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**Help-Seeking for 'Memory Loss' by Older Adults in India:
Patient, Caregiver and Health Providers' Perspectives**

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Dedicated to Sailesh Mishra

As a person abandons worn-out clothes and acquires new ones,
so when the body is worn out, a new one is acquired by the Self, who lives within.

-The Bhagavad Gita

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Abstract

Background. In India, prevalence rates of dementia and prodromal amnesic Mild Cognitive Impairment (MCI) are 3.1% and 4.3% respectively. Most Indians refer to the full spectrum of cognitive disorders simply as ‘memory loss.’ Barring prevention or cure, these conditions will rise rapidly with population aging. Evidence-based policies and practices can improve the lives of affected individuals and their caregivers, but will require timely and sustained uptake.

Objectives. Framed by social cognitive theories of health behavior, this study explores the knowledge, attitudes and practices concerning cognitive impairment and related service use by older adults who screen positive for MCI, their primary caregivers, and health providers.

Methods. I used the Montreal Cognitive Assessment to screen for cognitive impairment in memory camps in Mumbai. To achieve sampling diversity, I used maximum variation sampling. Ten adults aged 60+ who had no significant functional impairment but screened positive for MCI and their caregivers participated in separate focus groups. Four other such dyads and six doctors/traditional healers completed in-depth interviews. Data were translated from Hindi or Marathi to English and analyzed in Atlas.ti using Framework Analysis.

Findings. Knowledge and awareness of cognitive impairment and available resources were very low. Physicians attributed the condition to disease-induced pathology while lay persons blamed brain malfunction due to normal aging. Main attitudes were that this condition is not a disease, is not serious and/or is not treatable, and that it evokes stigma toward and among impaired persons, their families and providers. Low knowledge and poor attitudes impeded help-seeking.

Conclusions. Cognitive disorders of aging will take a heavy toll on private lives and public resources in developing countries. Early detection, accurate diagnosis, systematic monitoring and quality care are needed to compress the period of morbidity and promote quality of life. Key stakeholders provide essential insights into how scientific and indigenous knowledge and sociocultural attitudes affect use and provision of resources.

Chapter 1: Introduction

Over the course of the 20th century, a confluence of public health initiatives and medical and technological advances set into motion an unprecedented “demographic transition.” Shaped by reductions in fertility and mortality, this trend has led to global population aging—initially in more developed countries, and now and for coming decades, in less developed countries. The achievement of increased longevity is an indisputable triumph, but it does engender a host of novel, challenging circumstances that will likely be magnified in resource-constrained settings.

Non-communicable diseases, which rise precipitously with advancing age, are among the greatest challenges. Other than primary prevention, the main objectives for managing these long-term, incurable conditions are to shorten the period of morbidity by slowing decline and to ensure an acceptable quality of life. Governments are politically and morally obliged to pursue these goals; but in low-resource settings these diseases seriously strain the capacity of over-extended, ill-prepared health professionals and health care systems that must compete with other, compelling social and economic development demands. Long-term institutional care is non-existent; the locus of care is home and the source of care is family. A chronic care model that focuses on educating and supporting patients and their families in managing daily symptoms is thus needed, but scarce resources must be directed to acute, potentially curable health conditions.

Late-life neurological diseases are among the most challenging of all non-communicable diseases, as they tend to play out over many years, even decades, and cause extraordinary physical, mental, social and financial strain for patients, families and societies. Absent primary prevention such as a vaccination or outright cure, these diseases must be managed through secondary prevention strategies designed to reduce the period of morbidity. For individuals who are symptomatic, tertiary measures may help reduce the negative impact of disease, restore some

function and prevent complications. Specific strategies to prevent disease, delay progression and improve symptom management vary depending on etiology and course. This study explores the experience of cognitive impairment of functionally intact older adults in India. The Montreal Cognitive Assessment (MoCA), a standardized screening tool for Mild Cognitive Impairment (MCI), was used to ensure that participants had clinically significant levels of impairment.

