualitative approach 18 adult street dwellers (both male and female) were individually interviewed – along with 6 key informants working in the public and non-governmental health sector. This was accompanied by a process of participant-observation. The results were analyzed by identifying recurrent themes associated with barriers and facilitating factors for access to health care by the homeless, following which a set of recommendations related to the homeless, have been developed so as to inform those working in the public health sector. In terms of ethics, informed consent was taken from each interviewee and they were explicitly given the option not to participate without adverse consequences to themselves. If any participant was found with acute health problems immediate assistance was facilitated.

The study reveals a number of barriers faced by the homeless in attempting to access health care services. While minor ailments are taken care of by local private practitioners, they need to access public health care services for major problems. There they encounter many barriers due to the lack of money, delays and being shunted from place to place. Moreover, they are not able to get admission for reasons such as lack of address and the lack of an attendant. Facilitating factors include assistance for transportation, facilitation of admissions, arranging money for out of pocket expenditures on drugs and consumables,

arranging blood and providing after-care. The role of social contacts in enabling access is also demonstrated through this study.

The recommendations that emerge from the study are intended to assist in policy advocacy towards a comprehensive health care system for them, as well as assist health care providers to provide a better service for homeless people.



DECLARATION

I declare that the work presented herein; A Study to Understand the Barriers and Facilitating Factors for Accessing Health Care Amongst Adult Street Dwellers in New Delhi, India, is original and that it has not been submitted for any degree or examination in any other university or institution for the award of a degree or certificate and that all sources of information and data used or quoted have been duly indicated and acknowledged.

Full Name: Vandana Prasad

Signature:



UNIVERSITY of
WESTERN CAPE

Dated: 09 November 2011

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LIST OF ACRONYMS

BPL	Below Poverty Line
PDS	Public Distribution System
FGD	Focus Group Discussion
GDP	Gross Domestic Product
GOI	Government of India
HIGH	Health Initiative Group for the Homeless
HW	Health Worker(s)
IDI	In-depth Interview(s)
IGSSS	Indo -Global Social Service Society
NGO	Non Governmental Organisation
OPD	Out Patients Department
PHRN	Public Health Resource Network
RSBY	Rashtriya Swasthya Bima Yojana
TB	Tuberculosis
UDHR	Universal Declaration of Human Rights
US	United States (of America)
WHO	World Health Organisation

TABLE OF CONTENTS:	PAGE
Title page	i
Key Words	ii
Abstract	iii
Declaration	v
Acknowledgements	vi
List of Acronyms	vii
CHAPTER 1: A DESCRIPTION OF THE STUDY	1
1.1: Introduction	1
1.2: The Research Problem	2
1.3: Study Setting	3
1.4: Introduction to Research Design and Methodology of the Study	6
1.5: An Outline of the Report	6
CHAPTER 2: THE LITERATURE REVIEW	8
2.1: The Problems of Enumeration and Identification of the Homeless	8
2.2: Ill-Health and Homelessness: A Two-Way Relationship	9
2.3: Expenditures on Basic Survival and Health Needs	12
2.4: The Health Care System and Entitlements in India	14
2.5: Barriers to Accessing Health Care	17
2.6: Health Systems Response to Homeless Persons; Facilitating Factors	20
CHAPTER 3: RESEARCH DESIGN AND METHODOLOGY	25
3.1: Aims of the Study	25
3.2: Objectives of the Study	25
3.3: Study Design	25
3.4: Methods	26
3.4.1: In-depth interviews	26
3.4.2: Observation	27
3.5: Study Population	28
3.6: Study Sample and Sampling Procedures	28
3.7: Data Collection Instruments and Procedures	31
3.7.1: In Depth Interviews	31

3.7.2: Observation	33
3.8: Data Analysis	35
3.9: Rigour	36
3.10: Study Limitations	38
3.11: Ethical Considerations	39
CHAPTER 4: FINDINGS OF THE STUDY	41
4.1: Introduction	41
4.2: Participant Profile	41
4.2.1: Age	42
4.2.2: Sex	42
4.2.3: Literacy	42
4.2.4: Current Occupation	42
4.2.5: Previous Occupation	43
4.2.6: Current Income	43
4.2.7: Social Security	43
4.2.8: Reasons for Homelessness / Loss of Livelihoods	44
4.2.9: Duration of Living on the Streets	46
4.2.10: Health Problems for Which Care Had Been Sought	46
4.2.11: Other Relevant Characteristics of the Participants	47
4.3: The Barriers for Accessing Health Care	47
4.3.1: <i>Paise Lao</i> ; The Lack of Money	48
4.3.2: <i>Chakkar Katna</i> ; Delays, Shunting and Dismissals	53
4.3.3: <i>Koi Aadmi Nahin Tha</i> ; The Lack of Carers and Attendants	58
4.3.4: <i>Parche Nahin Hain</i> ; The Lack of Documents	62
4.3.5: <i>Mooh Dho Ke Aao</i> ; Attitudes of the Health Care Providers and Homeless Participants	64
4.3.6: <i>Main Garib Hoon Injection Nahin Lagwa Pai</i> ; Irrational Care by Local Private Practitioners	69
4.4: Facilitating Factors	70
4.4.1: Getting Financial Assistance	72
4.4.2: Being Treated with Respect and Familiarity at a Facility	75
4.4.3: The Facilitation through Social Contacts	77

4.4.4: Facilitating Factors Working in Tandem	80
CHAPTER 5: DISCUSSION	86
5.1: Introduction	86
5.2: The Determinants of Homelessness; Denials of Basic Rights	88
5.3: Prohibitive Costs of Health Care	92
5.4: Quality and Access to Health	94
5.5: Facilitation by NGOs; an Ambivalent Relationship	100
5.6: Social Capital; Facilitation through Social Relationships	103
CHAPTER 6: CONCLUSIONS AND RECOMMENDATIONS	108
6.1: Conclusions	108
6.2: Recommendations	110
6.2.1: Recommendations for Policy	110
6.2.2: Recommendations for Public Health Systems	111
6.2.3: Recommendations for Facilitating / Service Providing Social Organisations	112
REFERENCES	114
LIST OF ANNEXURES	124
Annexure 1: Participant Information Sheet for Homeless Participants	
Annexure 2: Participant Information Sheet for Key Informants	
Annexure 3: Informed Consent for All Participants	
Annexure 4: Interview Schedule for Homeless Persons (General Group)	
Annexure 5: Interview Schedule for Homeless Persons (Facilitated Group)	
Annexure 6: Interview Schedule for Key respondents	
<u>List of Tables</u>	
Table 1: Distribution by Age	42
<u>List of Boxes</u>	
Box 1: The Case Study of Participant Mahmud Alam	81
Box 2: The Case Study of Bhuvan	83

CHAPTER 1: A DESCRIPTION OF THE STUDY

1.1: Introduction

Urban health has been a vastly neglected area in India in terms of health policy, health status and availability of public health systems. This is despite the fact that health indicators amongst urban slum dwellers are often far worse than in rural areas (Saxena, 2007; Public Health Resource Network (PHRN), 2010) and that a third of the poor population in India live in urban areas (Supreme Court Commissioners, 2008; PHRN, 2010). The neglect of urban health in policy is best exemplified by the fact that whereas there has been a significant response by the government to provide for rural health needs through its flagship programme; the National Rural Health Mission (NRHM) (GOI, 2005), a proposed National Urban Health Mission (NUHM) (GOI, 2008) is yet to be finalized.

Amongst the urban poor the most marginalized and socially invisible are those living on the streets. The urban homeless in India are a highly heterogeneous group of persons ranging from recent migrant workers to people suffering from a variety of disabilities (including mental illness) – many of whom survive through begging. Existing laws against begging criminalize the homeless and prevailing public opinion sees the homeless as “vaguely dangerous and intractably on the wrong side of the law” (Mander, 2008:4) rather than as persons suffering from some of the severest forms of human rights violations. This attitude is also reflected in the derogatory behaviour of government health care providers towards homeless persons as referred to in a study by Health Initiative Group for the Homeless (HIGH, 2003). Many other factors inhibit the homeless from approaching public health care services. Along with socio-cultural barriers, such as illiteracy, difficulties with speaking the local language, isolation and unfamiliarity with the local area and the lack of family carers to assist during hospitalization, structural barriers are also likely to exist that inhibit the homeless from using public health care services. These include the lack of money (Rai, 2008) to pay the required user charges and a lack of proof of identity and address.

The experience of agencies working with the homeless in the capital city of New Delhi, such as Aman Biradari, Aashray Adhikar Abhiyan and Indo -Global Social Service Society (IGSSS) also suggests that although the homeless spend substantially on health care services (including on medicines), they are reluctant to use government health care services which are far less expensive and are, in fact, meant to be free for persons who fall below the poverty line (BPL¹). BPL persons are also eligible for free services in select corporate and private hospitals in New Delhi that have been given considerable concessions by the government for land use in return. However, this system of ‘free beds’ in private hospitals is functioning poorly with much resistance by the private hospitals in admitting poor patients and providing entirely free health care. A legal battle² is on between them and the Delhi Government to ensure that these hospitals comply with their commitments to provide free care to people identified as very poor (Jha, 2011).

1.2: The Research Problem

Most of these barriers to accessing health care have only been noted anecdotally by agencies working in the field, rather than having been formally documented. The lack of systematic information about the health care experiences of the urban homeless, in turn, seems to have impeded effective advocacy initiatives that seek to increase their right and access to health care.

Thus, whilst there have been advocacy campaigns for the rights of homeless in Delhi led by non government organizations (NGOs) like Aman Biradari and Aashray Adhikar Abhiyan, these have tended to concentrate on issues related to shelter and food and not on healthcare. Some of these efforts in the national

¹ The Below Poverty Line status is a very important distinction in India since it forms the basis for targeting of services to the extremely poor in policy. Therefore, a BPL card holder would be entitled to greater concessions or free services such as for food, health and education. The BPL category is selected on the basis of periodic surveys but the methodology for this selection has been vastly criticized for causing huge errors of exclusion and inclusion. It is considered that the most poor tend to get left out the surveys and many powerful people get included. Even currently, the planning commission is under attack by ‘civil society’ for projecting a very low cut – off for the BPL category. The matter is in the Supreme Court pending judgement. The issue of BPL is further explained in Chapter 5 during the discussion of the study findings. Interested readers are referred to Mahamallik, M. and Sahu, GB. (2011). Identification of the Poor: Errors of Exclusion and Inclusion. *Economic and Political Weekly*. XLVI (9): 71-77 for further details.

² Writ Petitions (civil) 5410/1977 and 2866 / 2002 of the Delhi High Court

capital of Delhi have resulted in entitlements for homeless persons in relation to food security in the entire country (People's Union for Civil Liberties, 2001). This suggests that the potential exists for being able to advocate for other rights for the homeless, like appropriate access to healthcare. However, the organizations that are currently providing some form of health care services for the homeless lack methodically collected and documented evidence to initiate the process of policy advocacy for better public health care services for the homeless. Systematic analysis of the factors that would help these NGOs to improve their own efforts to facilitate access to health care services is also lacking.

This study aims to document the difficulties faced by homeless people in New Delhi in accessing health care, especially from the public health system. It also aims to document various interventions that have facilitated their access to health care. This study thus attempts to reduce the information gap by gathering evidence that may assist both in policy-related advocacy initiatives for making health care more accessible to the homeless, as well as the provision of better services for homeless people by health care providers (both NGO and public). The latter aim is particularly pertinent within the setting of the study, given it is in an area where an NGO (AB) is currently providing some basic health care services for the homeless as well as enabling referrals to government and private hospitals for more advanced levels of health care.

1.3: Study Setting

The setting of the study was Nizamuddin, an area of central New Delhi which has a significantly large concentration of homeless persons (estimated at about 10,000 by NGO AB) due to the proximity of a large historical religious institution, the Nizamuddin mosque. This mosque is frequented by pilgrims who are encouraged to give alms and donate food to the poor. An NGO, Aashray Adhikar Abhiyan, runs a free temporary tent shelter in the area where the homeless may sleep for a night. The government also runs a shelter in a permanent building in the area which charges a small fee. However, most of the homeless live on the pavement by a busy road or within two parks and a large vacant area on either side of the

road. One of these parks is thickly overgrown with vegetation and serves as a toilet area for the homeless. The same park is used by drug abusers and drug dealers for their activities. The other park is better cared for by gardeners and has a water supply that is used by the homeless for bathing and washing clothes. The vacant area where many of the homeless live was in the process of being cleared by the government in order to make another park.

Many private health practitioners exist in Nizamuddin. Of these, some are trained in indigenous forms of medicine but also practice allopathy for which they are not formally qualified. Others are unqualified practitioners who may have had some experience of assisting doctors as paramedical workers or pharmacists who have started practicing allopathy on their own³. There are also many persons related to the particular religious community dominant in the area who claim to have healing powers. These various kinds of practitioners make their services available at very low cost and around the clock. Since they are in the vicinity and accessible, they are popular amongst the local community.

An NGO, referred to in this thesis as NGO AB, has been working for a number of years in this area. This organization runs a small clinic specifically for the homeless, which is located close to the vacant area. The clinic is run six days a week by a general practitioner with two part-time specialists offering paediatric and obstetric-gynaecological clinics on a weekly basis. The clinic is supported by a nurse and three community health workers. The community health workers go on rounds on the streets, identify sick homeless persons and encourage them to come to the clinic. They also do the registration at the clinic and assist the doctors. The clinic is only able to provide out-patients services on site and receives about 25-30 patients daily. It suffers from a shortage of space and uncertainty about funds which have to be periodically solicited from funding agencies and individuals. It receives no support from the government. Its health personnel encounter a variety of severe illnesses amongst the homeless such as fractures,

³ This is indicative of the lack of regulation upon the private health care sector in India which comprises of a wide range of providers from super speciality tertiary care corporate hospitals to smaller private nursing homes and clinics to such individuals practicing both indigenous forms of medicine as well as allopathy.

burns, substance abuse, cancers, severe mental illnesses – many of which require hospitalisation and after-care, for which they facilitate referrals to nearby government services, private hospitals as well as facilities such as de addiction centres run by other NGOs. Recently, a street clinic has also been started by NGO AB which operates thrice a week and is run by a general physician as well as the health workers. This clinic; held by putting up chairs and tables in the vacant area occupied by homeless people, has been started to improve access to the services offered for the homeless. Periodic health camps are held at the government night shelter by the NGO AB for providing basic treatment to the residents as well as identifying people who require referral. This NGO has acquired the reputation of being especially interested in providing basic health care for homeless people and facilitating access to health care through referrals as and when required.

A government polyclinic also runs in the area close to the government shelter but it is not known to be frequented much by the homeless. This operates from Monday to Friday and offers daily services of a general physician and twice weekly services of dermatology, gynaecology-obstetrics and ENT (Ear, Nose Throat). The health workers report that it receives 80-90 patients a day from the shanties and settled community in the area. The polyclinic does not offer any in-patient facility or have a system for referral services to a government hospital. There is no government primary health care centre in the area which could have been charged with looking after maternal and child health services as well as preventive public health action such as malaria control, water and sanitation etc⁴. The next nearest government health service to those living in Nizammudin is a large tertiary care teaching hospital⁵ which is about 5 kilometres away.

The researcher is a paediatrician currently working in the area of public health with an organisation called Public Health Resource Network (PHRN). She has

⁴ In fact, unlike rural India, the tiered public health system comprising of primary secondary and tertiary care facilities does not exist in urban areas at all. This point is discussed further in Chapter 2.

⁵ A tiered system for referral from primary urban health centres to tertiary hospitals in urban areas is envisaged by the draft National Urban Health Mission, 2008, but not currently in existence. At this time anyone may walk in to a tertiary-level hospital's emergency service or out patients department without a referral. Thus the term tertiary care hospital is related more to the level of services available than to being part of a tiered system

also been involved with delivering primary health care to poor children on construction sites and in slums of Delhi through another NGO for almost two decades. As part of this work, she is familiar with the organisation AB and has led a study on the nutritional status of homeless persons in Nizamuddin along with them in 2010 (Prasad et al, 2010). She is also a member of the executive board of NGO AB.

In this setting, the aim of this study was to explore the barriers and facilitating factors, both perceived and experienced, by the adult homeless in Nizamuddin area of the city of New Delhi, in accessing health care, especially from the public health system.

1.4: Introduction to Research Design and Methodology of the Study

This descriptive study used a qualitative research methods approach. A qualitative approach was selected since it allows better understanding and documentation of perceptions and complex experiences, and allows for free, unstructured expression which is not limited by pre-determined boundaries such as are placed by the quantitative approach and reflected in quantitative tools and methods (Pope and Mays, 1995). Since the study was concerned with understanding *how* certain factors became barriers for homeless people in accessing health care, and how other factors helped them to access health care better, this methodology was considered most appropriate. The methodological aspects of the study have been further detailed in Chapter 3.

1.5: An Outline of the Report

The report of the study comprises of six chapters as follows:

Chapter 1 introduces the study. Chapter 2 reviews the literature for information that is likely to be relevant to the aims and objectives of the study. It also provides details from literature on the characteristics of the setting which have implications for the findings of the study, such as the extant public health systems that operate in New Delhi. Chapter 3 describes the research design and methodology used for

data collection as well as data analysis procedures, rigour, ethical considerations and limitations of the study. Chapter 4 presents and analyses the results of the study in terms of barriers and facilitating factors. Chapter 5 discusses these findings in the context of existing information from previous studies as well as from the point of view of existing theory. Lastly, Chapter 6 summarises the key findings of the thesis and suggests recommendations based on these findings.



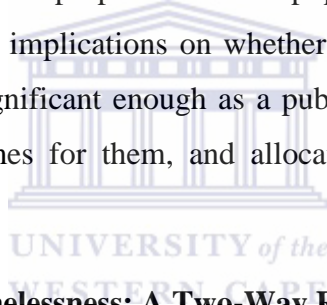
CHAPTER 2: THE LITERATURE REVIEW

The Universal Declaration of Human Rights (UDHR) of 1948 states in its Article 25 (1) that, “Everyone has the right to a standard of living adequate for the health and well being of himself and his family, including food, clothing, housing, medical care and necessary social services, and the right to security in the event of unemployment, sickness, disability, widowhood, old age or other lack of livelihood in circumstances beyond his control” (UN, 1948:5). These rights are often denied to the poor in general, and the homeless are the most vulnerable, least powerful and most invisible amongst them. Thus, the UDHR forms an important framework to be able to evaluate the living conditions in which the homeless find themselves and the impact these have on their health as well as their ability to access health care services. On account of their invisibility, ensuring their identification amongst other categories of people who have been denied their basic rights becomes an important first step towards being able to intervene on their behalf. As a group working on issues related to homeless people in Europe puts it, “homeless and severely excluded people are usually invisible to traditional national statistic instruments and mechanisms” (FEANTSA, 2009:4).

2.1: The Problems of Enumeration and Identification of the Homeless

It is estimated by a former UN special rapporteur on the right to adequate housing, that there might be over a billion homeless people in the world (Kothari et al, 2006). The numbers are likely to be the highest in Africa, Asia and Latin America, but with substantial numbers in the developed world as well (youthXchange, 2009). It is also commonly acknowledged that official counts suffer from severe underreporting and that data from developing countries is very scanty (youthXchange, 2009). The WHO Commission on Social Determinants of Health (CSDH, 2008) states in its final report that more than 2000 million people live in life-threatening and health-threatening housing and living environments.

Where India is concerned, the 2001 census suggested that there are 1.94 million homeless people, 0.77 million of whom live in cities and towns (Supreme Court Commissioners, 2008). The number of homeless people counted in Delhi by this census process was 21,895 (Rai, 2008). However, a headcount conducted in 2000 by Aashray Adhikar Abhiyan (an organization working with the homeless in Delhi) found 52,765 homeless people in Delhi, and it was estimated that for every one they could count there were one or two homeless people that escaped their enumerators. Similarly, in 1985 the Delhi Development Authority estimated that the houseless population of Delhi in 1995 would be 1 percent of the total population. By this estimation, the homeless in Delhi would be about 0.15 million in 2008 as per 2001 census⁶ figures for the total population in New Delhi (Rai, 2008). Thus, the numbers of homeless persons in the world, India and the city of New Delhi are a significant proportion of the population, and suffer from gross underreporting. This has implications on whether policy makers would consider their health problems significant enough as a public health problem to construct special health programmes for them, and allocate such programmes sufficient financial resources.



2.2: Ill-Health and Homelessness: A Two-Way Relationship

It is remarkable that so little is known about the lived experiences of those without a home: why do they live on the streets, how do they survive; how do they manage to sleep, where do they bathe; what do they eat; what work they do, do they access public services? (Supreme Court Commissioners, 2008: 54)

Unlike Europe and the USA, very little published material exists about the health status, health-related experiences and/or the access the urban homeless in India have to healthcare.

‘Homelessness’, or the lack of shelter has obvious implications upon health; it usually signifies extreme poverty, exposure to violence and abuse and

⁶ 2010 census is in process and results are not currently available

vulnerability to environmental conditions. Apart from the lack of shelter, homelessness is also associated with constraints in access to the basic human requirements of safe water, sanitation and safe and adequate food – without which the homeless are particularly vulnerable to ill health. Interestingly, whereas shelter is understood to be a key social determinant of health in the CSDH report, the impact of the *lack of shelter* or *homelessness* on health does not specifically find mention. The CSDH report, nevertheless, encourages all health personnel to have the knowledge and skills to work with other social services, especially in the provision of shelter for the homeless (CSDH, 1992). Similarly, while the WHO has detailed the relationship of housing with health in its report ‘Health Principles of Housing’ (WHO, 1989) it has not specifically detailed the relationship of health to homelessness.

Notwithstanding the lack of special attention by the WHO, agencies working specifically with the homeless have shown that a very high disease burden exists within the population of homeless persons.

Studies in the USA and UK suggest that common conditions such as infections, respiratory disease, gastrointestinal problems, fits and loss of consciousness are more prevalent among homeless people than the general population (McMurray-Avila et al, 1998; Findlay et al., 2010; Snyder et al., 2004, Quilgars and Pleace, 2003). Physical injury is also reported to be common amongst the homeless. For example, in his review of data available on homeless persons from various studies conducted in cities of US and UK, Findlay et al. (2010) reported that homeless people were 13 times more at risk of assault than the general population. They also find that 38-59 percent of homeless people were found to have multiple health problems.

Alcohol dependence and substance misuse are common amongst the homeless and they are 8 to 11 times more likely to suffer from mental illness than others (Findlay et al., 2010). The single most common disorder amongst homeless persons in US has been noted to be substance abuse (McMurray-Avila et al, 1998).

A small study conducted in Toronto found the prevalence of mental disorders to be as high as 73.5 percent in elderly homeless men (Joyce and Limbos, 2009). According to a fact sheet of the National Centre for Family Homelessness (USA), presenting a collation of research findings on the homeless; mothers experiencing homelessness were found to have three times the rate of post traumatic stress disorder and twice the rate of drug and alcohol dependence as other women. In addition, about 50 percent of mothers interviewed in another study had experienced a major depressive episode since becoming homeless (National Center on Family Homelessness, 2008).

Though there is lack of precise data from India, a survey of 340 homeless people in four cities of India in a report titled 'Living Rough' (Mander, 2008) states that 100 percent of respondents in every city reported major health problems in the past year, and 56 percent were advised hospitalisation but did not go to hospital. Similarly, the Health Initiative Group for the Homeless (HIGH), a coalition of organisations including Aashray Adhikar Abhiyan and Institute of Human Behaviour and Allied Sciences founded in 2000, reports from a survey of 2955 homeless respondents in New Delhi that "A high proportion of homeless people were suffering from serious respiratory ailments including tuberculosis, acute and chronic infections, skin diseases and diarrhoeal diseases" (HIGH, 2003: 26).