MCI is a condition in which the level of cognitive impairment exceeds age norms for cognitive functioning but does not impair functioning. The rationale for screening for MCI in this study is threefold. First, amnesic MCI (aMCI), a subtype of MCI that is defined by memory loss, is an established risk factor for Alzheimer's Disease (AD) (Alladi et al., 2014). The annual conversion rate is 10% - 20%, compared to 1% - 2% for same-aged cognitively normal people (Perquin et al., 2012; Winblad et al., 2004). Empirical models suggest a 3–5 year period of decline (Handels et al., 2013).

MCI does not always presage AD, but the urgency of this issue is greatly magnified by the sizeable and rapidly aging population of India (Shaji et al., 2010). Rates of dementia rise precipitously with advancing age, affecting one in four persons aged ≥ 80 -85 years. The share of Indians in this age sector is projected to more than double by 2050, from 0.7% to 2.3%, and to number 37,173,000 (U.N. Population Projections, 2012) – or more than 9 million *oldest-old* adults. Concerning the potential role of aMCI in this scenario, with a current overall population prevalence of 4.3% (55 million) and a mid-range conversion rate of 15%, more than 8.3 million persons (all ages) who currently have aMCI will go on to develop dementia.

Second, there is strong evidence that awareness and knowledge of cognitive impairment are very low. The colloquial term for this experience is 'memory loss,' and the dominant belief is that it is a function of normal aging. Detection, diagnosis and evidence-based interventions have

advanced greatly in recent years, but uptake requires an understanding of how people who stand to benefit construe their experience vis-à-vis sociocultural norms and local health and social service systems (Buschert, Bokde & Hampel, 2010). This type of data is best obtained through personal accounts, and persons who are mildly cognitively impaired are able to report and, to varying degrees, reflect on their experiences.

Finally, the Government of India's policies and services accord older adults in general, and the diseases that most affect them and, by extension their families, little more than passing mention. Mild cognitive disorders are heterogeneous in etiology, clinical presentation, prognosis and prevalence, but all of these conditions can profoundly impact quality of life for patients and their families and communities (Anstey et al. 2013; Bárrios et al., 2013; Maki et al., 2014; Teng, Tassniyom & Lu, 2012).

In sum, amnesic MCI is an established risk factor for AD, which is expected to reach epidemic proportions in India in the next few decades. Early detection, accurate diagnosis and effective interventions are essential for optimal outcomes, including prevention, compressing morbidity, and improving quality of life. Personal accounts can illuminate the illness experience and inform the development, design and delivery of best policies and practices.

This study aimed to explore the knowledge, attitudes and practices of a purposive sample of older adults who screened positive for MCI, their nominated primary caregivers, and a diverse group of doctors and traditional healers in Mumbai. Since any potential benefits of therapeutic and supportive services are contingent on use, data focused on seeking and giving help.

In Chapter 2, I review relevant literature on cognitive impairment. I set the context with a brief overview of the demographic and health trends that are producing a global epidemic of non-communicable diseases. I then narrow the topic to neurological conditions that feature

dementia world-wide, in low- and middle-income countries (LMIC), and in India. Here I focus on AD, the most common type of dementia, while acknowledging that it is neither invariably nor incontrovertibly linked with MCI. Next, I discuss MCI, including its definition, epidemiology, diagnosis, course and risk factors. I conclude with a discussion of policy and service gaps that worsen encumbrances on patients, families, health systems and societies.

Chapter 3 lays out the theoretical and conceptual foundations of the study. I begin with the general biopsychosocial model that underpins two major theoretical approaches to help-seeking, *viz.*, Common Sense Model of Illness and Explanatory Models of Illness. I integrate key elements of these approaches with the Knowledge, Attitudes and Practices (KAP) framework, which is widely used to study health outcomes in less developed countries.

In Chapter 4, I explain the methodology, including the study site and sampling, data collection and data analysis. I use an extended excerpt of text from a focus group discussion with middle-income men to illustrate the rationale and procedures used in data analysis. Chapter 5 presents findings on participants' knowledge and attitudes concerning 'memory loss' and their influence on health behaviors, particularly help-seeking. In Chapter 6, I discuss limitations of the study and summarize findings on study participants' experiences of cognitive impairment and integrate these narratives with extant research. Finally, I suggest potential areas for policy, practice and future research.

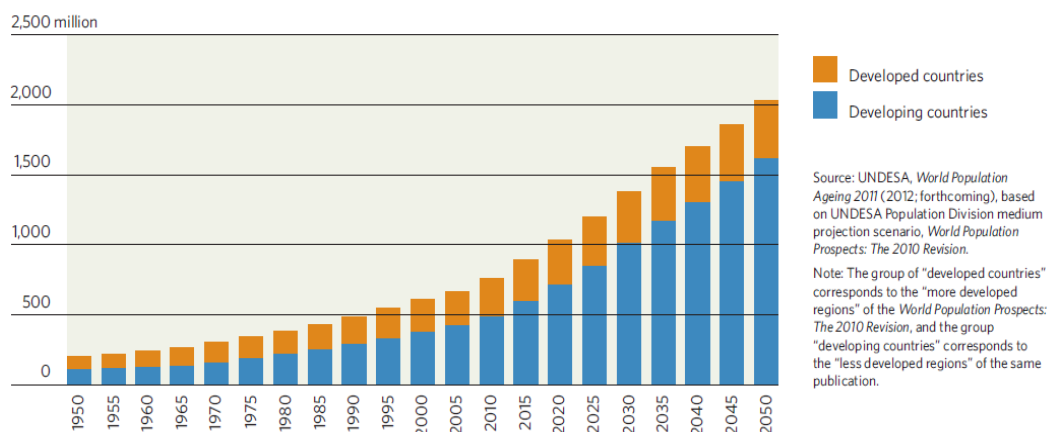
Chapter 2: Literature Review

Demographic and Epidemiological Transitions

Twentieth century declines in fertility and mortality have led to unprecedented growth in the absolute numbers of persons aged ≥ 60 years and in their share of the global population. In 2010, this age group numbered 765 million, or 11% of the population. Persons who reach age 60 now can expect to live 18.5 to 21.6 more years; by 2050, more than 2 billion, or one in five people, will be at least 60 years old, and will for the first time in history outnumber children aged ≤ 15 years (United Nations Population Fund (UNFPA, 2012)). The older population is also aging. Persons aged ≥ 85 years comprise 8% of the global population aged ≥ 65 years -- 12% in more developed and 6% in less developed countries. From 2010 to 2050, this age sector is expected to increase by 351%, compared to 188% for persons aged ≥ 65 and 22% for those < 65 .

Rates of population aging vary depending on the status of a society's transition from high fertility and mortality to low fertility and mortality. In the future, the most rapid and extensive population aging will occur in less developed countries, where this dynamic is more recent. The number of older adults in these countries is projected to increase by more than 250% between 2010 and 2050, as against 71% in developed countries. Another way to think about this trend is that of the 15 countries that now have more than 10 million people aged ≥ 60 years, 7 are classified as developing. By 2050, 33 countries (22 of which are now classified as 'developing') will have at least this many people in this age sector, and 5 countries will have more than 50 million older adults (UNFPA, 2012). (Figure 2.1)

Figure 2.1. Population Aging in Developed and Developing Countries (1950 – 2050)



This demographic transition is rightly heralded as a triumph of scientific and social progress. It does however raise weighty questions about the capacity, most notably in resource-constrained settings, to meet even basic needs of rapidly aging populations. Chief among these concerns is the “epidemiological transition” (Omran, 1971), or a shift from acute and infectious diseases of childhood to chronic, degenerative non-communicable diseases that tend to affect adults, especially as they age. Major conditions are cardiovascular diseases (including strokes), diabetes, cancer, chronic obstructive pulmonary diseases, mental health problems and injuries.