Conversely, health issues may be the *reason* for homelessness in the first place. Mander (2008) suggests that while extreme poverty remains the main cause of homelessness, mental illness, mental retardation and stigmatising illnesses are also contributing factors that precipitate homelessness. This dialectic relationship between health and homelessness is also referred to by other authors. European Federation of National Organisations Working with the Homeless (FEANTSA) is an umbrella of more than a hundred not-for-profit organisations working on issues of homelessness in Europe. Their website states that

there is a range of factors, which may lead to a person eventually becoming homeless and often health issues are among them. Health and homelessness have a relationship of both cause and effect: illness (such as

mental illness, substance abuse or illness leading to loss of employment) may be among the trigger factors that lead to homelessness (FEANTSA, ud)

In a policy statement on how health professionals can work towards meeting the health needs of homeless (FEANTSA, 2004), FEANTSA describes how mental illness can be both the cause and effect of homelessness. Similarly, Findlay et al (2010) note that health problems are not only a consequence but also a reason for homelessness. Quilgars and Pleace (2003) also describe the two-way links between homelessness and health from their work with the homeless in Scotland.

However, while an extensive report on human rights to housing in the Indian context provides a comprehensive list of structural causes of homelessness as quoted below, health issues do not find specific mention:

[Structural causes of homelessness]...include migration caused by diminishing rural livelihoods and economic opportunities, the lack of equitable land reform, social persecution, development-induced displacement resulting from the construction of dams and other infrastructure-related projects, rural land alienation, forced evictions, drought and famine, domestic violence, and child abuse... (Kothari et al, 2006:53)

2.3: Expenditures on Basic Survival and Health Needs

A sudden illness is known to seriously deplete the savings of poor people in India, in the absence of equitable access to health care; an illness termed ‘catastrophic’ by the Macroeconomic Commission on Health set up by the Government of India (MCH, 2005:71). The same commission recommends that

... a basic safety net...[should be]...provided to shelter vulnerable populations from impoverishment due to catastrophic care [sic] (MCH, 2005: 88]

Reddy et al (2011) in the recent Lancet Series titled ‘India: Towards universal health coverage’ go on to say that costs of health care are a leading cause of poverty in India today.

According to Mander (2008), 75 percent of homeless people earned less than Rs 100 (\$ 2) a day in his sample of 340 homeless persons from four cities in India including Delhi. He also notes that for 50 percent the reason for becoming homeless was extreme poverty. Since poverty seems to be one of the major causes of homelessness, expenditures on basic needs such as food and health care would certainly be expected to have a bearing on the perpetuation of homelessness apart from leading to it, by depleting the resources that could have otherwise led to rehabilitation.

The report ‘Living Rough’⁷ (Mander, 2008) shows from studies done in four cities of India, that homeless people spend a large amount of their entire daily earnings on basic needs. For example, 50 – 90 percent of daily earnings may be spent on food alone despite also taking some charity meals. It was also found that 5.4 percent of those studied were paying for drinking water, 33.3 percent for defecation and 22.6 percent for bathing.

However, little data is available on their expenditure on health specifically and only anecdotal accounts provide a glimpse of the hardships faced by homeless people with respect to being able to access health care. For example, the Delhi City Report (Rai, 2008) of ‘Living Rough’ states that in four cases where hospitalization was required the respondents could not afford the treatment and that even though most of the homeless people visited a government hospital they had to spend a considerable amount of money on their treatment, ranging from Rs. 500 to 4000⁸ (approx \$10 to \$800 – with over 75 percent of homeless people earning less than \$2 per day as described above).

⁷ This is a compendium of 4 studies and review articles on homeless people in India prepared on behalf of the Planning Commission of India

⁸ At the conversion rate on 22.9.2011 a dollar is equivalent to 49.03 Rs. This has been rounded off to Rs 50 for the purposes of this study

Having to pay for basic amenities would not allow for enough savings to be accumulated to find better living conditions and exit the state of homelessness which, in turn, itself leads to further ill health. The economic consequences of a catastrophic illness upon the homeless in the Indian context can only be imagined since they are the poorest of the poor. It can also be postulated from the literature cited that expenditures on health may also be a potential reason for homelessness as well as a barrier for being able to access health care at all.

In this context, it is important to understand the health care system that currently exists in India to assess on what terms the homeless might have to be interacting with it to access care for health problems and what entitlements they currently have to health care.

2.4: The Health Care System and Entitlements in India

Despite a rapid economic growth in the last decade, India has failed to do correspondingly well in improvements in health indicators (Horton and Das, 2011). Much of this failure is attributed to the inequitable systems of health care that currently exist in the country (Reddy et al, 2011; Balarajan et al, 2011).

India has an enormous private health sector which is characterised by being unregulated and expensive (Duggal and Gangolli, 2005). This sector is not homogenous and has a range of private providers from large private hospitals to small nursing homes and clinics (Baru, 2005; Kumar et al, 2011). In addition there are a large number of unregulated practitioners of indigenous systems of medicine as well as unqualified practitioners⁹ delivering health care services in both urban and rural areas (Abraham, 2005). As described in detail in a recent paper on 'financing health care for all', 78 percent of the total health expenditure is out-of-pocket (OOP) and the private sector accounts for most of this. Only 10 percent of households have a member with health insurance. A government insurance scheme; Rashtriya Swasthya Bima Yojana (RSBY) has only very recently been introduced for persons below the poverty line to allow them to access accredited

⁹ Often referred to as 'quacks'

private health facilities (Kumar et al, 2011). Getting this insurance requires proof of residence and would be almost impossible for a homeless person in India in the present circumstances.

The government-run system is called the *public* health system as against the *private* health sector, though it largely delivers curative services (Dasgupta, 2005). The facilities of the public health system are organised in tiers in rural areas to deliver services from primary to tertiary levels. This system has been recently buttressed through the National Rural Health Mission set up by the government of India in 2005. Referral between these is one of the major weaknesses of the system apart from other issues such as the lack of human resources and poor infrastructure leading to poor quality (MOHFW, 2010).

While services in the public health system are meant to be largely free, user charges have steadily been made to apply (MCH, 2005). However persons in the BPL category are entitled to exemptions from user charges.

Urban areas do not fall under the purview of the National Rural Health Mission and do not have similar tiered structures for health care delivery. There is a high concentration of private health care providers and a multiplicity of government agencies running health care services. In the capital of New Delhi which has the status of a state, some services are run by the Municipal Corporations, some by Government of Delhi and some by the Central Government (of India). There is little coordination between these agencies to ensure continuity of care and the availability of comprehensive services (PHRN, 2010). The same system of user charges and exemptions to the BPL applies as for rural areas. An Urban Health Mission has been in the pipeline but is yet to be set up. There is also a concentration of large government teaching hospitals and tertiary care hospitals in Delhi. In addition to all the problems noted with the rural public health facilities, they are overcrowded and cater to patients coming from many states of Northern India apart from Delhi itself. Though they offer the best possible medical care available through the government health care system, they are known to have very long waiting times and complicated procedures that are very confusing for poor

and semi literate people (Hospital Employees Union et al, 2007). They are not structurally linked to primary and secondary care services that could help to filter their patient load.

To date there has been no specific policy or programme intervention on the part of the Indian government to reach out to homeless people and assist them to access public health services. However, the draft National Urban Health Policy (2008) offers some hope as it acknowledges

... a fraction of the urban poor who normally do not reside in slums, but in temporary settlement or are homeless, comprise the most disadvantaged section. Under the NUHM special emphasis would be on improving the reach of health care services to these vulnerable among the urban poor, falling in the category of destitute, beggars, street children...(GOI, 2008: 21)

Overarching the existing systems, a National Health Policy (GOI, 2002) does exist but has been criticised for being ineffective and promoting the private sector (Duggal, 2005). Attempts at public-private partnerships to improve access of the poor to health care services have had mixed results and the problematic attempt to extract free services from private hospitals in New Delhi through locating 'free beds' within them has been described in Section 1.1.

Currently there is no legal instrument that defines the right to health in India. However, there has been a long standing demand for the same by health activists and a draft National Health Bill has been created by government in 2009 which remains to be finalised. Meanwhile, India has one of the lowest public expenditures on health in the world, which has been about 1 percent of the Gross Domestic Product (GDP) (Kumar et al, 2011).

Since information about the homeless in India on health issues is poor, the barriers that the homeless face in varying circumstances, as described in the following section, can be juxtaposed with this overview of health services in India to provide better insights towards how these barriers may operate in India.

2.5: Barriers to Accessing Health Care

Access to social services in India is strongly related to factors of class, gender, caste¹⁰ and education, and is difficult for poor people in general. As such, poverty affects all the social determinants of health as well as the ability to access health care in case of illness. The prevailing situation of a highly privatised health care system and high out of pocket expenditures make access to health care difficult for all poor people in general. As described by Balarajan et al (2011) in a recent paper on health care and equity in India, costs of care may be a reason for the poor to forego care altogether. Individuals who are disadvantaged and poor are more likely to receive poor-quality services and dissatisfaction with the quality of care in the public sector might be the reason why individuals who are poor seek care in the private sector.

However, within the broad category of the 'poor', there are various sub categories characterised by specific vulnerabilities that face specific barriers to accessing health care; such as the homeless.

Despite a high burden of disease the homeless are found to be wary of approaching health care services for a variety of reasons. Whilst these reasons are described in a variety of geographical settings and amongst different age and sex groups in developed countries, the commonalities suggest that they may have universal relevance and relationship to homelessness per se rather than to their more specific contexts.

The reasons range from characteristics of the facilities themselves, such as insulting behaviour of health care providers, inconvenient timings and high costs (Quilgars and Pleace, 2003), particular characteristics of being homeless - such as the absence of a fixed address (Findlay et al, 2010; Quilgars and Pleace, 2003), a lack of literacy and inability to fill in forms (Quilgars and Pleace, 2003), and a lack of financial assistance such as insurance (Hudson et al., 2010). Characteristics such as lack of transport, high degree of mobility (Findlay et al,

¹⁰ A system of social stratification where people belonging to 'lower' castes may be discriminated against

2010), an unsettled lifestyle and mutual distrust between the health care providers and the homeless (Findlay et al, 2010; McMurray-Avila et al, 1999; Quilgars and Pleace, 2003) further cause barriers to health care and follow up.

A recent qualitative study of 24 homeless drug-using young adults in Santa Monica, USA found that both structural barriers (e.g. limited clinic sites, limited hours of operation, priority health conditions, and long wait times) and social barriers (such as the perception of discrimination by uncaring professionals) contributed to their failure to access care (Hudson et al., 2010).

Even in European countries where health care is organised systematically and is relatively equitable as compared to India, FEANTSA notes the barriers experienced by the homeless as follows:

- Stigma: Homeless people tend to encounter negative reactions when they try to access healthcare services. Trying to deal with administrative personnel can be particularly difficult;
- Discrimination: Homeless people find it harder to register with a General Practitioner than members of the general public. Requests for a permanent address and other details can constitute a real or a psychological barrier;
- No continuity of care: The lifestyle of homeless people tends to be a mobile one, but there is frequently no flexibility in the healthcare system in this regard. A move from one district to another may mean that a homeless person finds himself or herself outside the system again;
- Difficulty accessing drug and alcohol services: services may be insufficient and sometimes have very long waiting times, but they are crucial for the health of homeless people;
- Lack of knowledge about entitlements: some homeless feel that they don't know what they are entitled to in the line of healthcare and services. If they were better informed they would be more confident about trying to access them;

- Financial obstacles: in many countries there may be cost associated to accessing healthcare that makes it inaccessible to homeless people (FEANTSA, 2004).

An evaluation of services for the homeless in Scotland reveals that the main barriers for the homeless relate to the administration of the health system (the National Health System or NHS) itself. These barriers include the requirement for a permanent address. It also highlights negligent behaviour amongst medical professionals as well as the neglect of their own health by the homeless as a result of low self esteem. In particular, drug and alcohol dependency and mental health problems have been correlated with poorer health seeking behaviour (Quilgars and Pleace, 2003).

The health systems presumed in the analysis above, such as having a geographical (district-wise) catchment area for facilities, and widespread drug and alcohol services for the homeless do not exist in India. While not much information is available from Indian studies on barriers for access to health care, the two main reports cited previously; 'Living Rough' and the HIGH report; Health Care Beyond Zero, provide many insights through their case studies of the difficulties faced by homeless people in this regard. For example, Mander notes that the homeless "found the government hospitals unwelcoming, discriminating because of their unclean unwashed bodies, and expensive (because of the costs of medicines and sometimes illegal charges by the public health practitioners)" (Mander, 2008:27). The HIGH report offers greater detail on health issues and mentions cost being the major reason that the homeless fail to access government hospitals. They also find not having proof of residence and the attitude of health care providers as a barrier. Further, they relate that it takes a long time to get attended to in public facilities and add a unique insight; how the lack of family support for care during hospital admissions becomes a barrier (HIGH, 2003).

Combining the understanding of the health system in India from Section 2.4 with the barriers faced by the homeless, it is possible to understand that while the barriers described in literature are a combination of both structural and socio-

cultural barriers, structural causes are likely to predominate in India. High costs of care, even in the government-run (public health) system and the failure of the system to be able to cater to a population that is mostly illiterate, has a high burden of disease and does not have fixed residence and attendant family emerge as the main potential structural issues. These are then likely to compound the general problems with quality in public health systems such as long delays and complicated procedures that poor people are often not able to comprehend, as described in the reports from India.

Discrimination and stigma on the part of the health care providers, illiteracy, language difficulties and health seeking behaviour of the homeless themselves, especially those that suffer from substance abuse and mental illness are likely to form the main socio-cultural barriers. In addition, low self esteem and confidence arising from poor socio economic status could further create socio cultural barriers for health seeking from a system that is far more powerful than the homeless individual.

2.6: Health Systems Response to Homeless Persons; Facilitating Factors

Specific health programmes have been set up in Europe and US by NGOs and governments working separately or in partnership, which can be analysed to identify facilitating factors that would allow better access to health care by the homeless. Examples are available from Austria, Portugal, Scotland and US and some of these are described in the FEANTSA (2004) report on 'How Health Professionals can Work towards Meeting the Health Needs of Homeless People'.

A partnership between two NGOs and the local government was put together in Graz, Austria to offer emergency and basic medical care to those who need a system with easy access or who are without health insurance; the Marien-Ambulanz (FEANTSA, 2004). Essentially, this offers a telephone helpline and a centre that runs for two hours daily for emergency and ambulance services. The ambulance carries some basic primary health care services and thus also functions as a mobile health unit.

The idea behind the Conde Ferreira Hospital Centre in Porto, Portugal, is that the intervention should take place in the geographical location where the excluded population is located. It “is centred around promotion of personal growth, self-determination, improvement of social relationships, employment, recreation and leisure” (FEANTSA, 2004: 15). Outreach is through mobile units and the services offered are holistic and include medical care, counselling and housing and employment support.

The Scottish government has been running an extensive health programme for the homeless which has also been well documented and formally evaluated (Quilgars and Pleace, 2003). The evaluation strongly suggests that services for the homeless must include strategies for prevention of homelessness itself, such as close coordination with other agencies for housing and employment. In terms of direct interventions by the health system, a very helpful framework is developed by the authors as follows:

1. Adaptations of the existing system: through providing a link worker at the level of the facility, discharge arrangements for post-admission care and special training of medical personnel
2. Primary health care services: through outreach as well as fixed locations, including facilitation through health workers
3. Specialist services: for mental illness and drug abuse which need to be of high quality, tolerant, flexible and individually tailored. Dental services, podiatry and physiotherapy are also recommended as additional specialist services.
4. Health Promotion: including peer group learning, in settings such as on the street, in hostels and shelters.

FEANTSA (2004) appreciates that the programme in Scotland is backed by political, legislative and social changes and that special legislation exists for protecting the rights of the homeless.

A significant symposium paper from the US (MacMurray-Avila, 1998) details the changes necessary in clinical practice to improve access by the homeless. The

authors also identify nine general principles for facilitating health care for the homeless: the importance of outreach, respect for the individuality of each person, cultivation of trust and rapport between service provider and client, flexibility in service provision, including location and hours of service, as well as flexibility in treatment approaches, attention to the basic survival needs of homeless people which may be their first priority rather than health care, the importance of integrated service provision, clinical expertise to address complex clinical problems, including access to specialized care, need for programs combining housing with services and finally, a longitudinal perspective that ensures continuing care. The authors consider outreach to be best delivered through formerly homeless people and also advocate the use of multidisciplinary mobile teams. They end by saying “Until such time as there is universal health care coverage and adequate housing for all, people experiencing homelessness will need access to a health care system designed specifically to respond to their unique needs” (MacMurray-Avila, 1998: last para).

The emerging discipline of ‘street medicine’ refers to the delivery of health care services in the locations where the homeless are to be found and is centred on medical outreach teams. In an analysis of eight street medicine initiatives in various cities of the US, authors find the best practices to be the use of mobile clinic vans, keeping electronic medical records, collaboration with community clinics and hospitals, and provision of comprehensive social support (Howe et al, 2009). They also suggest two short-term outcome measures for such programmes, namely, patient engagement and patients’ subjective assessment of their well-being.

Thus, the facilitation described in literature ranges from relatively limited interventions through mobile units such as in Graz, Austria to the provision of comprehensive care including GP, nursing and specialist services such as drug and alcohol workers, dentistry, podiatry and opticians in the initiative taken by the Scottish Government. Desirable health services for the homeless include features of outreach to engage clients in treatment, respect and trust, flexibility in service provision; including location and hours of service, convergence with social housing and social care services as well as flexibility in treatment approaches;

including clinical expertise to address complex clinical problems and access to specialized care. Most of these facilitatory strategies focus on the structural barriers that inhibit access by the homeless. However, the strategies of training of health care providers and health promotion amongst the homeless intervene in socio-cultural barriers.

In the Indian context, the enabling interventions of NGO AB have been described already in the section on settings. It is notable that they correspond to some features listed above, such as having health workers for outreach, running basic health services and facilitating referrals for advanced care. The HIGH initiative also provides services for the homeless in Delhi and states as its strategies and aims

1. To provide street based free medical services, suiting the needs and priorities, for the general health problems of the homeless [through community health workers and clinics]
2. To attempt to engage in treatment at the outreach service, Mentally Ill Homeless Persons (MIHP), specially persons with Severe Mental Illnesses (SMIs)
3. To provide street based counselling and treatment for homeless substance dependents and persons with common mental disorders.
4. To create awareness amongst homeless people regarding their health rights as provided by the Indian Constitution and equip them to access health facilities.
5. To sensitise government hospital staff to recognise and respond to the rights of the homeless for medical treatment.
6. To develop a referral system between the outreach health service and government hospitals.
7. To formulate a database for further intervention and research. (HIGH, 2003: 16)

It should be noted that they add the component of a rights based approach to improving the socio-cultural aspects of the problem of poor access. Informal

internal evaluation has led them to consider some additional approaches such as creating a pool of volunteers for attending to homeless people being admitted to hospital, enabling more laboratory tests, providing drinking water at outreach points and extending the timings of the outreach facilities, as reported in their report.

In summary, it is clear from the descriptions above that, whilst the health problems of homeless persons and their access to health care have been studied to some extent in developed countries and some interventions have also been tried, interest in this issue is at a germinal stage in India. Similarly, whilst recent reports such as 'Living Rough' (Mander, 2008) and 'Health Care Beyond Zero' (HIGH, 2003) have highlighted the overall context of homelessness in the major metropolitan cities of India including New Delhi, the burden of disease and the costs and consequences of ill health for the homeless has not been extensively researched to date. In addition, little in-depth research has been conducted about the physical, socio-economic and cultural barriers that reduce the access homeless people in New Delhi have to health care – specifically with a view to providing evidence for efforts to reorient public health services to be able to accommodate the particular needs of the homeless in New Delhi. While small but significant enabling efforts have been made by a few NGOs, these have not been evaluated with a view to policy advocacy for scale-up through the public health system.

CHAPTER 3: RESEARCH DESIGN AND METHODOLOGY

This chapter describes the methodological approaches to the study and describes the research design and strategies in detail.

3.1: Aims of the Study

The **aim** of this study was to explore the barriers and facilitating factors, both perceived and experienced, by the adult homeless in Nizamuddin area of the city of New Delhi, in seeking and accessing health care, especially from the public health system.

3.2: Objectives of the Study

The **objectives** of the study were:

1. To identify and describe the physical, social, cultural and economic barriers, both perceived and experienced, by the homeless in Nizamuddin with respect to seeking and accessing health care, with special reference to the public health care system.
2. To identify and describe the facilitating factors, both perceived and experienced, by the homeless in Nizamuddin in seeking and accessing health care from the public health care system.
3. Based on the above, to explore what implications this could have for the public health facilities in New Delhi with regard to their future policy and practice in relation to safeguarding the health of the homeless in areas such as Nizamuddin.

3.3: Study Design

This descriptive study used a qualitative research methods approach. A qualitative approach is more suited to studies of this nature since it attempts to understand and document perceptions and complex experiences, and seeks to allow for free, unstructured expression which is not limited by pre-determined boundaries such as are placed by the quantitative approach and reflected in

quantitative tools and methods (Pope and Mays, 1995). The study was intended to take place in the natural setting (as opposed to a research institution or environment) so as to decrease inhibition (Genzok, undated; Green and Thorogood, 2004, Jones, 1995) and in places and at times that were convenient to the study participants. It must be borne in mind that major differences in class and privilege existed between the researcher (a doctor) and the participants. Thus, it was felt that allowing the ‘voices’ of the homeless to be heard (for example, through the qualitative method of conducting an in-depth interview and through the documentation of participants’ quotations in the research report) might facilitate a more empowering process of engagement with the participants. It was also considered that since most participants would have limited literacy, they could very well be intimidated by the tools usually used in a quantitative study such as a survey or questionnaire. The human resource and time required to administer quantitative tools to a large enough sample size for a rigorous quantitative study were also not available.

3.4: Methods

Two methods were used to collect qualitative data; in-depth interviews and observation. While observation was not originally planned as a method to be used in the study, as the researcher became more familiar with the study setting she realised that it was important for her to conduct observation in order to complement the data obtained from the individual interviews. This was expected to strengthen the researcher’s understanding of the context in which the participants lived and the kinds of issues they were likely to face in this context on a regular basis. Other public health researchers have also used the combination of IDIs and observation for this purpose (Kamat, 2006; Russell et al, 1998; Holmes and Gifford, 1997). These methods are further described in the sections that follow.

3.4.1: In-depth Interviews

In-depth interviews (IDI) were selected as the method for this study rather than focus group discussions (FGDs) though both have their advantages (Liamputtong

and Ezzy, 2005). Time, trust, greater privacy and a relaxed pace was considered likely to be required for homeless people to open up and relate personal experiences that may be painful or embarrassing and IDIs seemed to be the better option for this to be achieved. Since one of the objectives of the study was to get a rich, detailed description of the difficulties and the challenges the participants have faced in accessing health care, it seemed that a more leisurely, one-to-one interaction at a time and place that was suitable and natural for the interviewee was the best option.