The Global Burden of Disease Study 2010 (GBD 2010)¹ estimates lifetime prevalence of mental health problems (mental, neurological and substance use (MNS) disorders) to be 12.2% - 48.6%, and 12-month prevalence to be 8.4% - 29.1%. These conditions account for 14% of the global burden of disease, more than cancer and cardiovascular disease (Patel, Minas, Cohen & Prince, 2013). With respect to neurological diseases, Prince et al. (2013) estimate that 35.6

¹ The *Global Burden of Disease (GBD) 2010* studied 291 types of diseases and injuries and 67 risk factors in 187 countries. It used a new metric, disability-adjusted life year (DALY) to quantify burden of disease. DALY combines information on impact of premature death, and of disability and other non-fatal health outcomes. The project also introduced years of life lost (YLLs), indicating loss from premature mortality based on early death as judged against average life expectancy in the population of a developed country. Burden of disease thus measures the gap between current health status and an ideal situation in which everyone lives into old age, free of disease and disability. <http://www.who.int/trade/glossary/story036/en/>

million people are living with dementia and that their numbers will roughly double every 20 years--to 65.7 million in 2030 and 115.4 million in 2050. Age-standardized prevalence for persons aged ≥ 60 years in the 21 GBD-2010 regions that were examined varied in a narrow band, with 5%-7% in most regions, 8.5 % in Latin America and 2% - 4% in the four sub-Saharan African regions. Also in 2010, the worldwide social and medical costs of dementia were estimated at US\$600 billion (Wimo et al., 2013), and 58% of persons with the condition were living in LMIC, a share that is expected to rise to 63% in 2030 and 71% in 2050 (Prince et al., 2013).

Likewise, Ferri and colleagues (2005) projected that between 2001 and 2040, dementia in developed regions will start from a large base and see a moderate increase of 100%; Latin America and Africa will start from a low base and see a rapid increase (235%–393%); and India, China and other south Asia and western-Pacific nations will start at a high base and see rapid growth (314%–336%). There is thus an urgent need to understand how milder forms of cognitive disorder, including MCI as an established risk factor for AD, are perceived and acted on by people in India.

MCI and Dementia: Characteristics and Course

Dementia is a broad clinical term for a cluster of symptoms common to many neuro-cognitive disorders. More than 60 diseases and conditions can cause a dementia syndrome. In some cases, dementia progresses as pathology pervades the brain; in others it remains stable. There is a steep age gradient; only 2% of cases begin before age 65; prevalence then doubles every 5 years until by age 85, 1 in 4 persons is afflicted. The DSM-IV-TR (American Psychiatric Association (APA), 2000) grouped this constellation of conditions under “Delirium, Dementia,

Amnesic and Other Geriatric Cognitive Disorders.” DSM-5 (APA, 2013) replaces this category with “Neurocognitive Disorders.” Classified according to etiology, these disorders are AD, Lewy-body disease, frontotemporal dementia, vascular neuro-cognitive impairment, traumatic brain injury, HIV, Huntington’s disease, and ‘other’ causes of major neuro-cognitive disorders.

AD accounts for 60% - 80% of all dementia; about half of these cases solely involve AD pathology whereas others exhibit pathologies of other dementias (mixed dementia) (Alzheimer’s Association, 2014). To intervene in any disease requires knowledge of its etiology and course. In 2009, the U.S. National Institute on Aging (NIA) and Alzheimer's Association (AA) (2011) appointed an advisory group to incorporate the best current scientific and clinical knowledge into a long overdue update of AD diagnostic and research criteria for DSM-5 (APA, 2013; Jack et al., 2011). Seeking greater specification in evaluating, differentiating, and diagnosing various forms of dementia *and* prodromal conditions, the group sought to incorporate evidence of bio-markers of underlying disease states in stage-related diagnostic criteria (see Dickerson, Wolk & A.S.D.N. Initiative, 2013; Forlenza, Diniz, Teixeira, Stella & Gattaz, 2013).

This review process resulted in a proposal for a three phase model of AD that comprises: 1) dementia; 2) symptomatic, pre-dementia; and 3) asymptomatic, preclinical dementia (Figure 2.2). Criteria for Stage 2 and Stage 3 are intended to guide diagnosis in clinical settings whereas recommendations for preclinical AD are solely for research purposes (Budson & Solomon, 2012; Croisile et al., 2012; Ganguli, 2013).

Figure 2.2 Revised Stages of Alzheimer’s Disease and Diagnostic Criteria

Stage	Comments	Citation
Dementia due to Alzheimer's disease.	Impairments in memory, thinking and behavior reduce the ability to function independently in daily life. This guideline updates and clarifies clinical criteria to diagnose dementia from all causes and specifically from AD. These criteria are sufficiently broad and flexible to be used by community practitioners without access to neuropsychological testing, specialized brain imaging, or CSF testing and by specialists engaged in research or clinical studies with access to such tools. In the future, biomarker evidence may improve diagnostic certainty, but much more research is needed to identify most accurate biomarkers and confirm their usefulness.	McKhann , G. M. et al. (2011)
Mild cognitive impairment (MCI) due to Alzheimer's disease	Mild changes in memory and thinking are noticeable and can be measured on mental status tests but aren't severe enough to disrupt one's day-to-day life. This guideline details 4 levels of certainty for ruling out other causes of MCI and arriving at a diagnosis of MCI due to Alzheimer's. Only the first level of certainty, which relies on core clinical criteria similar to those used today, is recommended for widespread use in general clinical practice. More research is needed before the other three levels of uncertainty, which incorporate biomarkers, may be useful outside research settings.	Albert et al., 2011
Preclinical Alzheimer's disease	This is a newly defined stage of the disease reflecting current evidence that measureable biomarker changes in the brain may occur years before symptoms affecting memory, thinking or behavior can be detected by affected individuals or their physicians. While the guidelines identify these preclinical changes as an Alzheimer's stage, they do not establish diagnostic criteria that doctors can use now. Rather, they propose additional research to establish which biomarkers may best confirm that Alzheimer's-related changes are underway and how best to measure them.	Sperling et al. 2011

Source: Alzheimer’s Association and National Institute on Aging, 2011

The DSM-5 introduced the important distinction between ‘Major Cognitive Disorders’ and ‘Mild Neuro-cognitive Disorders (mNCD).’ The latter, which pertain more to this study, are defined by noticeable decrements in cognitive functioning that exceed normal changes associated with aging, and represent a decline from a previously attained level of cognitive functioning but do not meet criteria for dementia. Blazer (2013) cites the following advantages of adding mNCD in the DSM-5: (1) reflects improvement in early diagnostic techniques and recognizes the neuropathology of these disorders, which emerge well before the onset of clinical symptoms of

dementia; (2) permits identification of this group for research on slowing progression; (3) meets patients' needs and search for help in dealing with the onset of problems and planning for the future; and (4) improves outcomes of treatment as they become available since intervention is most effective early in the disease course, regardless of etiology. Most current knowledge about mNCD is based on research on MCI, and MCI and NIA/AA diagnostic guidelines for mNCD and MCI due to AD are virtually identical (Albert et al., 2011; see also Geda, 2012; Sachs-Ericsson & Blazer, 2014).

Mild Cognitive Impairment (MCI)

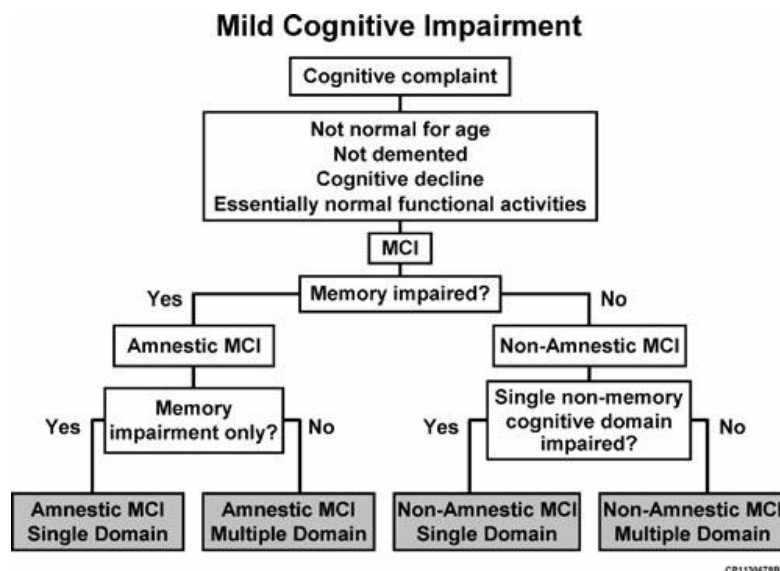
Definition and Subtypes

Working with the Mayo Clinic Alzheimer's Disease Center / Alzheimer's Disease Patient Registry in Rochester, Minnesota (U.S.), Petersen and his colleagues (1999) consecutively evaluated 76 community-dwelling older adults who exhibited noticeable cognitive impairment that did not appear to affect their overall functioning. They referred to the condition as Mild Cognitive Impairment. Comparing these individuals with 234 healthy controls and 106 patients with mild AD, the investigators concluded that individuals who meet criteria for MCI comprise a separate clinical entity that can be targeted for interventions.