Additionally, having to survive on the streets often requires that the homeless be wary, especially of persons of a more privileged class, and this may inhibit frank conversation in public – and with a peer group. The researcher's previous experience in working with the homeless has illustrated the difficulty of getting a group of homeless people (particularly women) together at one point, as compared to sitting with individuals at their convenience (Prasad et al, 2010). This is because they are quite busy with the challenges of routine activities for themselves and their families such as cooking, or being in the vicinity of a tap during the timings water is released through public taps.

3.4.2: Observation

The interviews were preceded and further supplemented by observation which is defined as “systematic watching of behaviour and talk in naturally occurring settings” (Pope and Mays, 1995:43). This was considered important from the point of view that homelessness denotes a very specific socio economic context with many peculiar characteristics that would influence the ability to access health care services. It was considered that a working knowledge of the daily lives of homeless persons and their interactions with health care services and providers was required to be able to fully appreciate the contents of the interviews as well as to be able to design the tools for the interview. Additionally, ethical considerations (as discussed in section 3.11) required that health related assistance

be made available to those participants who needed it. Participation by the researcher as a doctor and public health worker was anticipated and also likely to affect her interpretation of the context and the evidence from the interviews. Thus, the researcher felt it would be more appropriate from the point of view of reflexivity, i.e., “sensitivity to the ways in which the researcher and the research process have shaped the collected data, including the role of prior assumptions and experience” (Mays and Pope, 2000: 51), to make it a part of the formal design. In the context of research with homeless persons in India, detailed ‘methodology notes’ of the report ‘Living Rough’ describes how “observation yielded information about the surroundings of w[h]ere they [the homeless] live, their physical appearance, worldly belongings, facial expressions and highs and lows in the voice as they spoke” (Tulsyan, 2008: 96) and the researchers have used it to supplement other methods of investigation.

3.5: Study Population

The study population comprised of all adult homeless persons between the ages of 18 - 65 years in the Nizamuddin area of the metropolitan city of New Delhi. The study population included a range of ages and a range of other categories such as single men and single women; persons living on the streets with families; those with a disability; those with a substance abuse problem; those that have been living on the streets for a significant number of years in the area, and those that have moved into the area more recently. These characteristics had been identified as important from the survey of literature as well as conversations with NGO AB in preparation for the study. It was considered that these sub categories may significantly affect the access to health care services. Thus, attempts were made to include potential participants for the study from all these sub categories as far as possible within the limitations of the study.

3.6: Study Sample and Sampling Procedures

A sample size of twenty homeless people had been decided by the researcher on the basis of the multiple participant-characteristics (as discussed in the previous section) that had to be kept in mind while sampling, as well as the limitations of

time. However, the sample finally consisted of eighteen homeless participants due to lack of time. The sampling was a mix of purposive and convenience sampling. Participants were selected to belong to two distinct categories as described further in this section, and nine participants were finally selected for each category.

Purposive sampling was done from as many of the sub-categories mentioned above as was possible in order to achieve a high degree of variation and comprise a '**general category**'. A further nine persons were selected from those who had been assisted by NGO AB to access health care facilities; either the health clinic run by NGO AB in the area, or other services through the facilitation of NGO AB, to comprise a '**facilitated category**'. This sample was intended to maximise the chances of getting rich information about facilitating factors that enabled access to health care by the homeless, given that the sample comprised of those who had been known to suffer ill health and who had, in fact, managed to access health care. The NGO AB (described previously in Section X) may also have facilitated participant's access to the public health system in important ways and it was hoped that respondents from the 'facilitated sample' would then be able to describe their experiences of such a facilitated referral to the public sector – experiences which might add additional and important details about the pathways to care.

People with obvious and severe mental illness were not interviewed since there were ethical considerations in taking consent and the interview itself would require special skills. Similarly, people with a disability that precluded effective communication, such as deafness, or intellectual disability were excluded. Attempts were made to include as many women as men in both categories. However, only seven of the eighteen participants were women, four in the general and three in the facilitated category though special attempts were made to purposively find women participants such as attending the once-a-week gynaecology clinic at the NGO AB health centre.

Participants were found by using different techniques – those of the facilitated category were already familiar to the NGO AB community health workers since

the workers had played a role in facilitating care for them. The NGO AB health workers were able to draw up a list of such people and tried to locate them in advance of the researcher's visit. Since these potential participants were more familiar with the NGO AB health workers, they made the effort in many instances, of being available at a pre-planned time and place, such as the NGO AB health centre or the park. Some of the participants in the facilitated category were identified on the spot by the researcher and NGO AB health workers while the researcher attended the NGO AB health centre as an observer.

Participants for the general category were selected during rounds of the pavement and parks in the area in which homeless persons abound. The researcher was usually accompanied by the NGO AB health workers who were often able to identify homeless persons who had been unwell recently or in the past. Otherwise, the researcher was referred to such people by other homeless people during the rounds. Once or twice, participants were found by snowballing as an interviewee referred us to other potential participants. For six interviews, NGO AB health workers were not available during the field trip made by the researcher and participants were identified and interviewed by the researcher on her own after casual conversations with homeless people on the pavement and in the park. During the latter part of the field work, attempts were made to purposively search out persons with characteristics that were missing in the sample hitherto.

In addition, six key informants were selected for purposes of triangulation which aims "to increase the understanding of complex phenomena (Malterud, 2001: 487). Since the NGO facilitators and health care providers would have been witness to the experiences that homeless persons have had with public health care services, they would help to obtain further perspective and insight into the key issues explored with the homeless respondents from the alternative perspective of the service provider. This triangulation between observation, interviews with the homeless and interviews with key informants would further help to assess the credibility (Sandelowski, 1986) of the data gathered through each. Thus, advantages of using mixed methods for research on health services such as

“triangulation, complementarity, and expansion” (Johnstone, 2004: 264) may be achieved.

The six key informants who were interviewed as part of the study comprised of the following:

1. Health Programme Manager of the NGO AB
2. Two community health workers of the NGO AB
3. Two doctors at the NGO AB clinic; one general physician and one gynaecologist
4. One senior consultant surgeon at the tertiary care public hospital.

The interviews with key informants were timed strategically through the course of the data collection period to allow for better understanding and course-corrections to the interview process and tools. Thus, the interview with the Health Programme Manager of the NGO AB was done before the interviews with the homeless participants, the health workers were interviewed after a few interviews with the homeless, one NGO AB doctor was interviewed early in the course of the study and one later, and the senior consultant at the government hospital was interviewed last of all.

3.7: Data Collection Instruments and Procedures

3.7.1 In Depth Interviews

For the individual interviews, a semi-structured interview guide was designed (Annexures 4 and 5) for each category of participants which included demographic information such as the age, employment status, level of education and marital status as well as details of migration to New Delhi, duration of homelessness and reasons for homelessness. The opening questions were related to the experience of being unwell and elicited the description of such times. The researcher used a theme list or interview guide and probes were used to steer the conversation towards greater depth or to obtain clarity on key issues related to the specific objectives of the study. The researcher specifically listed probes also to

elicit any positive experiences the interviewees may have had with the services offered by the NGO-run centre or the public health services.

Most of the interviews with the homeless participants took place in their natural surroundings while a few interviews of participants in the facilitated category were held in a room at the NGO AB clinic. The interviews held on the pavements and parks had some challenges of being extremely noisy and many interviews attracted the attention of other curious street dwellers, which had to be attended to before the interview could take place. As recommended during the peer debriefings prior to the beginning of the field work (see Sections 3.9, 3.11 for details), the researcher was introduced as a doctor and verbal consent was taken from the participants before the interview. Once, while the researcher was introducing herself, a participant was advised by another street dweller not to cooperate for fear of exploitation, but the participant agreed to be interviewed nonetheless. The interviews were recorded and notes were also taken.

All participants were offered refreshments / a meal at the end of the interview but the majority declined and many were reticent about accepting. Those who did accept made it a point not to ask for expensive items on the menu even though they were encouraged to order whatever they wished to eat. Some, instead, requested medical help such as the allocation of an inhaler or a longer-lasting prescription for a chronic illness. At the commencement of an interview, many of the participants would quickly dust a mat or the pavement for the researcher to sit on or offered her a cold drink or tea from their meagre resources.

Despite some of the interviews being extremely animated, the researcher did experience that for the most part the homeless participants were rather succinct in their responses and rarely spoke at length on any of the issues, preferring to make brief answers. This may be reflective of the way in which the participants communicate generally – many of whom were living in relative isolation, or of a relative paucity of words due to illiteracy. They may have also been slightly ill at ease by being interviewed by a person who belonged to a very different socio-economic stratum.

For interviewing participants in both the categories, the NGO AB health workers played some important roles; they helped to identify potential participants and created an atmosphere of familiarity for the participants most of whom had seen the health workers on their rounds. They sometimes interpreted colloquial phrases or words used by the interviewee that the researcher was unfamiliar with though all the interviews took place in Hindustani¹¹ that the researcher spoke fluently, being a resident of New Delhi herself. The health workers, when available during interviews stayed through the entire duration of the interview in some cases, and left for other work on other occasions. When they stayed, they were requested not to intervene during the interviews, though sometimes they had clarifications to offer from their own experience of a particular episode. The additional information was received later and noted in the journal being kept by the researcher. Some of this has been referred to during the analysis of the findings in chapter 4. The researcher and the NGO AB health workers ensured that any participant who needed immediate health care was attended to through the NGO AB clinic.

The key informants were similarly interviewed with the help of a guide (Annexure 6) to determine their experiences with directly delivering health care to homeless persons as well as facilitating care for them through referrals. Similar procedures of introduction and informed consent and recording the interviews were followed during these interviews which were held in the NGO AB office, the NGO AB clinic and the home of the senior consultant with the government hospital.

3.7.2: Observation

Field work took place over a period of five months between late January and mid July of 2011. This comprised of a number of visits to the study site to conduct the interviews as well as a process of observation. As advised by her peer during debriefing, the researcher introduced herself as a doctor and on occasion became involved in providing immediate minor medical advice or a link-up to the NGO

¹¹ Hindi is the main official language used in Northern India and Hindustani alludes to the spoken form of Hindi commonly used in Delhi that incorporates words from Urdu and other northern regional languages.

clinic for dressing / investigation/ nebulisation etc. Thus, a familiarity was achieved with the field area, the homeless participants and their relationship with health care services in the area that was over and above the information received from the interviews. No specific tool or checklist was used for the observation. However, a diary was maintained for recording the researcher's observations during the interviews and the time spent in the area of the study.

During the interviews themselves, notes were taken about significant non-verbal communications such as mood, responses to being interviewed, body language and actions, facial expression and gestures, the physical environment of the interview and the personal characteristics of the participant, such as 'frail', 'animated' and so on.

Observations also occurred in five specific locations; at the evening clinics being run by the NGO AB at the centre, their street clinics, as well as on the streets and in the 3 parks in the area where the homeless tended to cluster. The author also conducted a late evening medical camp through NGO AB at the government shelter for homeless in the area. This helped to understand the facilities that could be provided during such camps, which are organised frequently by the NGO AB, and their limitations. During the field work period a participant in the general category was found to have a surgical problem requiring admission. The researcher, along with NGO AB, facilitated this admission to a 'free bed' in a large private hospital (see Section 1.1 for details on 'free beds') and observed the issues that related to the objectives of the study directly. A further six participants were referred by NGO AB and the researcher during this period for further management at various public hospitals¹². Thus two systems of care were directly observed; the various facilities provided by NGO AB (including referral) and the 'free beds' system of the private hospital.

By the end of the five months of field work and interviews, it was felt by the researcher that rich data had been accumulated and no additional information was

¹² All of these are still pending treatment / admission.

forthcoming from the strategies decided for the present study. Thus, it was decided to bring the data collection to a conclusion.

3.8: Data Analysis

Recordings of the interviews were in Hindustani and these were then translated to English and transcribed by the researcher. The transcripts of the eighteen interviews with homeless participants and six key informants formed the primary source of data for the study. This was complemented by the data obtained from the process of observation. Preliminary analysis of the interviews occurred simultaneously to that of data collection; the researcher summarised key themes that emerged from each of the interviews so as to enable a more focused investigation of some of these emerging themes in subsequent interviews. Once the data collection was over, thematic content analysis was used to analyze the data. As Green and Thorogood (2004) and Pope and Mays (2000) have prescribed, this entailed a process of the researcher becoming familiar with the data, indexing and charting the themes that emerge from the data, and using this process of analysis to allow for comparisons between and within the identified themes and categories.

Two transcripts were shared with the supervisor, and the researcher and supervisor both independently listed the significant factors that were emerging from these two transcripts. The preliminary themes were determined by the researcher after deep reflection on the entire data set. These were then reviewed by the supervisor to arrive at the final construction of the themes.

Once the themes had been finalised, the notes from the observation were perused carefully to see how they contributed to the themes. Information from observation was inserted within the themes wherever it was considered that it would add insight, value or a different perspective.

3.9: Rigour

Rigour, or thoroughness, in order to achieve quality in qualitative research has been the subject of much debate and discussion (Malterud, 2001; Sandelowski 1986, 1993; Mays and Pope, 2000, Marshall and Rossman, 1995). According to Mays and Pope “the basic strategy to ensure rigour, and thus quality, in qualitative research is systematic, self conscious research design, data collection, interpretation, and communication” (2000: 52).

Five strategies have been consciously chosen in this study in order to achieve better rigour: leaving an audit trail (Cresswell and Miller, 2000, Sandelowski, 1986), the use of thick rich description (Ryle, 1968 in Geertz, 1973), the use of researcher reflexivity (Mays and Pope, 2000; Marshall and Rossman, 1995, Sandelowski, 1986, Malterud, 2001; Cresswell and Miller, 2000; MacCoun, 1998), triangulation (Malterud, 2001) and the process of peer debriefing (Cresswell and Miller, 2000).

The particular choice of strategies related to the context and setting of the study as well as its aims and objectives. For example, reflexivity was considered important because of the significant difference between the socio economic status of the researcher with the homeless, her pre existing experience in the health sector and her pre existing relationship with NGO AB. All these factors could influence the process of the study itself as well as lead to a bias in her interpretations. As part of reflexivity, the researcher has attempted to be transparent about these issues wherever significant. She has also carefully recorded her own feelings (such as any negative feelings towards the homeless) and experiences in the observation record, and attempted to consciously examine any impact these factors might have had on the study.

Peer debriefing was chosen as a method since the researcher was conscious of needing periodic advice from a senior researcher who had more experience in research with the homeless and could assist with ethical considerations. A senior person who heads NGO AB and has been leading research with the homeless and advocacy efforts for their rights was requested to play this role. Three debriefings

were undertaken by the researcher during the preparatory phase of the study. The study proposal was also shared with this senior researcher, and his advice shared with the supervisor. Since the senior researcher was heading NGO AB, the researcher chose not to discuss the findings of the study with him while it was in process and relied upon supervisory inputs.

Auditability implies the provision of clear documentation of all research decisions and activities (Cresswell and Miller, 2000, Sandelowski, 1986). As part of leaving an audit trail, the changes in methods, sampling and data collection during the course of the study and the reasons for making the change have been described. The researcher has also related supervisory inputs as well as the inputs from the peer debriefing (see Section 3.9).

Making thick rich descriptions available rather than only facts and analysis, offers the readers many advantages; it creates an immediate intimacy creating closeness to the actual situation – verisimilitude (Cresswell and Miller, 2000) and also enhances credibility (Sandelowski, 1986). The survey of literature confirms that multiple contextual elements may affect access to health care by the homeless in different settings; and the setting of this study has many unique characteristics. Thus, an attempt has been made to use thick rich descriptions to illustrate the themes emerging from the study wherever appropriate, so that the reader may be able to get a direct sense of the specific context of the findings. Though this qualitative study is not intended, by design, to arrive at generalisable conclusions, it is hoped that the use of thick rich descriptions will enable credibility and allow readers to come to their own conclusions of transferability of the findings to other settings.

As mentioned previously, the interviews with key informants along with homeless participants have served the purpose of triangulation of *data*. The observations of the researcher have, in addition, allowed a triangulation of *methods* (Denzin, in Jick, 1979). Both these strategies are intended to provide enough information for the reader to assess if findings are sufficiently verified. Care has been taken to describe such findings that do not fall in line with emerging dominant findings,

i.e., 'negative' or 'deviant' descriptions (Sandelowski, 1986; Cresswell and Miller, 2000; Green and Thorogood, 2004).

3.10: Study Limitations

The final sample size of eighteen participants might not allow for what authors describe as the saturation of data (Strauss and Corbin, 1994; Pope and Mays, 2000; Green and Thorogood, 2004; Annells, 1996, Glaser and Strauss, 1967; Strauss and Corbin, 1990) or adequate coverage of all the participant sub categories identified as having a potential impact on access to health care. However, the researcher was limited by time, budgetary constraints as well as the guidelines of the MPH programme. The difficulty in reaching women participants has already been referred to in Section 3.6. It will have to be borne in mind that the study further excluded categories of homeless people, such as those with severe intellectual or physical disability who would not have been able to communicate with the researcher. Thus, the experiences and perspectives of a significant category of homeless people were not gained despite the fact that they might find it even more difficult to access appropriate health care than the homeless people who participated.

Sometimes it was difficult to understand what was being said by a participant because of their accent or the use of an unfamiliar phrase (as discussed in Section 3.7.1) and some information may have been missed on that account. Similarly, the noisy surroundings also caused difficulties in obtaining good quality recordings and transcriptions of each interview that were a hundred percent accurate.

The power differential between the researcher and the participants due to marked differences in socio economic and educational status may have caused a hindrance in allowing participants to rapidly achieve a sense of trust with the researcher. A longer process of obtaining familiarity with the respondents, or being known within the community may have assisted in achieving better results. Additionally, the limited experience of the researcher with issues related to homelessness may have constrained the information she was able to probe, explore and gather through the interviews.

Finally, the study findings may not be replicable to all contexts of homeless persons since the setting contains some very specific characteristics as pointed out in the description of the study setting (Section 1.3). As mentioned in the discussion on strategies for achieving rigour in the study, qualitative studies do not intend to produce generalizable results; however, the study hopes that it has represented the experiences of homeless persons in accessing health care in this particular setting adequately.

3.11: Ethical Considerations

The study was conducted only after approval was obtained from The University of the Western Cape Ethics Committee.

While consent forms and information sheets had been prepared by the researcher (Appendix A, B and C), it was clear even during planning that most participants were likely to be illiterate. During peer debriefing just prior to the field work, it was suggested by the senior and experienced researcher who had been requested to review the process, that signing a form would be taken with suspicion by the participants and he expressly recommended that no written material be exchanged. It was anticipated that there might be a reluctance of homeless persons to sign on any piece of paper as a result of wariness that their 'blank' signature may be used against them by the authorities. The presence of the familiar and experienced NGO AB health workers accompanying the researcher was hoped to provide a sense of security. It was also recommended that the researcher explicitly introduces herself as a doctor to further increase trust. This concern was communicated to the supervisor and it was agreed that verbal consent, in the presence of the NGO health worker as far as possible, would be the process followed. Thus, all the interviews were only initiated and recorded after obtaining verbal consent.

Participants were explicitly given the option not to participate without adverse consequences to themselves. During the interviews, the researcher helped to facilitate any immediate or acute problems that the homeless person may be facing at the time of the interview, such as hunger, cold or ill health. Every effort

was made to ensure that none of those interviewed were left in extreme vulnerability. As it happened, all the interviews were conducted in an atmosphere of congeniality. No ill effects of the interview itself had been anticipated and none were observed. The researcher retained contact with the NGO AB health workers even after the data collection was over to ensure that no participant had suffered any harm.

A high level of confidentiality was strictly adhered to during the study. All tapes and transcribed materials were kept in a safe place at the researcher's home. Both the NGO health workers involved in the study were informed of the importance of ensuring privacy of personal information.



CHAPTER 4: FINDINGS OF THE STUDY

4.1: Introduction

This chapter describes the main findings of the study. A detailed profile of the participants is provided in Section 4.2 since it is deemed to contribute to greater understanding of their unique histories and current situation. This insight may help to locate the accounts of the participants in their particular socio economic context. Thereafter, as per the objectives of the study, the chapter describes the various barriers and facilitating factors that the adult homeless in the Nizamuddin area of New Delhi encountered in accessing health care, with special reference to the public health system.

4.2: Participant Profile

Accurate demographic data was difficult to get from the homeless participants. Detailed facts and specific dates were not always known or remembered, such as, for example, dates of birth and their early history of schooling. Participants were also reticent to discuss their incomes since the majority lived from begging and their income was inconstant. Since it was obvious that they were mostly illiterate and extremely poor the researcher did not spend too much time in interviews attempting to get clarity on these factual details.

In total eighteen homeless persons and six key informants were interviewed. Of the eighteen, nine were those who had attempted to access health care without the facilitation of NGO AB (referred to as general category in Section 3.6) and nine were those who had actively been assisted by NGO AB (referred to as the facilitated category in Section 3.6). However, during the interviews it was noted that the facilitated category also provided rich information on the pre facilitation phases of their health problems. The facilitated category added information that the researcher had expected from the general category, such as on previous struggles to access health care, as well as information on their experience of facilitation for access to health care. Thus, this category became a source of richer more concentrated data rather than merely a comparison group.

The information that is available on age, sex, literacy, income, occupation and other relevant characteristics of these eighteen participants is described below:

4.2.1: Age

The age of the participants ranged between approximately 30 to 70 years.

Table 1: Distribution by Age

Age (years)	No. of Participants (General Category, Facilitated Category)
30-45	10 (5,5)
45-60	5 (3,2)
> 60	3 (1,2)

4.2.2: Sex

In all, seven of the eighteen participants were women, four of whom were in the general category and three in the facilitated category. It was more difficult to find women participants in the facilitated category as discussed in Section 3.7 on sampling strategies.

4.2.3: Literacy

Fourteen participants were illiterate and four were literate including only one woman, who had mental health problems and two young men with drug dependence. One of the latter spoke fluent English and had taken an English speaking course.

4.2.4: Current Occupation

One woman was engaged as a sweeper, one man as a casual labourer and another man as a painter. The wife of one participant worked as a domestic help. The rest of the participants (14) depended on alms or donations for survival.

4.2.5 Previous Occupation

The majority (seven) of the participants that currently depended on alms (namely eight men and three women) had been regular workers in the informal sector before they became homeless. They had lost their livelihoods to age, chronic disease or post traumatic disability. Their occupations comprised of casual labour, construction work, vending, cycle-rikshaw plying (for the men) and casual labour, domestic work and sweeping (for the women). The two women who had not worked for wages were elderly and had been housewives before their homelessness; one of them had a mental illness. One man who had not worked for wages was young with a history of substance abuse and was a graduate involved with a petty crime syndicate.

4.2.6: Current Income

Participants that depended on alms reported earning between 5 Rs a day (10 cents) and 100 Rs (two dollars) a day. The daily wages for casual, uncertain construction work was reported to be Rs 100 by one female participant which is less than half the prescribed Rs 247 (approx. \$5) which is the minimum daily wage in Delhi (Delhi Government, 2011). The wife of one participant was earning Rs 1500 per month from regular domestic work which is one-fourth of the current prescribed minimum wage.

4.2.7: Social Security

The elderly mother of one of the female participants reportedly had a ration card that enabled her to receive food rations from government. This contributed significantly to feeding the family of the participant, her three children and her mother. One of the elderly female participants was getting an old age pension from a government scheme of Rs 1000 per month which contributed to feeding her and her mentally disabled daughter. None of the other participants had a ration card or benefited from any government social security scheme, though one participant showed old receipts for various surveys that would have entitled him to a ration card. He said he had been surveyed again and again but never actually

received the entitlement. Significantly, no respondent possessed a BPL card though many BPL surveys have been carried out in the city.