The DSM-5 workgroup on neurocognitive disorders noted that mNCD encompasses a range of disorders that include mild acquired impairments in younger people and impairments that can be transient, static or even reversible (Ganguli et al., 2011). MCI is defined more specifically as “a change in cognition reported by the patient, client, or clinician, objective evidence of impairment in one or more domains, preservation in functional abilities, and not

demented” (Sachs-Ericsson & Blazer, 2014, p. 2). Winblad et al. (2004) describe MCI as a heterogeneous category with subtypes that are based on the presence or absence of memory domain impairment and the number of cognitive domains involved. This schema entails first distinguishing between amnesic MCI (aMCI) and non-amnesic MCI (naMCI), and second, determining whether impairment is in one or more than one domain. Four subtypes of MCI emerge from this process: (i) MCI single domain, memory type; (ii) MCI-single domain, non-memory type; (iii) multi-domain, including memory domain; and (iv) multi-domain, no memory involvement. (Figure 2.3)

Figure 2.3 Decision process for diagnosing subtypes of MCI



Adapted from Agronin & Maletta, 2006, p. 21

Prevalence, Conversion Rates, and Risks Factors

Using Petersen’s (2011) revised criteria, the prevalence of aMCI in community-dwelling older adults ranges from 2.1% (Palmer, Backman, Winblad & Fratiglioni, 2008) to 11.5%

(Petersen et al., 2010), with a typical range of 3%-5%. These estimates, and most others, are based on populations of North America and Europe. Using data from a 10/66 Dementia Research Group survey, Sosa et al. (2012) estimated aMCI prevalence among 15,376 persons aged 65 and over without dementia in Cuba, Dominican Republic, Peru, Mexico, Puerto Rico, Venezuela, China and India. The overall crude prevalence was 4.3% (95% CI, 3.3 - 5.2) and standardized for gender and education across countries, was 4.6 (95% CI, 3.7 – 5.4). In both scenarios, the highest prevalence rates were in India.

As noted, aMCI is widely regarded as a transitional stage, or at-risk condition between normal aging and AD-type dementia (Grundman, Petersen, Ferris, Thomas, Aisen, Bennett et al., 2004), although Alladi, Arnold, Mitchell et al. (2006) argue that the relative rarity of a pure aMCI subtype makes it likely that MCI study samples include a mix of amnesic single and amnesic multi-domain subtypes. Persons with aMCI develop dementia at a rate of 10% – 15% per year compared to 1% - 2% in the general population (Petersen et al., 2001).² The most recent UN *World Population Prospects, 2012*, shows 61.1 million persons aged 65 and over in India in 2010. Extrapolating from a crude prevalence of 4.3%, more than 2.6 million Indians meet criteria for aMCI, with 10%-15% converting to dementia each year.

MCI incidence and conversion rates can vary considerably by definition, setting and risk profile. Sachs-Ericsson and Blazer cite efforts to identify neurological tests to detect likelihood of conversion (Egli et al., 2014) and bio-signatures that include neuroimaging, demographic, genetic, and cognitive measures (Eskildsen et al., 2013; Torosyan, Dahlbom, Czernin, Phelps, & Silverman, 2013). Conversion rates are higher among persons with more severe symptoms and those who seek help (Crocco & Loewenstein, 2005), most notably in specialty settings where

² These rates use Mayo Clinic diagnostic criteria and may be conservative. Using neuropsychological testing, Busse, Bischof, Riedel-Heller & Angermeyer (2003) found conversion rates over 2.6 years ranged from 23% to 47%.

rates may reach 39.2%, compared to 21.9% in the general population (Mitchell & Shiri-Feshki, 2009). Multiple domain MCI (Crocco & Loewenstein, 2005) and neuropsychiatric disorders, which often co-occur with MCI (Blazer, 2013) also confer risk of conversion. Finally, risk profiles for MCI and progression to dementia differ by gender, with men faring worse in both instances (Artero, Ancelin, Portet, Dupuy, Berr, et al., 2008; see also Roberts et al., 2012).

The Indian Context

Owing to public health related declines in infant mortality and improved old-age survival, life expectancy at birth in India rose from 37 years in 1950 to 65 years in 2011 (Arokiasamy, Bloom, Lee, Feeney & Ozolins, 2012). The share of India's population aged 50 and older is now 16%. The U.N. Population Division (2012) projects that by 2050, the proportion will rise to 34%, at which point the country will be home to one of six older adults worldwide, second to China.

In India, non-communicable diseases co-exist with ongoing struggles with communicable diseases, including HIV and AIDS and tuberculosis, and maternal and child health problems. At any point in time, an estimated 6.5% of the population suffers from a major mental or behavioral disorder (Gururaj, Girish & Isaac, 2005). The Government of India (2005) expects this figure to rise amidst ever more stressful social and economic conditions, e.g., frequent disruptions in incomes, unemployment, internal and out-migration and eroding social support systems.

Of the 90 million Indians who are aged 60 and over, 30 million live alone. Lacking social security, 37 million still engage in productive work. Most are illiterate or have limited education. Half of older female workers are from the two poorest consumption quintiles, signaling the need for paid outside work to survive. Social and economic risks greatly affect physical and mental health of older adults, and common health problems increase the risk of mental disorder. But

these associations are not widely recognized or well understood, and most mental ill health in this age group goes undetected and untreated.

A series of policies and legislative initiatives has been developed to address the needs of older adults in general and the specific needs of those with health and mental health problems. In 1999, India's Ministry of Social Justice and Empowerment initiated a *National Policy on Older Persons* to cover issues of aging comprehensively. Implementation of the program failed and the government moved on to the 2007 *Maintenance and Welfare of Parents and Senior Citizens Act*, then the 2010 *National Programme for Health Care of the Elderly*. These legislative milestones also suffered from poor implementation. The latter program was designed to provide age-segregated, comprehensive health care to older adults by establishing geriatric departments in eight regional geriatric centers and strengthening health care facilities for older people at various levels in 100 districts. The scheme was supposed to expand under the Twelfth Five Year Plan (2012-2017), but regional geriatric centers are not yet operational due to lack of space in the identified institutions.

Meanwhile, the Ministry of Health is now formulating new policy called the *Integrated Programme for Older Persons*, which aims to help older people live productive and dignified lives. A grant-in-aid scheme awards financial assistance to voluntary organizations such as old-age homes, day-care centers and physiotherapy clinics to operate needed projects. Initial uptake has been tepid, in large part because the scheme's underlying concepts are alien to most Indians.

Research on non-communicable diseases under the Indian Council of Medical Research led to national health initiatives that included the 1996 District Mental Health Program (DMHP). The DMHP is a community-based mental health service program that operates in 123 of the country's 652 districts. Selection of districts is based on recommendations of state governments

that are concerned about persons being underserved by existing mental health services. The DMHP aims to deliver comprehensive mental health services through partnerships of district mental health teams, primary health care teams, community-based and non-governmental organizations, users, family groups and government. Goals are early detection and treatment in the community such that: 1) patients and families no longer need to travel long distances to hospitals or nursing homes in cities; 2) pressure on overburdened mental hospitals is reduced, 3) stigma attached to mental illness is lessened through public education, and 4) patients are discharged from mental hospitals and treated and rehabilitated in the community.

These aims are unrealistic in the current context. India has no separate budget for mental health and only 0.83% of its total health budget goes to mental health. Most people lack access to care due to inadequate facilities and lack of human resources. There are 0.25 mental health beds per 10,000 persons, the vast majority of which are occupied by long-stay patients in mental hospitals and are thus inaccessible to the general population. The mental health work-force amounts to 0.4 psychiatrists, 0.04 psychiatric nurses, 0.02 psychologists and 0.02 social workers per 100,000 population (Kumar, 2011; Pathare, 2005). There is some evidence that older people may have begun to access DMHP services (Therayil, Thomas, Balan, & Shaji, 2013). But their numbers are small, it is unclear whether they have cognitive impairment, and the geographic scope of the DMHP remains severely limited.