4.2.8: Reasons for Homelessness / Loss of Livelihoods

Of the eight participants who earlier had regular work, all had lived in temporary shelters (*jhuggis*) or proper dwellings and were pushed into homelessness by certain common factors. These ranged from expenses on health, demolition drives by the government to simply becoming too old to work and be able to pay rent.

Health reasons were one of the significant causes of a loss of livelihood and financial insecurity for participants and, in a sense, tipped them into being homeless. Five of the eighteen participants had a traumatic episode resulting in injuries that were left untreated or partially treated due to unaffordable medical expenses. The resultant disability cost them their livelihood. Some of them were already homeless but lost their ability to work and some of them became homeless as a result. The costs incurred on treatment cost two of the participants their homes. One participant had to sell their family home for the treatment of his mother. Another young woman participant's family had to sell their already mortgaged house and their rikshaws to pay for the operations of their baby daughter as quoted below:

[It cost] total 13-14000 [Rs]; 7000 [Rs] for coloured X- Ray [barium X ray].

... [Our] home [was] mortgaged. [We] sold the two rikshaws. Now he plies a rented rikshaw.

Five persons simply became too old or too sick to continue working. These included the participants with leprosy, asthma and tuberculosis. Only one of these receives old age pension of Rs 1000 (\$20) a month from government and that contributes significantly to her survival as well as that of a dependent disabled daughter.

None of the participants who had suffered trauma reported any formal compensation; in the case of an occupational injury one got Rs 50 (equivalent to a dollar) from his employer. Another woke from a hit and run injury to find Rs 140 (\$3) in his pocket.

However, one participant who had lost his village land from a natural disaster (an earthquake) was offered land in compensation by the government – he chose to migrate to the city and on the streets because he lost his entire family in the episode.

Apart from the six participants described above, four had lived in *jhuggis* close to the study area which were considered unauthorised by the Delhi Government. These were demolished and the participants did not get any alternate accommodation as part of rehabilitation. Three of these participants were women.

One single young mother had to leave domestic work to look after her baby. She had sent her older daughter to the hostel being run by the NGO AB rather than engage her in sibling care since she wanted her daughter to have a better future. She said:

“I thought – I am begging - let her not have to look to anyone to eat. She should stand on her own feet. I am dependent - she should not be.”

One of the participants lost his job as a horse-rides man due to government regulations that forbade him to practice his profession in the city. Alternative arrangements for him to practice his profession were not made by the local government officials. One participant had left home as a child because he was regularly beaten up by his parents and another young participant had left home because of disputes with his wife.

The explanations the participants provided the researcher as to why they had become homeless or more helpless than previously have been given prominence as a way of giving voice to the participants, since all of them appeared very keen

that the researcher appreciates the predicaments that led them to the situation they were in.

4.2.9: Duration of Living on the Streets

Apart from one participant who had been homeless for just three or four months and one for four to five years, sixteen had lived on the streets for over ten years. Of these, seven had lived on the streets for over twenty years.

4.2.10: Health Problems for Which Care Had Been Sought

The range of health problems discussed by the participants, and the reasons for which health care was required, solicited or encountered comprised of fractures and other post-traumatic disabilities, chronic respiratory disorders (asthma and COPD), mental illness, TB, diabetes, leprosy, diabetes, neonatal sepsis, bowel obstruction, hernia, substance abuse. Care during pregnancy and deliveries, was discussed with the women participants.

Of these, the commonest problems encountered in the sample were of trauma and its consequences such as mal united fractures, residual physical disability and upper limb paralysis due to damage to a nerve plexus in the armpit. One third (seven) of the people interviewed had encountered health care facilities following trauma with two of them suffering trauma twice. Four of these episodes were a result of road accidents and three from falls. Two were the result of a fight. The next commonest health problem in the sample was that of chronic respiratory disorders such as asthma and COPD described by four persons. Two women participants reported giving birth to their children in the nearby park under cover of darkness or a bush. They were unaccompanied during the childbirth.

Some participants described more than one episode or more than one type of illness. For example one respondent had asthma and also had to undergo two hernia operations; one participant had episodes of mental illness as well as a fracture resulting from a fight, one participant had suffered a fall and a road traffic accident and another participant had experienced two fractures (one as a result of

a fight and another as a result of a road accident). The single mothers with children often described a number of different episodes of ill health relating to their children. Thus the number of episodes of illness described was far more than the number of participants.

4.2.11: Other Relevant Characteristics of the Participants

Four men were currently addicted to drugs, one in the general category, three in the facilitated category. Two of these were addicted to marijuana and two to ‘smack’ (a form of heroin). Thirteen out of eighteen participants were single (four women participants, of whom two were single parents of young children and two were elderly) and five with families (including two women). There were four male participants with significant physical disabilities related to their limbs (two in each category) and two women participants with a history of mental illness (one in each category).

4.3: The Barriers for Accessing Health Care

Rather than single, stand-alone factors, the interviews revealed a complex interplay of factors that collectively contributed to the barriers that the homeless participants experienced in accessing care. In fact, it is difficult to describe any *one* factor without having to also include a reference to other factors that serve to compound or interact with the initial factor. Together these various factors seemed to create barriers that collectively determined the final outcome of whether a homeless person was able to access health care or not.

Nonetheless, despite the existence of this web-like set of inter-related factors that served, in a variety of combinations, as barriers to health care access, a number of factors emerged that appeared to be more ubiquitous and dominant in comparison to others. The findings that relate to public health services have been given priority in this study as per its objectives.

The most commonly mentioned factor related to a lack of money. Ironically, it seems to be the lack of money that primarily led the homeless to try and access

public health institutions as compared to private services and yet it was the key factor that they experienced as a barrier to accessing health care at public health services as well. Another prominent barrier to accessing health care was the delays and shunting experienced by the participants in busy public hospitals which led many participants to give up before their health problem could be adequately addressed. There were also instances of what were perceived as unwarranted dismissals from the public hospital when participants expected to have been admitted into the facility. A few respondents reported insulting behaviour by attending doctors as one of the reasons they hesitated to approach the public health facilities - especially (but not only) in the government polyclinic that is based in the study site.

Many respondents mentioned difficulties due to a general lack of information about where to go, how to deal with required admission procedures, and how to cope with the demands of a health system that is not geared to accepting homeless people.

Other barriers commonly mentioned by homeless participants included difficulties related to the safe storage of their records. Many respondents also expressed feelings of helplessness where health care seeking was concerned. The inadequate or inappropriate treatment in some cases by local private practitioners was obvious to the researcher from the accounts, as a result of her medical background. In some cases, the participants commented on ineffective treatment by such practitioners but nevertheless, they themselves did not interpret this as a barrier.

4.3.1: Paise Lao¹³; The Lack of Money

As has been described above, the costs of health care resulting from a catastrophic illness was a contributing factor to homelessness and the loss of livelihood for a number of people interviewed.

¹³ Bring money

The single most common reason for not being able to access health care that emerged from the descriptions was the lack of money. Seven respondents reported instances when the lack of money had deterred them from accessing care.

Depending on the health problem at hand, respondents reported being deterred from accessing health care by costs that ranged from a relatively small amount of Rs 30 (60 cents) for an out-patients visit at a local NGO clinic in the case of an aged woman with diabetes, to Rs 20,000 (\$400) for setting a hip fracture at a government hospital in another city where the person had reportedly already spent Rs 35,000 (\$700), and 20,000 Rs (\$400) for another person with hip fracture at the leading government hospital in New Delhi. In other words, the lack of these amounts of money had become a barrier for the homeless to moving ahead in a process of medical care.

The following quotes illustrate the kinds of payments participants had been asked to make:

I was at AG government hospital. [I] spent 35,000. One month I was there. For [the] operation [for his leg injury] they said [I needed] – 4 bottles blood plus 20,000 more. I didn't have [the money] so I couldn't get it done. I got discharged. (Young male participant with a disabled leg due to his injury)

She [the doctor] said [it] will cost [Rs] 20,000 after seeing the x ray. They made two x rays. I said from where can we get 20,000? I came back. They made a railway pass [disability certificate instead]. (Elderly male participant with a disabled leg due to his injury)

They kept asking for money. [They asked for] 10,000-12,000 Rs. [they asked me to] bring blood [for the operation]. I said I don't have [the money]. They said bring [the money] or we will discharge [your child]. (Young female participant with a child who required an operation for a congenital bowel obstruction)

They keep writing [prescriptions] and say get this [consumables] from outside. They said for the pump [asthma inhaler] - get this quickly. Then they said [bring it-] for the net [hernia mesh which]... comes for 900 Rs. When the operation started they said [there was] no [longer any] need for the net. (Middle aged male participant who had asthma and had to undergo an operation for his hernia)

The fact that many of the medical supplies, for example drugs, blood, implants and hernia meshes had to be paid for by patients was confirmed by the key informant health workers that were interviewed as follows:

Any special [expensive] drugs we have to buy from outside. They are given to only people they know – staff or relatives. [We] only get drugs like deriphyllin. [We] don't get [expensive] antibiotics.

In the case of the facilitated admission of one of the participants into the government controlled 'free beds' in a private hospital, every tablet and even the thermometers and hand sanitizers for the doctors and nurses had to be paid for. Costs of approximately Rs 5000 (approx 100 \$) were incurred by the homeless patient on drugs and consumables during a 23 day stay. These costs (out of an overall expenditure of about 80,000 Rs (1600 \$) were paid for by an NGO while the rest was paid by the private hospital¹⁴.

A few reported not having money for transport as a reason not to be able to get to the hospital in the first place.

As described earlier, no respondent possessed a BPL card or any other automatic proof of their status as 'poor'. This would have entitled them to some lowering of costs, but, as informed by one of the key informants, the senior consultant at a government hospital, even someone with a BPL card would not have got an orthopaedic prosthesis without payment.

¹⁴ As described earlier in the survey of literature, a court case is currently on in the interpretation of the contract between the Delhi Government and private hospitals for covering the costs on drugs and consumables.

The three doctors who were interviewed as key informants, however, did not seem to think that the lack of money was an issue in the government hospitals. They claimed that treatment could be made available free to poor patients if the attending doctor was willing to attest that the patient was truly deserving, since he had the powers to do so. When some stories, as related by the homeless respondents in the study, were placed to him, the senior consultant at the government hospital did acknowledge that ‘the budget finishes in the first three months’ and ‘there is only the facility to get for free what is available at the hospital’ and that ‘implants etc have to be paid for’. However, both the doctors at the NGO clinic continued to hold the view that ‘where there was a will there was a way’, that the Medical Superintendent could waive costs or that NGOs could and should assist. The view that NGOs hold the answer to costs of care was also put forward by the senior doctor at the tertiary government hospital.

Most of the costs that participants had been asked to pay in relation to receiving health care appeared to be legitimate as per the existing rules regarding the institutions’ independence to apply user charges (or their interpretation by the authorities in the respective health facilities). However, in one case a participant referred to a demand for a bribe. As quoted below, an elderly male participant reported how a helper at the hospital asked for money from the accompanying NGO health worker which was refused. He believes that his fracture has remained poorly managed as a direct result of not paying the money.

The first day I went to hospital my full treatment should have happened. That day they [workers at the hospital] asked for money. [The] NGO did not give money. They [workers at the hospital] spoilt my arm [did not set the fracture well]. Being government [working in a government hospital]; they are meant for people like us. Still they did this [were purposely negligent].

Despite the problem with costs, participants seemed to relate free health care services at the public health system with a lack of quality. It was quite clear from the accounts of the participants that no costs were incurred at the public hospitals

on out-patients appointments or treatment of more routine or minor illnesses. The costs that were described were in the context of having been admitted for operations, especially those that involved special consumables such as implants. However, despite the fact that many services were free at the public hospitals, there seemed to be a preference for paying for services as compared to receiving free care. This was explained, in many cases, by the perception of participants that care offered to them free was of inferior quality. For example, a young male participant while comparing the care he received in two public hospitals declared:

I was treated well there [in another government hospital] because, there they write [prescribe] medicines [from the private chemist] – [they say] bring them [from the private chemist rather than be given them free from the hospital pharmacy].....Three times it has happened [in previous admissions to another government hospital] that I didn't get well [when given free drugs].

Another elderly male participant had a similar opinion about the government run polyclinic in the study area, as quoted below:

They give the same [free] medicines for everything..... But the same medicine for everything does not suit [the illness does not get better]....

In addition, many of the respondents related how, when they were earning better, their preference would be to spend money on health care in the private sector. For example, one participant reported spending Rs 1200 (\$24) for a fracture and another Rs 4500 (\$90) for a hernia operation. Another elderly female participant shared how her daughter chose to have a caesarean in a private hospital out of concerns of quality:

[I have] one daughter. [She has had] three operations to [her] stomach. (Names a government hospital) Both babies died. So she saved money and went to [a] private [hospital] for the third; [she] spent Rs 15,000. She thought [this is my] last chance for [a live] baby so let me go to[a] private [hospital].

4.3.2: Chakkar Katna¹⁵; Delays, Shunting and Dismissals

Seven of the eight respondents who had been admitted to government hospitals reported difficulties with making many visits for the same problem, being asked to come another day without being attended to, long queues and delays as well as having to go hither and thither without clear directions for many hours. Five reported having given up at one point just because they were not attended to despite much effort on their part. Of these, two were then successfully treated with the help of the NGO AB. Four of the seven who had faced difficulties reported delays and having to make many repeated visits even in the period they were being facilitated by the NGO AB. These problems are illustrated by some of the quotes below:

Then they said come later. Come after 2 weeks. So it stayed wrong [the fracture was not set] for 2 weeks...They [the NGO health workers] took me back after 3 weeks. They got my registration paper and took me to the doctor. But it was 'tiffin time' [lunch time]. It was too late. Again I came back [to Nizammudin without treatment]. (Elderly male participant with a fracture)

All [day I am in] line [queue]. First [there is a] registration line, then [there is a] medicine line. Oh – it takes the whole day. I don't like it. I get angry with the doctor. People break the line. [Yet] he [the doctor] sees the person who breaks the line. (Middle aged female participant with asthma)

I kept getting after them [for treatment]. This game kept going on. I was in the waiting room – will anyone give [me] food there? I didn't get food there so I had to go off wherever [away from the hospital] to get food. I used to go back every 4-5 days to the trauma centre. [The] doctor said – what are you doing here? Go and do some work. I said I am not able to work. I have been getting knocked about for so many months [in the hospital]. [I have] met different different doctors. No one said [told me

¹⁵ Going round and round, again and again

what can be done].... They [the doctors] said 'don't get after us just now [as] the [Commonwealth] games are on'. (Young male participant with a paralysed right arm resulting from a road accident)

The delays did not seem to diminish even when there was facilitation by the NGO workers but it is possible that there might have been fewer drop outs because of follow up and motivation by the health workers from NGO AB. The tedious journey to access health care with and without the facilitation NGO AB is described in detail by a middle aged male participant with asthma who required an operation for hernia:

They said come tomorrow, come day after so I stopped going... [I tried] many times. Must have been 20 times.....One has to stand in line. That is all. I went early in the morning. Then they registered me. Then I stood in a line. Then the doctor was not there. They [the hospital staff] said come back again. Then I went again...then the doctor saw me and wrote many tests. Then I got them all done. When I went for the report - they [hospital staff] said your reports are lost. Get it done again. Then I got my blood tests done again. Then they called me after three days for the reports. I went after a week and they said they [the reports] have gone to the doctor. I went to the doctor and the doctor said they are not here go to room number so and so. I went there [and] they said it is lunch time. I kept sitting there for a long time. Then I thought 'this is useless' so I came away. I did not go back again....No. It was useless going round and round....

...Then I got to know that these [NGO health workers] get it done [facilitate admissions to the government hospital]. So I went there [to the NGO AB clinic]. They [NGO AB health workers] said ok we will get it done. Then I went with them. I had to go many times with them also. Then the doctor gave me a date...He said to come back after 3-4 months. I went after 3-4 months. [But the] dates got cancelled. They [hospital staff] said go to the emergency. I went to the emergency they [emergency ward staff]

said ‘Oh brother! Why have you come here - go to the OPD’..... these are just excuses. That is all. If one doctor says it can be done in the emergency and the other says take him to OPD it must be excuses only.....I went to the doctors again [with the health workers this time]. They gave me a date for 5 months later again. I went after 5-6 months with these people. Then they admitted me and operated me the next day... [It took a] long time. 7-8 months [to get operated]

In some cases, the persons persevered and the delays were finally brought to an end by begging and pleading as is well illustrated by the story of a young participant woman who kept trying to get government doctors in various hospitals to take her baby daughter’s illnesses seriously; first for a scalp abscess as a neonate and then for abdominal pain. She spent two years going between four major tertiary care government hospitals in New Delhi. The child was admitted many times after many delays, shunting and attempts to dismiss. Each time the mother begged and pleaded (a phrase she used repeatedly – *haath pair pakade*¹⁶) to have the child admitted. The next bottleneck and delay was in getting a ‘coloured X ray’¹⁷. The child was finally discovered to have a congenital bowel obstruction that was operated. Her story below illustrates the desperation she expressed and her perseverance:

[The] doctor said your daughter will not survive, take her back. Why did you bring her [they asked]. They did not admit [the child]. Then I begged and pleaded. [I said] Madam please admit [my child]. [I did] so much begging and pleading. Then they admitted [the child]. She stayed [in hospital for] 19-20 days. They operated [on the abscess] and discharged [her] After 2 yrs she had pain in [the] tummy. She could not talk but she kept crying....[I] showed her to so many doctorsThen she started having fits and I got scared. So I went to X hospital [names a government hospital]. They sent me to Y hospital [another government hospital across the road from X] and from morning to 3 am next day they kept shunting

¹⁶ Literally ‘caught hold of hands and feet’

¹⁷ Presumably a Barium meal X Ray examination

me between X and Y¹⁸. Then again I begged and pleaded... They gave her only [a] glucose drip... then when [she got] better they discharged [her]. This would happen again and again. Someone said go to Z hospital [another government hospital]. So I went to Z. [The] same thing [happened there]. They would treat [her till she] got better then discharge [her] then again [the] same thing [would happen]... [After she got admitted the last time] I had been there for 1 month... I told madam [the doctor] if you are not going to do anything - discharge me. Someone said go to D hospital [another government hospital]. Then I begged and pleaded. [I] started crying... Then they finally did an operation....

Interestingly, it was difficult to get some of the participants to recount their inconvenience in rich detail and four of the respondents displayed a degree of irritation at being made to recall these difficulties. This was conveyed through phrases such as ‘haven’t I told you already’ or their body language.

The issues of delays, shunting and going round and round in the large hospital was accepted by all the key informants as expressed in some of the quotes below:

They get lost in the big hospital – [even] we get lost! [They] need a social worker to get around. [They] can’t read. [They] can’t stand in line for so long. (NGO AB health programme coordinator)

Many people line up all night [outside the government hospital to get their registration done early the next day]. They [the homeless] don’t stay there overnight because their begging will not happen. That [begging] happens at night. (NGO AB health worker)

The hospital’s attitude is also obstructive. They keep delaying. (Lady Doctor at NGO AB)

The senior consultant at the government hospital who was a key informant was quite concerned about the difficulties of his homeless patients though he

¹⁸ These are two large teaching hospitals across a busy main road from each other

considered the delays they faced were due to their own lack of education as stated below:

They are usually uneducated. They don't know where to go or what to do.

(Senior Consultant Tertiary Government Hospital)

The harsh working conditions and long working hours of the doctors working in the government health system was remarked upon by the health workers, clinic doctors and the senior consultant at the tertiary government hospital as a key explanation for the delays experienced by the homeless. The factor most remarked upon was their workload and the fact that they were required to cover many services such as outpatients, emergency and the wards simultaneously.

They are very busy also. They really have lots of work. In the mornings they are at the OPD [outpatients department]. Later, patients say 'they are not there, they have gone home, but when we go to the emergency we find the same doctors there. There is a lot of pressure on them. How can they cooperate with everyone? That is why they get irritable. (Health worker NGO AB)

The senior doctor at the hospital gave a more detailed account of his difficulties with providing a good service, some of which related to management issues.

We get all cases from all over the country... Our OT [operation theatre] timings are very low. We need much more OT time. We are busy in the OPD [out patients department] busy in the ward but not in the OT. [The] number of operative hours is too low. People have to wait for 6-7 months, 9 months together [for an operation]. Government is not bothered. We somehow manage. In the OPD also the doctor is made to work like a clerk! We spend more time filling forms than treating patients. Doctors should be provided with a clerk to write the forms. Even senior doctors like me - I have 22 years [of seniority] - without a chamber [and] not even a peon. Not even a parking place! Sometimes I get too much frustrated - yesterday my OT had started I couldn't find parking space! We are

frustrated. I call it a chakravyuh¹⁹ - neither you can stay in it neither you can get out of it [sic]..... There should be proper relief for the doctors. Proper working hours, proper chambers, proper parking space... we are sitting in the hot climate. It is very hot inside the hospital. There is no air conditioner even. (Senior Consultant Tertiary Government Hospital)

Understandably, no homeless respondent commented on the difficulties the doctors or hospital staff might be facing.

4.3.3: Koi Aadmi Nahin Tha²⁰; The Lack of Carers and Attendants

Government hospitals in the capital city of Delhi are known to be extremely busy and relatively short staffed. It is commonplace for there to be a heavy reliance on attendants (usually family members) to assist admitted patients and, to a lesser extent, to help with out-patient visits.

Attendants of admitted patients perform various tasks such as buying drugs and other consumables, fetching reports, accompanying the patient for various procedures and even, on occasion, nursing and dressing. The patient also relies on his / her attendants to take him / her to the toilet from the ward and to keep calling for the doctor or nurse when required. In the case of a medico legal case as a result of an accident (a common reason for the homeless to be brought to the hospital by the police), the attendants are also expected to respond to legal procedures as demanded by the police.

Elderly or disabled persons may need attendants to negotiate even out-patient services since there are long queues and the services are time-bound. The same would apply to people who do not have the ability to read signs and fill in forms, or the social confidence to approach designated help-desks which are also overcrowded.

¹⁹ A maze-like trap referred to in the Mahabharata

²⁰ There was no man (no one)

The fact that many of the participants did not have a companion to assist them during a period of illness or to accompany them to hospital came up on numerous occasions during the interviews. However, in a few cases only was being alone considered a bottleneck to availing out-patients services. Many participants lived alone on the streets without spouses or other family members. None of the participants with families had more than two adults within the group. Even when the homeless participant lived with a spouse or another family member, one adult would stay behind to earn or look after children while one adult was in the hospital, as explained by the young woman participant who had begged and pleaded for her child to be admitted:

[My husband was] pulling [the] rickshaw [for wages and] he was looking after the other kids [while I was in the hospital with my youngest child]. Someone may take the kids [if they are left alone on the streets].

Similarly, it appeared that while an elderly woman participant had felt able to mobilise her daughter's support for major problems such as admission for an operation, she was unwilling to ask for her help just to go to the clinic for a re prescription since the daughter worked. Very few respondents mentioned the fact that some acquaintance other than a health worker had ever accompanied them to the hospital (discussed further in Section 4.4 on Facilitating Factors).

The kind of services that were reported by the participants as being difficult due to the lack of an attendant during admissions ranged from arranging transportation to health care services or, once admitted, to fetching drugs, giving consent, accompanying to the toilet, arranging (or donating) blood, calling for a nurse, and responding to the police. As two participants described, if they went to the government hospital alone and needed to be admitted, they were even denied admission even though this is not permissible within the rules:

They just bandaged [my foot]. I said admit [me]. Then they said if you have some companion we can otherwise we can't. In MS hospital [large govt hospital in a different city] they didn't even bandage [the foot]. [They] just said bring a companion we will have to admit [you]. (Middle

aged single male participant requiring admission for a post traumatic fracture and non healing ulcer)

They would not have admitted me [had I gone without the NGO health workers]. They [the doctors] say 'if there is no one with you will we get your toilet done? If there is no one with you go [away]. [Even once I was admitted] They [the doctors] said who is with you? I said they [the health workers] will just come back. They said who will get you operated if there is no one here. They cancelled [my operation]. (Middle aged male participant with asthma requiring operation for a hernia)

The health workers confirmed this story. They had taken permission from the doctors to go off for the night at 12.30 am and they were told the patient would only be operated after 10am. They said they would be back in the morning and reached at 9.30 am. Meanwhile the doctors decided to take the patient up for surgery earlier and the operation was cancelled since the workers were not there. This was one of the two occasions this participant's operation was cancelled,

The key informant health workers from NGO AB added information about the role for an accompanying person as follows:

Registration for OP is done [without problems] but for admission we have to give address and phone number – our own. And sign consent.... We have to take full responsibility. No unaccompanied person can ever get admitted. There is no problem with getting an OPD card.... but doctors will not admit.... There is a precondition even if we are there that we will take responsibility and stay there [with the homeless patient]. They take our mobile numbers.....

.....Once I reached home at 1.30 am. I had just reached home when I get a call from the police in an MLC [medico legal] case asking who I am - am I related etc. We are not allowed to go till the police come. All responsibility comes on us....

... calling for attention has to be done by the caretaker. No one will listen even if he [a patient] keeps shouting in pain...

The information that patients are refused admission if they are not able to arrange an attendant was, however, disputed by the senior consultant of the tertiary government hospital who said he admitted whoever needed to be admitted on merit. He stated categorically that

We have not come across anyone who has not been admitted. Our policy is to admit if admission is required. Our motto is [to admit] otherwise where the patient will go? We never say no to a worthy patient. Even if there is no attendant we will admit.

The NGO AB health workers clarified that this particular problem of needing attendants for admission was not found so much in the private sector.

... In private [hospitals] no caretaker is required. They will phone us when required. In government [hospitals] they call us at discharge since we are guardians. In private [hospitals] there is no such problem.

Even when the NGO was facilitating care, the inability of the health workers to cope with their workload caused delays. Four homeless respondents commented upon the fact that they kept waiting for the health worker to have the time to take them to hospital for some specific task such as getting a fracture plastered or negotiating an operation date. Thus there seemed to be a high level of dependence on getting the support of the NGO health workers to get health related procedures done at the government hospital, especially those requiring admission. The notable exception to this was the woman participant who had insisted that her baby daughter be admitted for her bowel obstruction.

4.3.4: *Parche Nahin Hain*²¹; **The Lack of Documents**

Another common theme that emerged from the interviews and appeared to be a barrier to accessing health care was related to the lack of possession of medical documents (such as medical reports, X Rays and discharge slips).

Eight respondents raised concerns about storing documents and not having their documents with them. Of these, three respondents related the loss of documents due to fire or theft. For example, two related that

All her [my wife's medical] papers – my stuff [possessions] was at the mazar [holy shrine] and police set fire to all of it. My wife was disabled she could not move and save her stuff. (Young single male participant with a history of substance abuse)

All the papers [pertaining to my daughter's mental illness] got burnt in the fire. (Elderly female participant with a daughter with mental illness)

The loss of papers led to further delays in accessing health care as the whole procedure had to be repeated. The participants' valid concerns about losing their papers had meant that they had found alternative ways to safeguard their documents. For example, some participants described how they protect their papers by keeping them with someone who has shelter in another area of the city or with their extended family in the village.

*My papers are in Khadar*²² – *I was scared they would get lost so I gave it to one woman to safe keep.* (Young homeless woman who had had her baby daughter operated)

*I have kept my papers in Bihar*²³. (Elderly male participant with leprosy)

²¹ I don't have my papers

²² A colony in Delhi about 20 kms away

²³ A far off state about 24 hours by train from Delhi

Quite a few of the respondents related that the facilitating NGO had kept their papers and some commented wryly that they would have liked to have their own papers also since it would give them some freedom of action for their own health. For example, as a male participant who had commented on having to wait for the NGO AB health workers to take him to hospital explained:

It [my X ray] is with them [NGO AB] only. If I had it I would have done something or the other [to get myself treated].

On the whole, the participants displayed interest in their papers as an asset that had to be looked after and protected. As expressed by one participant:

I have a card from the place [a government clinic]. I show my card. I have it with me. There is one other big card – the doctor writes the medicine on that and they keep it there itself [at the clinic]. I just keep the number.....I keep it in my pocket right here.

Another participant was so conscious of his responsibility to take care of his medical card that he considered it quite justified that a bribe would be demanded from him to hunt out his medical file at an NGO run hospital if he had lost it.

The concern for medical papers extended to other documents such as driving license (of an erstwhile auto driver), ration cards, voter IDs, disability certificates, and pension cards; all of which brought in direct benefits. One participant brought out carefully kept receipts for forms he had filled for various social security schemes over the years, though he had not received any entitlement.

It seemed that the documents were all the more valuable since it took considerable hardship to get them in the first place. As described by the key informant NGO AB health workers

We had arranged [his operation] but then he disappeared. He thought he would get help elsewhere. He took his papers with him. When he came back he said his papers had got stolen. So we had to start afresh. We had

spoken with the MS [medical superintendent] also. We had put 2-3 letters also [to the MS] but [there was] no response.

However, it was also the impression of the researcher that the papers had value in themselves since having papers was associated with having identity. They were also one of the few assets that the homeless might have owned at all. This was evident from the pride with which they spoke of their documents, the fact that they brought up the issue spontaneously, sometimes many times in the conversation, as well as with the regret with which they reconciled to not having them. It is also evident from the fact that they sometimes kept these papers in places which were safe but not accessible for use (such as the village in Bihar or someone's house as quoted above). Another person stored forms for entitlements he never finally received, with great care even on the streets. Thus it seemed that *owning* papers was of more value to these participants than their primary usefulness or putting them to use on a regular basis.

4.3.5: *Mooh Dho Ke Aao*²⁴; Attitudes of the Health Care Providers and Homeless Participants

None of the respondents spontaneously spoke of ill treatment by health care providers at a health care facility, whether NGO, private or government with the exception of one woman participant who complained bitterly about the behaviour of a particular doctor at the nearby government polyclinic and mentioned it as a reason for not accessing care at that particular facility.

Like I am wearing [these] clothes now, I am with kids [and], clothes do get dirty. If I don't have clothes to change into and I go in these clothes- [the doctor says "You smell! Change your clothes and come!".... Madam [doctor] says [this]! She says this... to everyone. [Someone laughs in the background] She says "how many children do you have" Someone says two [and] someone says four. She says you are going on producing children...you are going on making a line [of children]. [Do] you think

²⁴ Wash your face and come. This phrase is used literally as well as a colloquial insult as though to say 'you are not worthy of my attention'

*[the] doctor is sitting here to give free medicines and water to all of you?
Would you go there?*

Judgemental and insulting remarks related to family size or child-bearing were also related by the key informant gynaecologist at the NGO AB clinic in another instance; a homeless woman requiring an abortion was denied it by the government hospital since she did not agree to a tubectomy.

I remember counselling a woman while I was with Hope project²⁵. We motivated her to go to the government hospital but they did not entertain her. They used bad language with her. [They said] ‘Why did you bear so many kids’ – things like that. So outreach workers motivate [homeless people to go to the hospital] but facilities do not admit. (Key informant lady doctor at the NGO AB clinic)

On probing, most respondents related being spoken to well by the doctors and staff at the government hospitals. This also was recounted by those respondents of the general category who had managed to access services without the help of an NGO. Thus, there was a marked contrast between the frustration that the homeless expressed with the delays and difficulties they faced at the government hospital and their lack of complaint about the attitude of health care providers. The fact that they did not attribute their difficulties in accessing health care to the attitude of individual health care providers seems to suggest that their frustration was more with the health institution and the system than with the individuals that worked within these institutions. It may also be related to what they would consider ‘bad treatment’ considering that life on the streets, especially as one seeking alms, is fraught with insult and demeaning behaviour from passers-by on a daily basis.

²⁵ Another NGO that works with the homeless in the same area

As illustration, when asked if they had ever been treated badly at a government health facility, a respondent replied as follows:

Never. When I don't treat anyone badly why would anyone treat me badly? If I abuse someone they will abuse me. If I don't abuse anyone no one will abuse me.

The key informant senior consultant at the government hospital also expressed a similar sentiment about his homeless patients:

They [homeless patients] are very nice. Our Indians especially those from BPL – they are very much obliged [to their doctors and] very grateful....

It was the health workers accompanying homeless patients to the government hospital who seemed to bear the brunt of the doctors' displeasure at having to see unclean and often smelly patients. As they described

They [the homeless] are not seen because of being dirty and smelly "What is this?" [gestures to a homeless person] they [the doctors] say to us. They don't want to touch [them]. Examination is just a formality. We have to fight with the doctors. Sometimes they refuse to handle [such patients] and refer [them] to seniors. When we say we are social workers then they might cooperate a little.

As a key informant health worker recounted, in the case of one participant, a doctor had become angry and refused to see him because he had removed his plaster cast himself. The participant explained during the interview that there were worms under the cast and they were causing him unbearable itching and that was the reason he got it removed by some friends. It seemed that the dissatisfaction expressed by some participants, the health workers from NGO AB and the doctors from NGO AB related to the fact that they were looking at the situation of a health crisis from different perspectives and trying to achieve differing objectives sometimes in contradiction with each other. For example, the doctor may have

wanted to achieve family planning targets while the homeless person simply wanted an abortion. The doctor wanted the patient's plaster cast to be kept on till it was time to remove it, but the homeless participant needed immediate relief for his itching. The doctor would have preferred a clean patient to examine but the homeless person had no facilities for washing, and there were no arrangements to fill in these gaps.

In the same way, the doctors at the NGO AB clinic as well as the health workers spoke about the apathy they encountered amongst the homeless with respect to 'cooperating' with them for their own health. Both doctors explicitly stated that they did not think the homeless were too concerned with their own health. This was specially alluded to with respect to the substance abusers, but also in general. Both doctors felt that the homeless only want immediate relief but are not willing to invest in long term measures. An example was given by the key informant lady doctor at the clinic run by NGO AB:

I feel that there is no priority to gynae problems... they only want immediate relief so they come for pain killers and all. Health itself is not their priority. They don't believe in antenatal care and it's very difficult to counsel them on family planning also..... There was a man with post trauma disability. His wife used to take him around in a trolley and beg for money to have him operated. We took him to the emergency and had him admitted....But he came back after a week! This is their mentality. His wife starting fighting with us "do you know how much money we lost in a week's earnings?" She calculated exactly how much they lost! His leg became worse and finally had to be amputated.

The facilitation offered was not enough to retain the homeless patient in care in this instance, since his immediate priority was his livelihood; another example of how perspectives differed between health care providers and their homeless patients.

The health workers specially commented on the fact that though they went to quite a lot of trouble to arrange things at the hospital the homeless person would

often go missing or fail to keep an appointment. This was seen as a major problem in facilitating services. They too related this to be more common amongst substance abusers.

Some of the apathy noted by the health workers and doctors is reflected in the interviews with the homeless respondents as expressions of helplessness or fatalism. This is obvious through the frequent use of many phrases such as ‘what can I do’ and ‘how can I go’ used by them sometimes and interspersed with sighs. As a participant put it:

What is in one's fate [as decreed] by god - that is [what happens]. The knocks that are written [in one's fate] one has to take, madam.

Another young homeless woman with a history of mental illness also seemed reconciled to her predicament and responded to why she had not sought care in the following way:

[About her episodes of mental illness]... what treatment can I get done... [Voice tails off].... Oh, my master [God] will look after me

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The researcher also observed that participants who seemed to be needing health care while she was on her rounds needed quite a lot of encouragement or support to even go to the nearby NGO AB clinic. This was noted on three occasions with one man and two women participating in the study. The two women were single and elderly. The man was already disabled and had suffered a recent accident and was in pain. Eventually, he was brought to the clinic in a rikshaw by his wife.

However, on the whole, it seemed to the researcher that what was perceived as apathy by the health care providers was mostly a realistic response to the helpless situation the homeless people found themselves in. As described in the sections above, many respondents had, in fact, gone to a great deal of cost and trouble to try to access health care for themselves as well as their loved ones. This included one of the two drug abusers on hard drugs who had been through a drug-rehabilitation programme.

Thus, though a multitude of differing opinions and perspectives were shared on health seeking behaviour by the participants of the study as well as the key informants, the evidence seems to suggest that there might be reasonable explanations for the homeless participants to behave in ways that were not in accordance to the wishes of the health care providers because of their differing priorities. It is also possible that some bias may operate on the part of health care providers as a result of their frustration in not being able to achieve health goals that would have been easier in another context.

4.3.6: *Main Garib Hoon Injection Nahin Lagwa Pai*²⁶; Irrational Care by Local Private Practitioners

Almost all the respondents reported going to local practitioners with their health problems and showed faith and satisfaction with their remedies. Though they identified them all as ‘doctors’, it was possible to tell by their titles, such as ‘bengali doctor²⁷’ and descriptions that many were unqualified practitioners. One of the respondents rued the fact that she could not afford injections (which such practitioners are known to recommend for practically all ailments) after her normal delivery and related that to the cause of her baby’s subsequent illness. Another one proudly said he got an injection a day for weakness whenever he can afford it for which he pays Rs 20. Two reported getting medicines for surgical conditions such as hernia and subluxation of the shoulder. Another person got her TB ‘treated’ by a local practitioner for a year at the cost of Rs 20 for 8 days of medicine; which is too low an amount for the proper medicines for TB. Two participants related their experiences with local practitioners thus:

So I went to show him [my hernia] – he said ‘it’s like this, my medicine will not work, still I will give you my medicine’. (Middle aged male participant who suffered long delays before being able to get his hernia operated)

²⁶ I am poor I could not get injections

²⁷ This is a term commonly used for non MBBS practitioners, who nonetheless prescribe allopathic medicines with alacrity. Some of them have been trained in indigenous medicines and some may have had some experience as pharmacists and paramedics assisting doctors previously

In Haridwar²⁸ there was this Bengali doctor. He said I can't operate but will give herbs). I ate them for a year. Nothing worked. He was an Ayurveda doctor. (A male participant suffering from recurrent dislocation of the shoulder)

A third participant with a history of mental illness said about advice from a local practitioner:

There is no treatment. [The] doctor says it's not a disease – it's a result of bad air [meaning a spell or witchcraft] ...[young woman with mental illness]

The homeless participants did not consciously perceive the possibility of irrational care as a barrier to accessing health care; in fact they found these practitioners very accessible as described in Section 4.4. However, the study does suggest that money and time were wasted as a result of their faith in such local practitioners.

4.4 Facilitating Factors

It stands to reason that many of the facilitating factors that emerged from the interviews were those that directly circumvented the barriers described above. As with the barriers, it was not single facilitating factors, but combinations of more than one that eventually led to better access to health care.

For example, if a homeless person was taken by a health worker to a hospital, the homeless person was helped by getting free transportation as well as an accompanying person who could assist in many different ways in the hospital setting, such as filling in forms, reading signs and leading the homeless person from place to place for various tests and procedures. The health worker would also then take care of costs of treatment and organise follow up.

It is also worth stating at the outset that few facilitating factors were identified by the homeless persons themselves as compared to the readiness with which they

²⁸ A holy city about 6 hours from New Delhi by bus

recounted barriers. Of the facilitated category, only one participant spontaneously described in full details how the NGO AB had helped him to recover. Another participant in the general category had received excellent care in a mission hospital and his account provided insights into the various enabling factors that went into providing comprehensive care (described in Box 1 below). The descriptions of the key informant health workers and NGO AB coordinator were very detailed in comparison, since their main task was to facilitate health care for the homeless on a daily basis.

The accounts of the homeless were used to verify or corroborate what was described by the health workers and coordinators of the NGO and they were able to do so when direct questions were asked. They also contributed some information spontaneously. Thus, it was possible to deduce some main factors that helped or motivated the homeless participants to seek health care and be able to access it.

The main facilitating factors identified from the interviews with participants included financial assistance, having social contacts that helped access to health care through facilitating referrals, and being treated with respect. Other points were made briefly by the homeless participants in relation to how the barriers mentioned previously were circumvented or overcome.

All these factors operated at the level of the treating facility, as well as at the level of getting to the facility in the first place. Thus they can be analysed at two levels; facility level enabling factors and facilitation through outreach. Participants mostly described help received at facility level, perhaps because of their interpretation of health care as something that is received once a facility is reached, while the KIs from NGO AB described outreach facilitation and considered it important from their experience of enabling homeless persons to receive health care.

All nine participants in the facilitated category had been assisted by the NGO AB as per the sample's definition and three persons from the facilitated category had been helped by social organisations other than NGO AB in the past.

One participant from the general category went on to be treated through the facilitation of NGO AB during the course of the study though he had entered the study as a general participant, and while other social organisations were found to be involved with facilitating health care for two participants from the general category. Three participants had received help from members of the local community, including one who had also received help from a social organisation. Understandably the extent of this assistance was far less than what the social organisations had been able to organise. Four participants had struggled on their own with their health problems and did not recount any assistance from any agency or any person. Apart from the fact that public health facilities like the polyclinic and the tertiary care hospital existed, no special facilitation was received from the government by the homeless participants either as outreach, facilitation of referral or post discharge care.

4.4.1: Getting Financial Assistance

It was quite obvious from the stories of the participants that the lack of money was a severe constraint in accessing health care services, as discussed above in Section 4.3 on barriers. All the participants who had provided accounts of facilitation through a social organisation had received entirely free care; either at a facility run by a social organisation, or because the costs had been picked up by a facilitating social organisation. This applied to out-patients services as well as admissions.

One participant was able to recount three different situations and ways in which he received financial assistance for getting his respiratory ailment treated. These were; getting free medicines at a clinic run by a temple, costs incurred by another religious organisation on his medicines in the past and what had been paid by NGO AB to the accompanying person to attend to him during an admission. As he described:

[I used to go to the] Sai mandir hospital (charitable religious clinic for the homeless near Nizammudin). No [it did not cost anything, it was] free. [I got] free medicines also..... Then I became worse. [I] got admitted twice

within 6 months. They [persons from another religious organisation] got me admitted. [It cost] 5000-6000 Rs which the S [names a cadre of religious workers belonging to this organisation] spent... [When I was admitted through NGO AB] they gave [me an attending] person.... [It cost them] 200 Rs a day to look after me.

Another participant replied when asked about costs of hospitalisation:

There is one X [names a person] who got me admitted – without money [to a mission hospital run by a social organisation] (elderly male participant from the general category with leprosy who needed an amputation)

The same participant also related that he had got all his medicines, food, transportation and crutches free at this facility. Financial assistance also came up in response to a question about having encountered good care. The same participant recounted, as a good attribute of a doctor who used to work at the local government polyclinic:

[The doctor] would give money from his pocket to refer [for transport]. [He] would give [me] money to get the treatment done.

Transportation was mentioned as an important facilitation by many participants and being taken to the facility and back by autorikshaw by the health workers of NGO AB was described by many of the respondents as helpful. One remarked that it would have taken her the whole day to travel to the hospital by bus even if she knew where it was:

They took me there they brought me back.... [I went] in an auto [not by bus]that [going by bus] gets very late. Firstly you don't get one. Then it gets late [for registration at the hospital]. The whole day gets wasted.

Thus, the humble autorikshaw was mentioned spontaneously by four respondents as a helpful mode of transport if they could pay for it.

However, on the whole, the homeless participants were not very aware of the nature and quantum of the costs involved in facilitating access to health care for them. Said a participant who had been admitted for hernia surgery about the costs of his operation:

I don't know. They [NGO AB] spent all the money. (Single male participant from the facilitated category operated for hernia)

The HWs as well as the NGO coordinator described the costs on an admitted patient as Rs 3000 (60\$) upwards per person with about Rs 200 (4\$) per day being paid to the attendant.

The other free services that were appreciated by two homeless participants were that of the drug rehabilitation centres being run by some NGOs. They had been referred there either by NGO AB or identified by other social workers. Like the mission hospital run by a social organisation, the drug rehabilitation centres were fully residential, offered long term care and were completely free.

In one case, a female participant who had struggled greatly to get her child operated for a congenital bowel obstruction reported being helped financially by a street vendor and how it helped her to take the first steps towards getting her child admitted:

Someone saw [that I was in need – he was] the vendor who sells dates. He said go to hospital. She [my daughter had been] ill for 6 days. The poor people collected donations for me – [they collected] 400 Rs...I took her in an auto [to the hospital] ... they [the doctors] said buy medicine from outside – that cost 300 Rs. I saved it from the 400 Rs... by sharing the food my daughter was given from the hospital

Though this participant had gone on to incur major expenditures which had required the family to sell their home and rickshaws, she considered this small contribution very significant in allowing her to access health care at that point of

time when she had no money in her possession. This was an example of outreach level facilitation by an agency other than a social organisation.

4.4.2: Being Treated with Respect and Familiarity at a Facility

Others had encountered good care or good service providers at some point of time which had motivated them to seek care at that particular facility. For example, one respondent had described why she had stopped going to the local government polyclinic because the current doctor was rude (see Section 4.3.5 describing barriers). In the same conversation, she mentioned a good doctor at the local government polyclinic who no longer attended, but who had been very popular amongst the homeless:

There was this Kashmiri [names a state of India] doctor ... he was here before [and] he used to give medicines nicely.... He has left... He would ask us to sit on a chair first [someone echoes "He would ask us to sit on a chair first] He used to ask [about our] good and bad [experiences] and [then only] he used to give medicines.

In the earlier section the interventions by local (mostly unqualified) practitioners was analysed as a barrier to rational or timely care. However, it appears that a familiar relationship with them contributed to the fact that the homeless participants regularly approached them for health care.

Five of the eighteen respondents mentioned local private practitioners positively. Interestingly, all these local practitioners were referred to by name with the expectation that the researcher would know them. Many were referred to as well known doctors or 'big' doctors; as in the quote below and some respondents spontaneously gave names and locality of up to five to ten doctors they had been to with great pride.

I showed it to him [the local practitioner]. He said 'this is a hernia. It needs to be operated. There is no medicine for this'. I thought maybe he is

wrong so I went to G [another local practitioner] I thought he is a big doctor let me show him.

In contrast, the doctors at the government hospital were always anonymous persons. The homeless persons also knew the name of a good doctor at the local polyclinic but not of the lady doctor who was rude. Thus it appeared that knowing a person by name had a correlation with finding his / her service good as a health care provider, while the anonymous doctor was also the one who would not inspire a homeless person to seek care. As described by a participant:

Before this there was a doctor N [names the doctor] – mahomedan²⁹. He used to see well. [He] Would write good medicine.

It was interesting that most often, along with the name, the researcher was specifically told of the religion of the doctor as ‘You know X? He is a Mussalman³⁰ doctor’ as in the instance quoted above. The term ‘Kashmiri’ used for the same doctor by another participant quoted previously also denotes belonging to a state which is predominantly inhabited by Muslims. Thus two participants referred to the good doctor at the government polyclinic by his religion. Another elderly participant with leprosy had also visited local practitioners and said emphatically about two local practitioners he had regularly visited:

*The doctor is a good muslim doctor [repeats a few times]....
....That A [names another] doctor. He was a musalman³¹.*

It was understandable that most of the local practitioners visited by the participants mostly belonged to the same religious community as them and were predominantly Muslim. Muslims predominated in the entire area as described in study settings and it appeared that religious affiliations were given a high degree of importance by the participants. However, there was an incidence of a participant from another religion also mentioning two Muslim doctors that he had

²⁹ This refers to his religion; Islam

³⁰ Musalman and Mohomedan refer to practitioners of the religion Islam

³¹ Follower of Islam

visited, so the converse – that there would be discrimination in choosing doctors on religious grounds – was not observed. He also preferred to go to that doctor on account of familiarity, as he explains below:

[I showed my hernia to]Dr J K [a Muslim name]. I used to take his kids for horse rides. So I thought he is a big doctor let me show him. So I went to show him also.

One of the respondents was a substance abuser and had been sent to another city for rehabilitation. There, he was involved in the day to day activities of the organisation including fund-raising and going to the homes of rich people to speak about the organisation. He recounted this with pride and it appeared from his account that being treated as a member of the organisation rather than just a recipient of care had contributed to his retention at this facility.

4.4.3: The Facilitation through Social Contacts

None of the participants described the membership of any social organisations, associations or unions. However, there were descriptions of how they had been helped to access health care through relationships with certain individuals. Despite the fact that homeless persons exhibited a general lack of community amongst themselves in terms of helping each other during illness, there were exceptions to this as described in this section. What was more obvious was the salutary effect of the links of homeless persons with people who had somewhat greater power or social stature.

These people were also generally referred to by name and with much gratitude. The help given ranged from writing a letter of referral, arranging an appointment and thus circumventing the delays and shunting they would have otherwise faced, to also paying for the costs involved such as transport, drugs and care.

For example, one homeless participant who used to ply a rickshaw while homeless describes how he was significantly helped by his employer after he fell:

I was breaking twigs from a tree. I fell off and could not get up. The person who was with me picked me up. I was unconscious. Someone came and gave me water and sprinkled water on my face. I said phone my home I will give you money. He said stupid I don't need money. I will take you home. He called my rikshaw owner. They [the employers] came and took me to hospital.

On occasion, the assistance came from acquaintances amongst the local community who were not homeless themselves. For example, a participant who was admitted to a mission hospital for leprosy describes two people who proved helpful; the servant of a doctor and someone who used to sweep at the leprosy mission hospital:

His [the doctor's] servant [told me how to get to him]I knew him [the servant] for a long time..... There is this brother [friend] here – he sweeps. He is a government sweeper. He used to work at the [mission] hospital earlier. He took me [to the mission hospital].

There were instances where the local private practitioners had assisted by referring their homeless participants to particular government hospitals or giving them directions that ultimately led them to correct treatment, albeit after attempting some treatment themselves. A homeless participant had been given drugs for his hernia even though the local practitioner had said they would not work. Ultimately, it was this practitioner that referred him to a contact at the government hospital for an operation. He relates this as follows:

So I went to show him [a local practitioner] also – he said 'its like this, my medicine will not work, still I will give you my medicine'. [Later] He said this needs an operation you get operated. He wrote [me a referral letter] for S. [tertiary care government hospital].

Thus, it appears that while local practitioners may have delayed appropriate care from the point of view of the researcher, the homeless participants found them accessible because of their familiarity. Eventually, as in the cases described

above, the same practitioners were often also the ones to refer the homeless to a facility that could offer better medical care.

No instances were found of a referral from the local government polyclinic. However, one participant recounted being referred from a government doctor at another location to (interestingly) a mission hospital for his operation:

He [a government doctor in a facility in some other area] said I am going to leave. You continue your medicine. Take it from PT. [mission hospital for leprosy]

The respondents were not forthcoming about receiving help from each other. On being probed, one or two remarked that people have to look out for themselves and only then can they help a little. This was confirmed by the health workers who also said that at the most some food would be shared or bags would be taken care of for a while.

Nonetheless, the researcher had heard differently from a drug addict who had suffered severe burns and had required nursing and feeding for many weeks; all of which happened through his peers and friends. He was provided at least one meal a day in this manner for many weeks. This account was gathered during the course of a previous investigation on nutrition and the person could not be located again to get a proper account during this study. Thus, it seems that there are exceptions to the general inability to be able to care for each other amongst the cohort of homeless people themselves.

All the participants from the facilitated category mentioned reaching out to the NGO AB health workers to access care. This was usually indicated in response to a direct question related to 'who helped you' by indicating the accompanying health workers of NGO AB by a gesture. They did not however, mention their names, though they knew the name of another worker from NGO AB who helped to place their children in a residential school. One participant in the general category had specifically come to the city to seek treatment for his post traumatic non-healing foot ulcer having heard of the reputation of another social

organisation, and from them, NGO AB, in organising health care. As he described:

[I am] coming from X [names a neighbouring state]. This foot was not getting well. It was getting worse. I was told to come to Delhi to meet the S (a religious cadre involved in social work) They treat [illnesses]. I went there they said your foot has rotted too much. We can't deal with it.... Then someone said there is an organisation in Nizammudin [referring to NGO AB]. They will help you.

Thus, even though the participants did not perceive the role of NGO AB as a social contact, it was in fact performing all the functions expected from a helpful social relationship in case of illness as a surrogate friend or family member. The precise roles it played have been also been described separately in Section 4.4.4 since they were comprehensive, interrelated and cross cutting across all the three facilitating factors consciously identified by the homeless participants.

4.4.4: Facilitating Factors Working in Tandem

It is evident from the descriptions above that the factors that enabled health seeking and access to health care were quite inter-related. Sometimes a single agency, like a social organisation, was able to provide the entire spectrum of facilitation that would eventually lead to better health care outcomes and sometimes other agencies or persons would provide more piece meal assistance. The following case study, drawn from the account one of the nine participants in the general category, represented for the researcher the best-case scenario of how the homeless in the study site were able to access health care that led to the eventual resolution of their health problem. The case study demonstrates many facilitating factors working in tandem for enabling access, as well as the value of a comprehensive health care service.

Box 1: The Case Study of Participant Mahmud Alam³²

³² This is a pseudonym

This elderly gentleman, Mahmud Alam, had lived on the streets with his family for over a decade. Originally from Bihar, Mahmud had come to Delhi to get treatment for what he thought was cancer of his foot but turned out to be leprosy. He happened to have met the servant of a doctor who worked at a government facility in Delhi and was referred by him to his employer. He was treated there for many months. Then, when the doctor was due to retire; he referred Mahmud to a mission hospital in East Delhi that specialises in leprosy care. He happened to meet '*a brother*' who was a government sweeper who had earlier worked at this hospital. He was admitted to the mission hospital in total for three months and five days. He gave his Bihar address at the time of admission. For the first ten days they gave him eggs and milk to build up his nutritional status. Once the wound in his foot dried up he was given the choice to have it amputated or be discharged on medication. The hospital doctors at the mission hospital recommended an amputation which he initially resisted. His wife persuaded him to have the amputation which would relieve him from taking any more drugs. So he agreed. He stayed at the hospital alone but had the support of the orderly there. He was given soap, clothes and food and there was a hand water pump and mobile toilet in the courtyard that he could use. People always spoke with him nicely. When visitors came the ward attendant would ask him to get cleaned up and they would get served special food.

After the operation when he was ready for discharge, a vehicle with a nurse took him to a shop for getting him crutches and slippers. His medical records remain with the mission hospital but he was given papers that had his case summary and a reference to his detailed records. He was instructed to take care of his papers and come periodically for follow up. The whole treatment and three month stay in the hospital was free and he was very happy with the care he got there.

The more detailed and also additional information received from the key informants (KIs) can now be juxtaposed against the backdrop of the information conveyed by the homeless participants. A description of NGO AB's interventions was received from the NGO coordinator and the health workers who were understandably articulate about the whole gamut of facilitation, from outreach to facility level enabling factors. The two doctors associated with NGO AB as well as the senior consultant at the government tertiary hospital had their own perspectives and experiences. It is notable that many of the facilitating factors brought up by the homeless were not echoed by the KIs and vice versa, reflecting some differences in perception and perspectives.

As per the NGO coordinator and the health workers of NGO AB, the following interventions were made to enable access to health care by the homeless in Nizamuddin area; firstly, the health workers of NGO AB did periodic rounds of the streets to identify sick homeless persons and invite them to the nearby clinic or the street clinic (see Section 1.3 on study setting). Next, the street clinic would provide some basic medicines and refer to the regular clinic in case dressings or detailed examination was required. Here the physicians would examine the patients and provide free treatment. If necessary they would instruct the health workers to arrange referral services. From there on, the organisation would take charge and make arrangements for further care either at a private hospital where subsidised care had been made available due to personal contacts of the NGO with the health care providers, to free beds in private corporate hospitals (described in Section 1.1) or to the government tertiary care hospitals. This included setting up of appointments and transportation.

They would also arrange full responsibility during any admission that took place. This included providing an address, covering the pre admission deposits of money (in the case of the free beds in private hospitals), giving consent, arranging for an attendant and paying him a per diem, arranging for blood if required, buying drugs from private pharmacies if required and providing extra nutrition.

After discharge, the health workers would organise facilities for recuperation such as admission into the government-run shelter, dressings, extra nutrition, drugs and follow-up. All the records were kept in the safekeeping of the NGO at the clinic.

The NGO coordinator also mentioned reminding people to take their medicines as part of their task as well as motivating them to join up for drug rehabilitation programmes. According to him, it was very important to be reliable and present so that trust could be built with the homeless.

Thus the KIs from NGO AB related outreach and facility level facilitation including post-discharge care. For illustration, another case study is presented that represents the facilitation of the NGO AB. This is related to a homeless participant who had entered the study as a participant in the general category and

then had an operation through the facilitation of NGO AB during the course of the study. Thus, this case study is a result of direct observation by the researcher.

Box 2: The Case Study of Bhuvan³³

Bhuvan had had a road accident resulting in a fracture and non healing ulcer of his foot in a city of a state neighbouring Delhi. He had heard of a religious organisation that offered health care to homeless persons in Delhi and came to them for help. They referred him to a tertiary care public hospital but he was not allowed through the gates by the security personnel. He then heard of NGO AB as a group that helps homeless sick people and came to Nizammudin. He encountered the researcher and health workers while they were on round. His ulcer was dressed at the clinic and antibiotics were started. He did not have any BPL card. He was admitted to a free bed at a private hospital after getting a qualifying letter from the health ministry and the local elected representative all of which was organised by the NGO AB. A deposit of 10,000 Rs was demanded before admission. The admitting senior consultant was requested to negotiate on behalf of the homeless patient by the researcher and the deposit was reduced to 5000 Rs. The NGO AB also organised an attendant for Bhuvan during his admission. Bhuvan remained admitted for 23 days during which a toe was amputated and skin grafting done. The total cost of this hospitalisation was Rs 82,500 (\$1230) of which Rs 5,000 (\$100) were incurred as the total cost by the facilitating group³⁴ on part-payment towards investigations, drugs and consumables and Rs 5000 was spent additionally as the per diem to the attendant. This was over and above costs on transportation and the hidden costs of coordination by the facilitating group. Once discharged Bhuvan was lost to follow up.

While some of this facilitation was recounted by the homeless participants as discussed in the sections above, some issues considered relatively important by the KIs were not mentioned by the homeless. For example, while three participants raised the issue of arranging blood as a *barrier*, none recounted that blood had been arranged for them. The issue of organising blood as part of the facilitation, however, came up from all the key informants; the HWs and doctors. As the key informant lady doctor at the clinic run by NGO AB recalled:

³³ A pseudonym

³⁴ NGO AB, another charitable foundation and the researcher

Two units of blood were required [for the operation of a homeless person]. I myself donated blood for him and a member of staff also donated. But he came back [to the streets] after a week.... His leg became worse and finally had to be amputated.

The key informant senior consultant had also similarly attempted to facilitate homeless patients through offering financial assistance, blood and generally enabling their course in the hospital:

I take the help of the attendants of the other patients. Somehow [I] manage. I take the help of other employees also. I say I will help you [the employee] but you have to help this other patient. Please take her and get [her] x ray done [and] show her the way.... We admit [and] we give consent [on behalf of the patient]. We arrange for blood also. Sometimes we donate blood also. We operate also. Many times it happens they are here for days together [or] months together. One fine day they get back their consciousness and we send [a] telegram [to their extended families] make phone calls but nobody comes. Then they ask for money – they say sir give me some money so we give [them] money also [laughs].

These findings reveal the interest of the doctors in helping their homeless patients but further elucidate the difficulties of doing so at an individual level alone, as has also been brought out in the previous section on barriers.

In summary, the participants and the KIs identified financial assistance as a critical facilitating factor for the homeless to be able to access health care. The homeless participants were sensitive to being treated with respect and dealing with familiar people whereas this point was not perceived by their health care providers. The range of facilitation described by the KIs from outreach to facility-level interventions was, in turn, not fully perceived by the homeless participants. Nonetheless, they appreciated what was visible to them at face value; being taken to the hospital in an auto rikshaw, having forms filled, having their documents taken care of and being cared for in the hospital by an attendant arranged by the NGO AB.

Clearly, the most substantial and comprehensive facilitation that was received by the homeless people who were interviewed was from NGOs and religious organisations specifically engaged in programmes with them. However, the community also participated in providing aid. The degree of aid provided by members of the community depended upon their social hierarchy and economic conditions. There was no government facilitation at all in terms of outreach, transportation or referral systems prior to the person reaching the facility, nor was there any government facilitation in terms of easing the process at the hospital for homeless persons in particular or offering post-discharge care through outreach. Whereas in almost all cases where health care could be accessed with relative ease, a social organisation or NGO was involved, exceptions to that rule illuminated the agency that was being exerted by homeless persons even without such facilitation and despite many barriers.



CHAPTER 5: DISCUSSION

5.1: Introduction

The objectives of this study were to gain an understanding of the barriers and facilitating factors perceived and experienced by the homeless in Nizamuddin area of New Delhi in seeking and accessing health care, especially from the public health system. This chapter further intends to explore the relationship of the findings of the study to existing policy and literature. It is hoped that this will help to understand the implications of this study for the public health facilities in New Delhi with regard to their future policy and practice in relation to safeguarding the health of the homeless in areas such as Nizamuddin.

Some of the issues being taken up briefly in the discussion pertain to the factors described by the homeless that either caused homelessness or exacerbated the vulnerability of those already homeless through the loss of livelihoods. The accounts of the participants demonstrate how homelessness is the end-stage of a spectrum of vulnerability for the urban poor that live on the threshold of economic insecurity and tip over into homelessness with even relatively small economic crises. In this context, the study found a near absence of social security entitlements that are meant for the poor in India amongst the homeless participants, such as pension or the BPL³⁵ card which has great significance since it is practically a prerequisite for getting free treatment. Homelessness itself is considered a social determinant for health and many authors have reinforced the need to work with social security systems to prevent or reverse homelessness. Thus the factors emerging from the study that cause or perpetuate homelessness by deepening economic hardship will also be briefly discussed, with special reference to how the inadequacy of health systems is one such factor. This study clearly documents the occurrence of catastrophic illnesses as a factor that has tipped poor people into homelessness; a factor not previously established in existing literature on the subject in India.

³⁵ Refer to footnote 1 for details

India has a peculiar context of inequitable access to health care as described previously in the survey of literature. Within this context, as far as the researcher is aware, this is the first study to specifically explore the experiences of homeless people with respect to health care and health care services, though all the existing Indian studies reviewed have referred to these experiences anecdotally. While the problems that the poor in general often experience with trying to access health care are relatively better known, this study confirms a severe neglect of and a systemic insensitivity to the rights of the homeless to health care. It also reveals issues of access to health care services from the specific perspective of the homeless. The information about the barriers and facilitating factors identified by the study may assist in being able to advocate for and fashion health systems that are more specifically amenable to the homeless.

The accounts of the homeless participants were often contradictory and inconsistent - a testimony to the complex and unique contexts each one was surviving in. Nevertheless, a range of common factors creating barriers for the homeless in accessing health care were revealed through the IDIs. These largely related to the prohibitive costs of care and the difficulties of negotiating the prevalent systems and facilities in large public hospitals to be able to get treatment. The study also suggested that perceptions about quality played a distinct role in the health seeking behaviour of the homeless participants. In particular, the study demonstrated that it is the combination of issues of quality, cost and ease of access that determine the usefulness of health care services to the homeless.

These issues are quite consonant with the findings of the entire body of health systems research that exists with respect to poor and vulnerable people in the country (Balaji et al, 2011) as well as some other studies with the homeless as discussed in the survey of literature. In addition, some new issues have also been documented, such as the specific requirements of having an attendant during admission and the need to present a fixed address. It is also clear from the study that there is a complete lack of outreach to the homeless from the public health system and they are left much to their own devices to struggle for their health and

often their lives. In effect, no special effort by the public health care system was visible in the study at any level, to provide health care for the homeless.

In comparison, social organisations were making the attempt to fill the many gaps between the homeless participants and health care systems, by providing a range of facilitation as well as direct services though these did not amount to a systematic provision of comprehensive health care.

The study reveals an ambivalent relationship between the homeless and the facilitating NGO AB. The inherent inequality of this relationship was revealed through situations in which, though the homeless were often assisted in many ways, they also felt occasionally disempowered. It also demonstrates the known but poorly documented disconnect between the perceptions and priorities of public health care providers working with the poor and those of their clients, through an analysis of the accounts of the homeless participants and the key informants. The homeless participants showed a preference for accessing the private sector even though they eventually sought care from the public sector, especially for illnesses requiring admission. Thus, the study throws up complex issues related to health care services both in the public and the private sector, each one worthy of full scaled investigations and discussions. These issues have been discussed by other authors in their work with the homeless in other parts of the world and will be explored further in this chapter.

5.2: The Determinants of Homelessness; Denials of Basic Rights

Previous reports on the health of homeless people have clearly reinforced the fact that homelessness itself is a determinant of ill health as discussed in Section 2.2 in the review of literature. Many authors working to provide health care services for the homeless have recommended that specific steps be taken to prevent or to reverse the state of homelessness itself. For example, the Quilgars and Pleace report appreciates that the Scottish policy on homelessness “recognises the basic argument that the healthcare needs of the homeless population can ultimately only be addressed through preventing homelessness where practicable and in supporting the resettlement of homeless households and individuals...” (Quilgars

and Pleace, 2003: 9). Thus, prevention of homelessness is an important part of a comprehensive strategy to provide health care for the homeless. For this to be done effectively, the factors that push people into homelessness must be understood and this section explores the determinants of homelessness itself, as revealed by the study.

While analysing the causes of homelessness from the accounts of the participants, the study demonstrates the downward slide to a state of homelessness from pre existing vulnerability due to poverty, and the reasons for such a decline. As described in detail in Chapter 4, most of the participants had been pushed into homelessness by factors ranging from expenses on health, demolition drives by the government, to simply becoming too old to work and be able to pay rent.

Some of these findings echo previous studies done with homeless persons in New Delhi (Kothari et al. 2006; Rai, 2008; IGSS, 2009; HIGH, 2003) on the causes of homelessness. This study additionally illustrates how the precipitating factor is often a health care problem itself, as in two cases; homelessness was directly caused by the expenses from a catastrophic illness. Out of pocket expenditures on health care also perpetuate homelessness by exhausting savings and resultant sale of assets such as homes and sources of livelihoods. This is described in the study in the case of a homeless woman who had to sell her already mortgaged house as well as the rickshaws belonging to her family to pay for care for her baby daughter in public hospitals. While the high incidence of catastrophic illnesses pushing people below the poverty line has been discussed in general by other Indian authors; Selvaraj and Karan (2009) and Balarajan et al (2011) put the figure at 39 million each year, this factor has not been reported in previous studies as a specific determinant of homelessness in India.

In terms of human rights, the study demonstrates an overarching violation of rights as defined by the UNDHR; the rights to “a standard of living adequate for the health and well being of himself and his family, including food, clothing, housing, medical care and necessary social services, and the right to security in the event of unemployment, sickness, disability, widowhood, old age or other lack

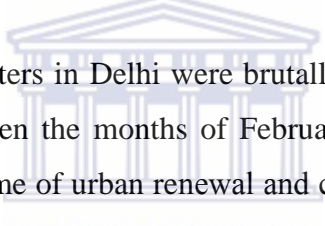
of livelihood in circumstances beyond his control” (UN, 1948:5). The lack of social services is evidenced by the fact that no participant held a BPL card and only one was able to avail of a pension. None of the homeless participants had any kind of health insurance.

It is possible to look at the situation of the homeless also from the lens of a widespread denial of labour rights. A study conducted by Lokayan in 2002 came up with the finding that 22% of the rickshaw pullers in Delhi are homeless (Rai, 2008). Conversely, the study by Rai finds that more than 75% of homeless persons surveyed were working. Thus, a large number of homeless persons are actually poor workers involved as casual labour, vending and domestic work etc, as was also found amongst the participants of this study.

The various factors that had lead participants to homelessness in this study can be related to the lack of labour rights and systems of social security such as old age pensions, maternity entitlements, health insurance and wage protection in India for poor people working in the informal sector. While many participants were engaged in casual labour, they were not being paid minimum wages and one participant had reported loss of livelihood due to government policy without compensation or rehabilitation. A young woman domestic worker had to leave work and beg after the birth of her daughter. One participant who had an occupational injury got Rs 50 (equivalent to a dollar) from his employer as compensation for the loss of his livelihood.

Minimum wages are meant to be guaranteed under law and there is a National Rural Employment Guarantee Act of 2005 which does not currently apply to urban areas. A law for social protection to workers in the informal sector has also been on the drawing board for a number of years. This study suggests that homelessness is often the net result of the state’s failures to implement its own laws, policies and safety net mechanisms with respect to persons working in the informal sector.

As described in Chapter 4, four of the participants had become homeless as a result of government demolitions and the other major determinant of homelessness that the study highlights is the connection between policies related to slum dwellers in the city and their vulnerability to homelessness as a result of demolitions. Urban slum policies have been debated for many years in this country and the city of New Delhi. Guidelines to provide 25 per cent of residential land to the Economically Weaker Sections (EWS) and Lower Income Group (LIG) have been given in the Delhi Master Plan 2001 (Ghertner, 2008) but continuously flouted. Despite previous constitutional rights and interpretations of the law supporting the right to shelter as well as to rehabilitation, there has been a shift in legal discourse that deems slum dwellers in Delhi to be a nuisance (Ghertner, 2008) to be removed through demolitions and forced evictions. This results in a surge in the homeless population. Says a report by Kothari et al


 Several slum clusters in Delhi were brutally demolished and bulldozed to the ground between the months of February and May 2006 as part of a much larger scheme of urban renewal and city “beautification”. More than 11,000 families have been rendered homeless in this period (2006:56).

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Yet this phenomenon remains unacknowledged in any of the policy frameworks for urban planning in Delhi.

There seems to be a specific neglect of the urban poor as compared to the rural poor, considering that there is a National Rural Employment Guarantee Act and a National Rural Health Mission in existence without counterparts for the urban poor who comprise almost 30 percent of the poor of this country according to the National Urban Housing and Habitat Policy, 2007 (MHUPA, 2007). This situation is then further compounded by the failures of implementation of general entitlements for the poor in the health sector as discussed in the following sections. It is in this policy environment that the homeless, who are the poorest of the poor and the most marginalised socially, attempt to access health care. The subsequent sections will discuss the specific issues of access to health care as raised by the study.

5.3: Prohibitive Costs of Health Care

As early as 1946, the Bhore Committee report (GOI, 1946), that laid much of the foundations for the notion of 'Health for All' in India, stated that no one must be denied health care because of inability to pay for it; a principle that the Indian State has further reiterated through some of its subsequent policies and programmes. The National Rural Health Mission (NRHM); government's flagship programme promises "social security to poor to cover for ill health linked impoverishment and bankruptcy" (MOHFW, 2005: 21) as a priority, and recognises "Large out of pocket expenditures even while attending free public health facilities- food transport, escort, livelihood loss etc." (MOHFW, 2005: 21). It further states that "economically catastrophic illness events like accidents, surgeries need coverage for everyone especially the poor" (MOHFW, 2005: 21). This has largely been implemented by making services free for persons categorised as BPL while progressively increasing user fees have been levied for others on most services within the public health system. No corresponding stated policy exists for urban areas, though what is followed in practice is largely supposed to be the same.

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However, this study showed that seven participants could not access appropriate health care due to the inability to pay for it. As noted earlier, not a single homeless participant possessed a BPL card. Where a participant had been able to access care as a result of immense effort, by acquiring money on loan or due to the facilitation of a social organisation, costs of up to Rs 10,000 were incurred on drugs and consumables. Three male participants in the study had held jobs in the informal sector till they had reversible injuries (fractures of the hip in two cases and brachial plexus transaction in the third) that could not be treated in the government hospital due to their inability to pay. This led to permanent disability and loss of livelihood and they were tragically relegated to beggary.

Similarly, the Rai (2008) study of the homeless in Delhi notes that four respondents had required hospitalisation but could not afford treatment. The

author also observes that the costs of treatment at government hospitals for homeless patients had ranged from Rs 500 to 4000.

The fact that user fees often marginalise the poorest of the poor in general has been referred to by other authors also (Creese, 1997) as well as the report of the National Macroeconomic Commission for Health (NCMH, 2005).

Much has been written about the perils of the process of identification of BPL in India and its propensity for massive errors of exclusion. As described by Mahamallik and Sahu, (2010) the errors occur due to problems with both methodology and implementation of the survey process. Besides these, the most vulnerable are often displaced from the list through corrupt practices by more powerful people who would like to avail of the benefits of the BPL card. The current study also clearly illustrates that the poorest of the poor in the city of Delhi; the homeless, are neither identified as BPL nor are they able to avail of the discretionary powers available with the health system for free care. The fact that they are not categorised as BPL also precludes insurance through the RSBY (see Section 2.4 for details).

Though the study suggests that the homeless may manage admission into the government hospital or even the 'free' beds, especially if it is facilitated, there are few situations in which they are not forced to make out of pocket payments. Out of pocket expenditures (OOPE) are known to be amongst the highest in the world in India (NCMH, 2005; Patel et al 2011) and this study shows the failure of the arrangements made by the government to protect the poorest of the poor from OOPE.

In the State of Delhi, the other arrangement that has been made is for 'free' beds to be available in large private hospitals in lieu of massive subsidies for land use, as discussed in Sections 1.1 and 2.4. These beds are available to anyone with a BPL card or earning under Rs 4000 per month and certified 'poor' by the local elected representative. However, a legal dispute is currently on to determine whether drugs and consumables will also be supplied free for patients admitted in these free beds since this was not spelt out in the agreement between the private

hospitals and the Delhi government. Thus patients are currently making partial payments for some investigations, drugs and consumables. Recent reports (Jha, 2011) have shown that in all, 90% of the very limited number of beds reserved for the poor were vacant while government hospitals overflowed.

It can be recalled that one participant of the study was admitted to such a free bed and underwent surgery and Rs 10,000 was spent on his behalf as OOPE. This study shows how despite this arrangement of free beds in private hospitals, the costs of drugs and consumables would make health care inaccessible to homeless persons in these facilities in the current course of affairs.

The study thus adds to the concerns that have been expressed previously about privatisation and the massive subsidies being made to private hospitals in the name of expanding services for the poor (Sengupta and Prasad, 2010); services which have not been forthcoming and which have resulted in a protracted legal battle with little benefit to poor patients (Mahapatra, 2011).

It can thus be argued that in the given situation, the existence of a comprehensive universally free public system of health care that does not require any cash transactions between the service providers and the users³⁶ would be best suited to the homeless for being able to surmount the barrier of prohibitive costs of care.

5.4: Quality and Access to Health

The issues of quality came up in two different ways from the findings of the study; from the opinions of the participants and from the observations of the researcher.

Participants expressed many views held by them regarding what constitutes good or poor quality in health care and this had a bearing on the choices they made within their limited resources. A study by Rao et al (2006) describes five main

³⁶ In other countries, such systems have been created through tax based or insurance based financing.

indicators of how users perceive quality in public hospitals in Uttar Pradesh³⁷; medicine availability, medical information, staff behaviour, doctor behaviour, and hospital infrastructure. Many of these issues were raised in the accounts of the homeless participants in this study, as described in the findings.

Secondly, the descriptions of the care they received also revealed many issues related to quality as would be assessed by experienced reviewers of health care systems, such as delays, unwarranted dismissals, denials of health care and irrational practices. As defined by Balaji et al (2011), factors relating to quality of health care include safety, effectiveness, timeliness, and patient focus, and can broadly be divided into those affecting service and clinical quality. It is difficult for users to identify some of these criteria such as effectiveness and clinical quality however, the study did reveal some details on these issues on analysis.

The problems of quality related by the homeless participants from the government hospitals related to the long queues and waiting times, being shunted from place to place (in their opinion) unnecessarily, being denied admission on various grounds such as the lack of an attendant or the lack of address, the suspicion that the free drugs being made available to them were substandard and being spoken with rudely.

The criteria of good quality as perceived by the homeless that emerge from this study are respectful behaviour, prompt attention, (paradoxically!) free services, ease of transportation, the provision of an attendant and nutritional support.

In addition, the study noted a preference for private services by the participants as well as instances suggesting irrational practices amongst the local private practitioners that had led to delays and inappropriate treatment, such as giving daily injections for 'weakness', not referring a hernia and a slipped shoulder to surgeons and treating TB inadequately.

Thus, the study was able to describe many factors that related to the quality of care that was available to the homeless participants; from the perceptions of the

³⁷ A neighbouring state of Delhi

user, as well as from the analysis of the data from the point of view of an informed participant-observer.

How the quality of services affects access to health care by the poor is a question not well articulated in existing literature. However, some relationships have been explored by other researchers. The following discussion will attempt to present how perceptions of quality affected access to health care for the homeless participants in this study, and try to link these findings to what is known about the relationship between quality of health care services and access for the poor. The first step to tracing the pathway to care used by the homeless could be to analyse the choices that were made by them in health care seeking.

The study demonstrated how the homeless participants could exert little choice about how and where to access health care. However, many participants showed a preference for availing of private health care services and two related using private services for the setting of a fracture and a hernia operation when they had been able to work and had more money.

Nonetheless, most of the participants who had in fact received health care for major problems requiring admissions had only been attended to in the government hospitals since they were relatively far less expensive than the private sector. This was the case amongst both groups of participants; general and facilitated.

The perception of a better quality of interaction with health care providers motivated the participants to use the services of the local private practitioners more than the free out patients services provided by the government polyclinic in their area, despite the fact that this interaction was sometimes ineffective or irrational and led to delays in the resolution of the problem as well as additional costs. Many showed a preference for attending the NGO AB clinic which was both free and familiar.

Similar findings have been described by other researchers in India. For example, data from the IGSS study shows that

60 percent of homeless people depend upon the medical facilities run by charitable institutions, religious organisations and NGOs. 15 percent avail cheap doctors/quacks in the same locality, whereas about 10 percent visit government hospitals.” (IGSS, 2009: 48).

The issues of quality of health care services for the poor in India and relationship to access are not well documented, especially from the point of view of the users. As Balaji et al put it “In India, quality in health care is not well understood, with insufficient evidence to infer how it affects equity” (2011: 508). However, they do note that the poor in urban settings are more likely to visit private practitioners who are not “sufficiently competent” (2011: 509). They further discuss the connections between dissatisfaction with quality and a preference for the private sector by the poor and conclude that these factors lead to the poor people getting a poor quality of services.

Amongst the general poor, this preference for the private sector is reflected in high OOPE, whereas for the homeless, it may reflect in not seeking care at all or delaying attempts to access care, as suggested by the reports from four cities of India in the report ‘Living Rough’ (Mander, 2008).

On face value, homeless persons in the study seemed to distrust free services though they recognised that they needed them. However, it can be argued that since free services (such as drugs) are made available only for the very poor, and not used by the rich, the interpretation the poor may make is that services, drugs and consumables used by those who can afford to pay must be of better quality than what is given to them free. Their perception is supported by authors who also feel that the poor do in fact get poorer services at the same facility (Kennedy et al, 2009).

However, it can be inferred that what the homeless would really prefer is to have free services of good quality. The fact that quality seems to be the main criterion

that is used when choices can be exercised by the homeless is evident from the fact that participants were quite satisfied with the services provided by NGO AB, the mission hospital for leprosy and the drug rehabilitation centres run by other NGOs; all of which were free. Thus the evidence presents a case for quality, and not for user charges³⁸.

It is possible that the existence of a universal system of free health care that is equally available for all rather than targeted upon the poor would increase user confidence where the poor are concerned over and above the benefits from belying the costs of care. Universalisation provides a quality of care to all irrespective of class, removes the requirement and difficulties for specific identification and also removes the not unwarranted suspicion that if only the poor are to get a free service in India, they will most likely receive a poor service. Additionally, international evidence also supports the fact that universalisation of free services (paid for through taxation) ensures that a pressure is kept up on the quality of services by people who are more powerful and articulate than the illiterate and most poor (Hennigan, 2010).

This study thus adds evidence to the fact that the homeless make judgements about, and exert choices within their limited resources based on their perception of quality. It also suggests that concerns about quality act as barriers to accessing *appropriate* health care by the homeless, as other studies have suggested for the general poor. The targeting of the poor for free services may be a reason for them to be distrustful of the public health system, and both trust and quality may be improved if the systems accessed by the homeless are universally free. Thus universalisation of free health care through the public systems offers two gains as suggested by the study; the improvement in quality and trust as well as removing the barrier of costs of health care, to markedly improve access of the poor to the public health system. This has been a long standing demand of health rights

³⁸ It has sometimes been suggested by proponents of user fees that user charges increase the ownership of participating poor people upon services. This point is being made against the notion that it might be a good strategy to apply user fees to gain trust and then reimburse them in some other manner. The composite evidence of the study suggests that user fees are more likely to do harm by creating barriers than good by increasing trust or ownership.

activists in India on these very grounds (Shukla, 2005; Jan Swasthya Abhiyan³⁹, 2006).

The reason that public health services are not able to provide care in the way that would be perceived to be of good quality by the homeless has also been analysed in the findings to some extent; the facilities are overcrowded and overburdened and doctors receive scant support. They also have to attend to all walk-in patients in the absence of a tiered system of referrals. Additionally, there are structural issues of inadequate financial and human resource investments in the public health system, which have created this situation. This has also been well described in literature pertaining to health care in India (Gangolli et al, 2005; Balaji et al, 2011).

The homeless in this study displayed a preference for the private sector. However, other studies also show how the formal private sector is more prone to irrationality of health care apart from high costs of care. For example, a recent study from Nigeria investigates private health facilities for rational drug prescriptions. While it finds that the factors for patronage of private services include absence of long queues and better attitude of staff, there was a high degree of irrationality in prescriptions including unnecessary injections and overuse of antibiotics (Tamuno, 2011). Thus, private services are not inherently better in quality in any sense, considering their high costs and irrationality. The problems of quality within both the public sector and the private sector in India are well described and analysed in the Report of the Macroeconomic Commission on Health (WHO, 2005) which concludes that “the private sector has by and large failed to provide quality care at a reasonable cost” (:126). Perhaps the true interpretation of the findings of this study would be that the homeless are sensitive to quality in health care and show a preference for services that fulfil their criteria of a good service. If the quality of services in public health systems improves, it is likely that the homeless will be more motivated to seek care from the public health system.

³⁹ Peoples' Health Movement- India

5.5: Facilitation by NGOs; an Ambivalent Relationship

In the setting of this particular study, non governmental organisations emerge as the main agencies involved with the facilitation of access to health care for the homeless. They seem to provide a most valuable service that ranges from identification of the sick, to treatment, referral, facilitation of care in public hospitals, post discharge rehabilitation, follow up and safekeeping of records. They also pick up the entire out-of-pocket costs of care. These facilitating factors have been recognised in studies with the homeless from other countries as described in the survey of literature. However, the requirement for an accompanying person seems to be an Indian phenomenon having been mentioned only by Indian authors (HIGH, 2003) previous to its description in this study.

The support from NGO AB was largely appreciated by homeless recipients, though they did not usually know all the details of how the NGO had assisted them. Nevertheless, the relationship between the NGOs described in this study and the homeless persons is an ambivalent one and worthy of further discussion.

Overall, from the findings of the study it seemed that the homeless were simply following directions rather than being facilitated for actions that had been proposed, demanded or led by them. This also seemed to explain the fact that they did not have much information about the degree of effort that had gone into facilitating their access to health care. The fact that safekeeping of papers by NGO AB and other social organisations was brought up with so much interest by the homeless and with some regret as well from having to relinquish this asset also seemed to point to some ambivalence in how the homeless viewed the NGO.

The HWs frequently used the phrase ‘we have to motivate them’ and the homeless respondents frequently used the phrase ‘I don’t know, they only know’ or ‘they did everything’. Some homeless participants complained about the delays at the level of the health workers and conversely health workers and NGO doctors described how it was sometimes difficult to work with the homeless. As described in the findings, doctors and health workers from NGO AB commented on the apathy of the homeless participants and the homeless participants often expressed

helplessness. The researcher, on her part, observed that the helplessness was a realistic response of the homeless to the harsh reality of having very few resources and choices.

As commented on earlier in Chapter 3, the researcher had witnessed an onlooker warning a participant not to speak with her on the grounds that NGO people only exploit them, make money and leave while they stay where they are. The researcher also witnessed the eruption of a verbal duel between a participant and an NGO worker⁴⁰ much on the same lines. However the same participant had earlier commented that these workers were like family to her.

This kind of ambivalence has been noted in other reports such as the IGSS report also based on a study of 88,410 homeless persons in Delhi which notes that “though aware about very few organizations (only 3) who work for their rights, but they [the homeless] also criticize their working”(IGSS,2009:10).

Thus, while a high level of dependence on the facilitating NGOs was observed during this study there was also some indication of resentment towards them.

Similarly, it was also noted that there were significant differences in and objectives between the homeless participants and health care providers as described in Section 4.3.5. While the health care providers were focused on clinical or public health goals, the homeless participants were often more concerned about issues related to their immediate survival or livelihoods, even at the cost of their health. This has been well described by other authors based on many years of experience in providing health care services for the homeless. Howe, Buck and Withers note that it may be required “to balance the patient’s goals (often broadly focused on immediate needs) with the practitioner’s goals (often more clinically focused) (2009:241). They confirm that “[homeless] patients also often function in a very present-centered survival mode that limits their ability to focus on future effects of medical problems” (2009:241- 242). Additionally, they remark upon the mistrust the homeless sometimes feel for the

⁴⁰ Not from NGO AB

clinical practitioner. The two short term indicators they suggest to determine the quality of street medicine programmes have been developed (also described in Chapter 2; the survey of literature) as a result of the understanding of the conflicts that may occur between the perspectives of health care providers and their homeless patients. These indicators, namely, patient engagement and subjective assessment of well-being have been designed to ensure that the health care programme on offer is patient-centred and that negotiations are carried out between the homeless and the organisations delivering health care to arrive at common goals. This “goal negotiated care” (2009: 245) ensures that the immediate needs of the homeless person have been identified and attended to, and that he / she has greater ownership on health related decisions. It is also said to counter helplessness; which the authors call a “learned helplessness” (2009: 245) and which could be akin to the helplessness noted in this study, through greater self-efficacy.

Promoting participation; as a major strategy to counter homelessness and its associated disempowerment, has been part of the discourse on interventions with the homeless in other countries, especially in Europe (Paasche, 2010). As far as the researcher is aware, current practices of providing health care for the homeless in India have not included such patient-centred or participation strategies even though in general work with the homeless, the IGSS report recommends that “the program should be participatory where the homeless people are equal partners and take up the responsibility of ensuring that the efforts coming in remain consistent and that resources are shared equally” (IGSS, 2009:12). The study also finds the absence of negotiated and participatory goal-setting in the practice of delivering health care services for the homeless in the context of this particular study. Incorporating such practices this could go a long way in decreasing the differences of perceptions and objectives between the homeless and the facilitating NGO, including its health care providers.

5.6: Social Capital; Facilitation through Social Relationships

It is evident from the findings of the study and the discussion in the section above that, in many ways, the social organisation NGO AB and others described by the participants play the role that would otherwise have been performed by family members, friends and other social contacts during periods of illness, such as helping with transportation, financial assistance, accompaniment to hospital, linking up with contacts within the health system for ease of access and so on.

However, it was also evident, especially from the general category of participants who had not been specifically assisted by NGO AB, that other micro networks also existed that offered the participants social support and enabled access to health care services in small but significant ways. For instance, a few participants mentioned the fact that some person other than a health worker had accompanied them to the hospital. In the case of an elderly widow, it was her daughter and in the case of another elderly man who suffered from leprosy two acquaintances had facilitated referrals at two different times. Another participant had been helped financially by a vendor⁴¹. These were best illustrated by the stories of participants from the general category who had managed to access care without the facilitation by the NGO AB.

These supports may be discussed within the framework of social capital to analyse their implications for facilitating access to health care services for the homeless. Social capital is a term that has been understood and applied variously by various authors (Macinko and Starfield, 2001). Whereas some have seen social capital as a largely individual resource of supportive relationships based on trust and mutual assistance, and described social assets in terms of 'goodwill, fellowship, sympathy and social intercourse' (Hanifan, 1920, in Macinko and Starfield, 2001: 389) or 'bounded solidarity' (Portes, 1998: 8), others have seen it as a characteristic purely of groups of persons (Bourdieu, 1985) and described it in terms of

⁴¹ It may be recalled that the researcher had also come across a young homeless person who had been cared for by other street dwellers for weeks as he recovered from severe burns, though he was not available as a participant during the period of this study.

organised relationships amongst groups related to recognition, approval and status.

It appears especially useful to apply the categorisation of bonding, bridging and linking social capital (Szreter, 2002) to the findings of the study in the context of facilitation for health care. ‘Bonding’ capital refers to the networks of people with similar characteristics, (Putnam, in Szreter, 2002) who would have common problems and objectives and would gain strength by working together. However, one must be able to leverage advantage for one’s own self and community through linking and bridging social capital which refers to the connections between groups of varying characteristics, power and status. Participants reported little social capital of the ‘bonding variety’, i.e., amongst themselves. The salutary effect of social capital was mostly in the form of the links of homeless persons with people who had greater power or social stature; ‘bridging’ or ‘linking’ social capital, such as the health workers of the social organisations and acquaintances who had contacts within the health system and helped to refer or place homeless patients within a facility. No evidence was found of any participant being related to an association apart from the account of one participant who had taken pride in engaging in the organisational activities of the NGO that was helping him with drug rehabilitation⁴² and his feeling of belonging to this organisation had helped to retain him in the programme.

One previous study with the homeless in Delhi notes

Whereas the rural poor have [a] wide variety of social networks on which they can depend at the time of crisis, for the urban poor such social networks are fragile, the reason for fragile social network[s] is due to the heterogeneous nature of the urban poor population. The difference in region, background, age and living pattern are the main inhibiting factors in the formation of strong social networks, added to it is the fact that [the] urban poor are [a] highly mobile category, which do not allow for

⁴² Incidentally, this participant also requested a job in NGO AB and promised to stay off drugs if he were to get one.

formation of social networks. However the above assertion does not mean that social networks and linkage do not exist (Rai, 2008:4).

One of the reasons ascribed to the lack of social capital is that the homeless tend to drift from place to place. However, this study found most of the participants had been stable residents of the area for many years. It was more probable that the lack of relationships and networks were related to extreme deprivation and not having resources to share. This was also supported by the fact that they did benefit from social relationships with people who were slightly better off to access health care, such as the vendor who collected Rs 400 for immediate relief and the sweeper who took a participant to the mission hospital.

The Rai study also found that found that “homeless people tend to rely on each other and strong friendships are formed. 16% of the male respondents who had no relatives on the streets told us that they have adopted relatives or people [on the streets] whom they treat as their own.....” However, 29% of the respondents said they had positive relationships with *non* homeless people. In terms of impact of these various relationships on being able to access health, the Rai study only mentions that some friends would buy medicines.

Since these relationships and micro networks were found to translate to access to health care to some extent in this study but not significantly so, it can be postulated that the gap between the homeless and the health care service is so vast that it would take a ladder of ‘bridging social capital’ to cover it. Perhaps each social relationship can only cover a few levels in terms of the capacity to facilitate access to health care. This also explains why it needs the full-fledged institutional structure of an NGO to achieve results from the facilitation of health care. However, social capital may emerge as an important potential enabling factor for interventions with the homeless.

This approach; to facilitate associations and peer support groups of the persons concerned, has often been used by other vulnerable groups such as those with mental health problems, disability or affliction with HIV / AIDS to improve their

access to health care (Stuart, 1990; Bhagwanjee, 1999; Simoni et al, 2011; Masterson and Owen, 2006).

Groundswell, as described in its website, is a charity in UK that is facilitating user involvement and self-help organisations in the field of homelessness in the UK. They state their three aims as “[to] enable homeless people to set up and run their own projects, increase homeless people's influence in policy and decision making [and] increase homeless people's meaningful involvement in the services they use” (Groundswell, 2006: para 2).

The formation of peer support groups by people in situations of common vulnerability can be considered a structured form of bonding capital. However, networks and campaigns that include not only the homeless but other sympathetic members of the community with greater power can provide linking or bridging capital to facilitate access to health care. Such networks or campaigns that include participation of the homeless may become effective lobbies for getting better access to better quality services.

Thus, Groundswell also attempts to “bring everyone together including policy makers, managers, frontline staff and homeless people to create effective solutions to homelessness” (Groundswell, 2011: para 1. Potentially, these social capital networks may result even in increases of economic capital by enabling jobs or work, as explained by Bourdieu’s theories of exchanges and interlinkages between social and economic capital (Bourdieu, 1985).

Interestingly, Butterflies, an NGO working with street children in New Delhi has a strong element of mobilisation and creation of collectives amongst its strategies. As stated in its website, their approach is

...democratic, participatory, rights based... to ensure that children actively participate in the decision-making process and this is done through their Bal Sabha (Children's Council meetings) and their own Bal Mazdoor Union (Child Workers Union). Monthly Bal Sabha meetings are forums

where they discuss all the issues which affect their lives, share their concerns and find collective solutions (Butterflies, 2011: para 1)

As per the discussion above, this strategy may have potential for application to homeless adults too, for the purposes of acquiring better access to health care.

The strategy of creating socially supportive local networks has been tried to some extent by the NGO Aashray Adhikar Abhiyan, though not specifically for health care. They report

During 2002-2003 winters, issue of shelter rights for the homeless became a movement where even the civil society groups and institutions like Market welfare Association, Resident welfare Associations, Colleges joined in providing medicines, blankets, food, etc to homeless and their attitude towards them also changed. Media played its part in raising this issue in both the electronic as well as print spaces, by doing stories and interviews (IGSS, 2009: 44)

Thus, facilitating NGOs may, apart from running participatory programmes themselves, build upon the micro networks that already exist amongst the community which includes homeless persons, their employers and sympathetic persons from the more settled community in the area. It is also possible to envisage the local private practitioners becoming a part of such networks since the study shows that the homeless found them accessible and helpful. Such networks may help individual homeless persons to access health care, as well as enable pressure upon the State to fulfil its obligations towards their rights to health care.

This discussion lays the ground for the recommendations that may emerge from the study for public health policy and programmes in New Delhi to allow better access to health care services by the homeless, especially to the public health system, as will be taken up in the concluding chapter.

CHAPTER 6: CONCLUSIONS AND RECOMMENDATIONS

6.1: Conclusions

This study concludes that there are a great many barriers between homeless persons in the setting of Nizammudin, New Delhi and the access to health care services. These barriers result from the inter relationship between the characteristics associated with homelessness, the lacunae of current socio-economic 'safety-net mechanisms' and the characteristics of the health care systems that currently exist.

Homelessness itself is found to be a social determinant of access to health care and is also demonstrated to be the net result of the failure of social security systems in the country. This study uniquely identifies out of pocket costs of health care as an immediate cause of homelessness amongst poor people. Once rendered homeless, the homeless are then relegated to invisibility by failures of identification, such as not being counted in the BPL list and not having voter identity.

In the hierarchy of barriers, the major barrier is the unaffordability of care, understandably in the private health care system, but also significantly in the public health care system that is meant to cater equally or preferentially to the poor.

If the main barrier of costs of care is set aside, the barriers are more marked in the context of public health systems as compared to the private sector and pertain to the lack of quality of care as perceived by the homeless. These relate to delays, unwarranted dismissals, procrastinations and insulting behaviour. However, the private sector facilities approached by the homeless often deliver health care that is inappropriate as well as expensive.

These barriers are known to be faced by the poor in general. The barriers that pertain to the state of homelessness in particular, apart from extreme poverty, are

related to the lack of carers and attendants to provide support through an illness. Most of the barriers have been found to be common across other settings in which studies have been conducted with the homeless. However, the need for an attendant during admissions appears to be peculiar to the Indian context.

Facilitation of access to health care is a task that is mostly being carried out by NGOs or religious organisations. This comprises of identification of the sick, providing primary care, transportation to referral centres, enabling admissions at such centres, negotiating with doctors, arranging blood, arranging for attendants during admission, paying for the entire costs of care, arranging for post discharge care such as dressings and nutritional support and arranging for drug rehabilitation.

Apart from the structural difficulties mentioned above, such as costs of care, lack of referral systems and the problems of negotiating the public health system successfully, the difficulties of facilitating care for the homeless include many differences of perceptions and objectives between health care providers and their homeless patients. The conflicting objectives between the health care providers and the homeless lead to some resentment and frustration amongst both. The perceptions amongst the health care providers are that the homeless are apathetic and rather uncaring about their own health, while the experience of the homeless leads to feelings of helplessness.

A slightly ambivalent relationship exists between the homeless and facilitating NGOs, perhaps because of the great differentials of power between the two. The relationship between facilitating NGOs and the homeless provides much needed immediate relief to the homeless, but more can be done to make it empowering in terms of self efficacy and participation. The study reveals this best, symbolically, through the regret the homeless feel about not being in possession of their medical records which are usually housed by the facilitating NGO for safe keeping.

The homeless themselves have been found to make much effort to seek health care and use the meagre resources that they have to be able to access it. This includes spending whatever they have managed to save, seeking out areas (even in

a different city) where an NGO is known to facilitate health care and using whatever social networks they have been able to build in the context of homelessness. The study concludes that the homeless are concerned not only with their own health, but also with having better control over their circumstances of helplessness. Whatever agency they have, they do seem to exert to avail of assistance for health care.

6.2: Recommendations

The study recommends that a comprehensive approach be developed to assist the homeless to access health care. This would require changes and improvements in policies relating to health as well as the social determinants of homelessness, and improvements in the public health care system. Further, facilitating social organisations may also need to change their practices in providing health care services as well as in their policy advocacy for better public health care services for the homeless. Thus, the recommendations have been focused on these areas of intervention.

6.2.1: Recommendations for Policy

1. The prevention of homelessness through greater attention to issues related to social justice, social security and labour rights must be given due priority in all policy advocacy related to homelessness.
2. The fact that costs of health care contribute to homelessness by leading to it and perpetuate it by exhausting the savings of the homeless needs to be acknowledged and dealt with through the public health policy and programmes.
3. The lack of identification of the homeless as extremely poor persons must be corrected with urgency. The state of homelessness should be taken to be a non negotiable criterion for the BPL list⁴³ and special effort needs to be made to ensure they are counted.

⁴³ This has just been accepted in principle for the on- going socio-economic and caste census 2011

4. The quality of services desired by the homeless from the public health systems may be best achieved by universalising free health care and removal of user charges.

6.2.2: Recommendations for Public Health Systems

1. Outreach to the homeless must be made an essential part of the public health care system in urban areas. This can be made available through trained health workers as exemplified by the health workers of the NGO AB.
2. Primary health care centres must be made available at sites within the areas inhabited by homeless persons.
3. The attending doctors and staff must be made to go through a specific sensitisation and training programme to ensure respectful behaviour towards the homeless and a proper understanding of their specific requirements.
4. Free referral transport needs to be provided between the primary centres and the public hospitals.
5. Sufficient numbers of trained social workers need to be deputed at the hospital to escort the homeless through the various processes.
6. A government order needs to be circulated to instruct the hospital authorities to admit homeless persons without proof of address or attendants⁴⁴.
7. The costs of care need to be completely free for the homeless in both the public facilities as well as the free beds in the private hospitals. This must include the costs of drugs and consumables.
8. An attendant should be made available to the homeless persons who do not have accompanying carers for the full duration of the stay in hospital.
9. Services need to be made available for post discharge care in the areas inhabited by the homeless. These could be arranged by

⁴⁴ An application was put by the researcher under the Right to Information Act to find out if the homeless can be barred from admission if they do not have an address. She was informed that no hospital can turn away a homeless person on the pretext of lack of address.

dedicated space in the government run shelters for those who have been discharged after admission. The outreach health workers could provide the human resource for this function as well.

10. Nutritional support is required for pre admission and post admission periods and this can also be facilitated through the health workers.

6.2.3: Recommendations for Facilitating / Service Providing Social Organisations

1. Involved NGOs should consider advocacy for public health systems that cater to the homeless as detailed above.
2. The intervening NGOs need to devise ways of better information to the homeless about the various health and social services that exist and their rights upon them. This could be a medium term empowerment strategy.
3. They may also apply the criteria of patient's engagement and subjective assessment of their own wellbeing to the health programmes they are running themselves. This would involve processes of negotiation to arrive at common health goals with the homeless patients.
4. As an immediate step towards allowing their homeless patients to be more involved in their own care, it is recommended from the study that they provide their patients with a summary record of their health in the form of a card that they can keep with themselves.
5. They should also consider the addition of longer term empowerment strategies to their interventions with the homeless that enhance social capital, such as creating associations and self help groups
6. Further health systems research is required to enable and improve access to health care services for the homeless that may build upon the findings of this exploratory study.

These recommendations are best brought to reality by continued dialogue with existing campaigns related to the entitlements and rights of the homeless. As noted in the introduction to this study, these campaigns have focused on many fundamental issues, specially housing, but issues related to access to health care have remained on the sidelines even as many participating organisations also run direct health care services for the homeless. The findings of this study will be systematically shared with the identified campaigns and participating organisations, so that they can be discussed, debated and taken up for policy advocacy by those already in dialogue with policy makers. Further, attempts need to be made to share these issues with the homeless themselves and ensure their participation in this process.

It is equally important that the groups involved with health systems reforms also be made aware of these issues and their support enlisted. This can also be done by dialogue with the health movements in India, such as the People's Health Movement- India (Jan Swasthya Abhiyan) and by facilitating direct links between the existing campaigns for the right to health care and the rights of homeless people.

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Finally, as the CSDH puts it the “unequal distribution of health-damaging experiences is not in any sense a ‘natural’ phenomenon but is the result of a toxic combination of poor social policies and programmes, unfair economic arrangements, and bad politics” (CSDH, 2008: 1). It is hoped that in a very humble way, the study presented in this thesis exposes the truth of this statement with respect to the health conditions of the homeless, the struggles which they have to undergo to access health care, and the many denials of the right to health that they encounter in their battle to survive against so many odds.

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ANNEXURE 1 : PARTICIPANT INFORMATION SHEET FOR HOMELESS PARTICIPANTS



UNIVERSITY OF THE WESTERN CAPE
School of Public Health

Private Bag X17 • BELLVILLE • 7535 • South Africa
Tel: 021- 959 2809, Fax: 021- 959 2872

Participant Information Sheet

January 2011

Dear Participant

Thank you for your time and willingness to hear and read about the research I intend to do. What follows is an explanation of the nature of the research and an outline of your potential involvement in the project. This study will be done as part of my fulfillment of the master's degree program requirements with the University of the Western Cape, South Africa. If there is anything you need clarity on, please feel free to ask me. At the end of this information sheet you will find my contact details as well as those of my supervisor.

TITLE OF THE RESEARCH

Barriers and Facilitating Factors for Health Care Seeking Amongst Adult Street Dwellers in New Delhi, India.

PURPOSE OF THE STUDY

The purpose of this study is to improve the understanding of the difficulties felt and faced by homeless persons – along with those things that have helped them access health care. Your views on what could be done to improve access will also be discussed. The findings will be used to strengthen the demands for better government health care services for homeless people in New Delhi.

DESCRIPTION OF THE STUDY AND YOUR INVOLVEMENT

The study will be based on individual interviews that are expected to last about 40 minutes. If you agree to it, I will be using a tape recorder as well as taking notes. Health workers and doctors at the NGO clinic, as well as some doctors at the nearest government hospital will also be interviewed individually. There is no anticipated harm in participating in this study.

CONFIDENTIALITY

At all times, I will keep the source of the information confidential and refer to you or your words by pseudonym or invented name which I would like you to choose. I shall keep all records of your participation locked away at all times, and destroy them after the data has been collected.

VOLUNTARY PARTICIPATION AND WITHDRAWAL

Your participation in this study is entirely voluntary and should you wish to withdraw from the study at any time you may do so without giving reasons. Your withdrawal will not affect your situation in any way, including being helped by the NGOs and health services in this area. The interview may touch on issues that you may not be comfortable to discuss. If there is anything that you would prefer not to discuss, please feel free to say so. I will not be offended and there will be no negative consequences if you would prefer not to answer a question. I would appreciate your guidance should I ask anything which you see as intrusive.

BENEFITS

You may not get any direct benefit from this study. However, if you are currently unwell I will do my best to facilitate immediate health care for you. You may also feel satisfied to have participated in a process that intends to help homeless people to access health care services from the government.

INFORMED CONSENT

Your signed consent is required for you to participate in this study. You may decide to participate or not. The consent form is attached to this participant information sheet.

CONTACT DETAILS

Dr. Vandana Prasad

Cell phone: 9891552425

E-mail: vandanaprasad@gmail.com

My supervisor's details are as follows

Ms. Nikki Schaay,

The School of Public Health, University of the Western Cape, South Africa

Tel: +27 842 115 544 or +27 217 884 186

E-mail: schaay@mweb.co.za



ANNEXURE 2 : PARTICIPANT INFORMATION SHEET FOR KEY INFORMANTS

UNIVERSITY OF THE WESTERN CAPE

School of Public Health

Private Bag X17 • **BELLVILLE** • 7535 • South Africa

Tel: 021- 959 2809, Fax: 021- 959 2872

Participant Information Sheet

January 2011

Dear Participant

Thank you for your time and willingness to hear and read about the research I intend to do. What follows is an explanation of the nature of the research and an outline of your potential involvement in the project. This study will be done as part of my fulfillment of the master's degree program requirements with the University of the Western Cape, South Africa. If there is anything you need clarity on, please feel free to ask me. At the end of this information sheet you will find my contact details as well as those of my supervisor.

TITLE OF THE RESEARCH

Barriers and Facilitating Factors for Health Care Seeking Amongst Adult Street Dwellers in New Delhi, India.

PURPOSE OF THE STUDY

The purpose of this study is to systematically document the barriers and facilitating factors for accessing public health care services by the homeless. The findings will be used to strengthen the demands for better government health care services for homeless people in New Delhi.

DESCRIPTION OF THE STUDY AND YOUR INVOLVEMENT

The study will be based on individual interviews with homeless persons. As part of the health team at the NGO clinic / field-based NGO / public health system you are requested to give your consent to take part in this study. Questions about what you perceive to be the barriers and facilitating factors for accessing health care services by the homeless and how these could be addressed will guide the interview which is expected to take about 40 minutes. I will be using a tape recorder as well as taking notes. There is no anticipated harm in participating in this study.

CONFIDENTIALITY

At all times, I will keep the source of the information confidential and refer to you or your words by pseudonym or invented name which I would like you to choose. I shall keep all records of your participation locked away at all times, and destroy them after the data has been collected.

VOLUNTARY PARTICIPATION AND WITHDRAWAL

Your participation in this study is entirely voluntary and should you wish to withdraw from the study at any time you may do so without giving reasons. Your withdrawal will not affect your future in the NGO or as a health care provider. The interview may touch on issues that you may not be comfortable to discuss. If there is anything that you would prefer not to discuss, please feel free to say so. I will not be offended and there will be no negative consequences if you would prefer not to answer a question. I would appreciate your guidance should I ask anything which you see as intrusive.

BENEFITS

You may not get any direct benefit from this study. However, the study results may improve your ability as a health worker / health care provider to address key issues of the problems faced by homeless people in accessing health care.

INFORMED CONSENT

Your signed consent is required for you to participate in this study. You may decide to participate or not. The consent form is attached to this participant information sheet.

CONTACT DETAILS

Dr. Vandana Prasad

Cell phone: 9891552425

E-mail: vandanaprasad@gmail.com

My supervisor's details are as follows

Ms. Nikki Schaay

The School of Public Health, University of the Western Cape, South Africa

Tel: +27 842 115 544 or +27 217 884 186

E-mail: schaay@mweb.co.za



ANNEXURE 3: INFORMED CONSENT FOR ALL PARTICIPANTS**UNIVERSITY OF THE WESTERN CAPE****School of Public Health**

Private Bag X17 • **BELLVILLE** • 7535 • South Africa

Tel: 021- 959 2809, Fax: 021- 959 2872

RECORD OF INFORMED CONSENT TO CONDUCT AN INTERVIEW

Date:

Interviewer's name: Dr. V. Prasad

UWC student no: 2968277

Tel: 9891552425

e-mail: vandanaprasad@gmail.com

Institution: Public Health Resource Network, 5 A Jungi House, Shapur Jat, New Delhi 110049

Interviewee's pseudonym:

Place at which the interview will be conducted: Nizamuddin, New Delhi

Thank you for agreeing to allow me to interview you. What follows is an explanation of the purpose and process of this interview which is to collect data for my research project in partial fulfillment of the requirements of the MPH program with the School of Public Health, UWC, South Africa.

1. Information about the interviewer.

I am Dr Vandana Prasad a student at the SOPH, University of the Western Cape, South Africa. As part of my Masters in Public Health, I am doing an operational research project. I will be focusing on the barriers and facilitating factors for accessing health care faced by homeless people. I would like your opinion, perceptions and feelings on this topic.

I am accountable to Ms Nichola Schaay who is my supervisor and is contactable on Cell +2784 2115 544 or c/o SOPH fax: +2721 959 2872 or by email at schaay@mweb.co.za

2. Purpose and contents of the interview

The purpose of this study is to systematically document the barriers and facilitating factors for accessing public health care services by the homeless. The findings will be used to strengthen the demands for better government health care services for homeless people in New Delhi.

3. The interview process

The interview will be carried out in a place of your choice which is conducive to an undisturbed conversation. The interview will last for approximately 40 minutes and will be guided by your views and experiences regarding the health care seeking experiences of homeless people. I will be using a tape recorder as well as taking notes.

4. Anonymity of contributors.

At all times, I will keep the source of the information confidential and refer to you or your words by pseudonym or invented name which I would like you to choose. I shall keep all records of your participation locked away at all times, and destroy them after the data has been collected.

5. Things that may affect your willingness to participate

The interview may touch on issues that you may not be comfortable to discuss. If there is anything that you would prefer not to discuss, please feel free to say so. I will not be offended and there will be no negative consequences if you would prefer not to

answer a question. I would appreciate your guidance should I ask anything which you see as intrusive.

6. Agreement

6.1 Interviewee's agreement

I (Full name) do agree to take part in the research interview.

Date:

Place:

Signature:

Signature of witness if relevant:

6.2 Interviewers agreement

I shall keep the contents of the above research interview confidential in the sense that the pseudonym noted above will be used in all documents which refer to the interview. The contents will be used for the purposes referred above, but may be used for published or unpublished research at a later stage without further consent. Any change from this agreement will be renegotiated with you.

Signed:

Date: Place:

ANNEXURE 4: INTERVIEW SCHEDULE FOR HOMELESS PERSONS (GENERAL GROUP)

Read out information sheet introducing yourself and the research project
Take written consent

General Information

Name:

Age:

Sex:

Duration as street dweller:

Location:

Single / accompanied:

If accompanied, by whom:

Disabilities (describe if 'yes'):

Known Chronic Health Problems, including Substance Abuse:

Opening question: Can you tell me about a time when you were unwell recently?

Interview Guide

1. Description of the illness

Probes:

- What did you feel was wrong?
- When did you experience this?
- How did you try to ease the problem?
- When did you think of seeking help?
- Do you think your illness was related to being homeless (caught a cold at night, injured in a road accident, attacked by miscreants / police, sexually abused, ate bad food, bitten

by dog / rat, got a skin infection from not being able to bathe/ proximity to animals or humans for warmth)

2. Care sought

Probes:

- What kind of help did you look for?
- Where did you go?
- Why did you go there?
- How did you go?
- Who did you take along with you?
- How long did you stay at the facility (admitted, out patient)
- Who looked after you at the facility?
- What did you feel about the care offered at the facility?
- Have you ever been to a government facility?
- Describe your experience there.
- Who looked after you when you came back from the facility?
- Were you asked to come back for a check up?
- Did you go? (if not, why not)

3. Difficulties faced

Probes:

- How did you found the attitudes of health care providers? (in government facilities, in private facilities, in NGO run clinic if relevant)
- How did they behave towards you?
- What comments did you receive?
- How long did you have to wait to be attended to?
- What difficulties did you have in getting admission?
- What difficulties did you face in being nursed?
- What difficulties did you face in food arrangements?

4. Costs

Probes:

- How much did this illness cost you?
- What were the main expenses?
- From where did you get the money?
- How did you pay it back and at what cost (food, savings, assets)?

5. Positive experiences and coping mechanisms

Probes:

- Who helped you through this illness and why?
- In what way did they help?

6. Self-related barriers

Probes:

- Do you think the problems you faced had anything to do with being homeless?
- Do you consider that you might have contributed to those problems in some way? (violence, abuse, addiction, inability to stick to discipline / rules)
- Did the health carers at the facility criticize you for something you consider valid?

7. Recommendations

Probes :

- What do you think would help you to take care of your health and in getting health care?
- Can you list a few things that would be very helpful to you for getting health care?

ANNEXURE 5: INTERVIEW SCHEDULE FOR HOMELESS PERSONS (FACILITATED GROUP)

Read out information sheet introducing yourself and the research project

Take written consent

General Information

Name:

Age:

Sex:

Duration as street dweller:

Location:

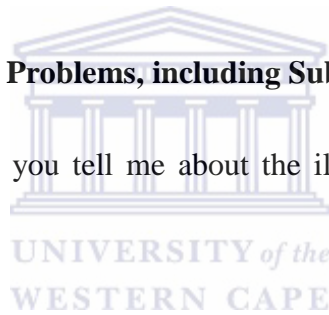
Single / accompanied:

If accompanied, by whom:

Disabilities (describe if 'yes'):

Known Chronic Health Problems, including Substance Abuse:

Opening question: Can you tell me about the illness which brings you to this clinic?



Interview Guide

1. Description of the illness

Probes:

- What did you feel was wrong?
- When did you experience this?
- How did you try to ease the problem?
- When did you think of seeking help?
- Do you think your illness was related to being homeless (caught a cold at night, injured in a road accident, attacked by miscreants / police, sexually abused, ate bad food, bitten by dog / rat, got a skin infection from not being able to bathe/ proximity to animals or humans for warmth)

2. Care sought

Probes:

- What made you come to this particular clinic?
- How did you come?
- Who did you bring along with you?
- How long have you stayed at the facility?
- Who all looked after you here?
- What do you feel about the care offered at the facility?
- Have you ever been to a government facility?
- Describe your experience there.
- How long have you been visiting this facility?
- Have they ever helped to admit you to a government facility?
- Who looked after you when you come back (from the facility/ from the government hospital)?
- Have you been asked to come back for a check up?
- Will you come? (if not, why not)

3. Difficulties faced

Probes:

- How did you found the attitudes of health care providers here?
- How have they behaved towards you?
- What comments did you receive?
- How long did you have to wait to be attended to?
- Have you faced any problems at the NGO clinic?

4. Costs

Probes:

- How much did this illness cost you?
- What were the main expenses?
- From where did you get the money?
- How did you pay it back and at what cost (food, savings, assets)?

5. Positive experiences and coping mechanisms

Probes:

- Who helped you through this illness and why?
- In what way did they help?

- How was coming to this clinic better than / different from going to any other place?
- In what ways has this NGO helped you to access health care?

6. Self-related barriers

Probes:

- Do you think the problems you faced in getting health care had anything to do with being homeless?
- Do you consider that you might have contributed to those problems in some way? (violence, abuse, addiction, inability to stick to discipline / rules)
- Did the health carers at the facility criticize you / advise you for something you consider valid?

7. Recommendations

Probes :

- What do you think would help you to take care of your health and in getting health care in general?
- Can you list a few things that would be very helpful to you for getting health care even at this clinic?
- Can you list a few things that would be very helpful to you for getting health care in the government facility?

ANNEXURE 6: INTERVIEW SCHEDULE FOR KEY RESPONDENTS

Read out information sheet introducing yourself and the research project

Take written consent

General Information

Name:

Age:

Sex:

Location:

Designation:

Duration of tenure at this post:



Opening question: what barriers do you think the homeless experience in accessing health care?

Interview Guide

1. Can you relate any specific instances related to government health services?
2. Can you relate any specific instances related to private / NGO health services?
3. Can you relate any specific instances related to the positive interventions (at the NGO clinic or elsewhere) to circumvent these barriers?
4. Have you made any intervention yourself on behalf of the access of homeless persons to health care?
5. Are you aware of any assistance from government on their behalf?
6. What do you think of the costs of health care at your facility for homeless persons?

7. Have you noticed any specific coping mechanisms used by the homeless during ill health?
8. What problems have you faced while trying to take care of homeless persons?
9. How do you think these problems can be solved? (list a few things that will help to solve these problems)
10. What are the characteristics of a 'good' health care system for the homeless in your opinion and from your experience?

Probes:

- Systemic interventions (transport, ID, vouching for, carer, financial assistance)
- Behaviour change interventions both for providers and for the homeless themselves