Finally, Birjnath (2008) reviewed legislative and policy documents on dementia care in India, including the Mental Health Act of 1987 and the National Mental Health Programme. He concluded that the invisibility of dementia care in public policy translates into the absence of adequate treatment facilities and qualified mental health staff and leaves the enormous task of informal caregiving wholly unsupported. There are initial efforts, at least on paper, to begin to

address these gaps. In 2010, partly in response to past failures of policies and services in aging, health and mental health, the Alzheimer's and Related Disorders Society of India released *The Dementia India Report: Prevalence, Impact, Costs and Services for Dementia*. This document represents a significant effort to synthesize the best available information on dementia in India and to suggest policies and practices to improve the diagnosis and care of persons with related diseases and to support their families. The report estimates that 3.7 million Indians are living with dementia at a societal cost of 14,700 crore (\$3 billion USD, 2010). By 2030, this number is projected to double, and costs to triple. The greatest burden, now and into the future, will be for persons who suffer from these diseases and their caregivers, as they remain a largely hidden and stigmatized population in India, especially in areas of high poverty and low literacy (p. 9).

The WHO has recently designated 'non-communicable diseases and mental health' as priority areas for India. The country's Mental Healthcare Bill 2012 was headlined in a *Lancet* article as "set to revolutionise care in India" (Sachan, 2013). The government's Twelfth Five-Year Plan for the Health Sector further identifies mental health and ageing-related diseases, including dementia (p.17), as priorities. A 10-point agenda endorses a public health perspective and a major focus on implementation research (p. 23).

Policies to ensure the formulation and delivery of high-quality health and mental health services are a necessary but insufficient step to close the treatment gap in India. Timely uptake, sustained engagement, and positive outcomes will require an understanding of how older adults with cognitive deficits, their families, and health care providers recognize, interpret, represent, and explain their symptoms and how these processes influence decisions about help-seeking.

Summary

A confluence of demographic and epidemiological transitions is producing world-wide population aging and an increased prevalence of non-communicable diseases. The latter include a range of neurological diseases that cause cognitive impairment and are highly consequential in aging populations. Cognitive disorders, including MCI, are important in India because current prevalence is high and increasing; awareness and knowledge are low; it is a known risk factor for AD and indeed can be difficult to distinguish from mild dementia; and it significantly diminishes quality of life for patients and families. Moreover, these problems are nested within fragmented and ineffectual policy environment. To address late-life cognitive impairment in India's very large and rapidly aging population, policies and services must target these issues and patients and caregivers must be willing and able to access and engage with them.

Chapter 3: Theories of Help-Seeking for Ill Health

This chapter lays the theoretical groundwork for this study on help-seeking for cognitive impairment. Theories of help-seeking for health and mental health problems are fundamentally rooted in the cognitive revolution of the 1960s, with a focus on social cognition. I thus begin with a brief introduction to the general biopsychosocial (BPS) model of health. I then discuss two main social cognitive models for conceptualizing help-seeking behavior, i.e., Illness Representations and Explanatory Models. Finally, I link the main tenets of these models with the broader conceptual frameworks of Knowledge, Attitudes and Practices (KAP), which is widely used to examine outcomes of health status and health services use in developing countries.

The logic of this approach is as follows. Cognitive impairment is a symptom of neurobiological problems that signal to an afflicted person that something is wrong. This alert sets into motion social cognitive processes to help the individual make sense of and cope with the problem. Coping behaviors, or practices, are rooted in formal and indigenous knowledge and shaped by attitudes, synchronized with positive and negative beliefs and organized in terms of available social and cultural scripts. A decision to seek help thus signals recognition that self-care is insufficient. Individuals typically first tap informal networks, i.e., family, friends and neighbors and if these are inadequate, they may move on to seek formal health and social services, or else to a mix of informal and formal care. A decision to initiate or continue to receive help with managing an illness is also informed by dynamic contextual conditions that can either facilitate or impede the help-seeking process.

The Biopsychosocial Model and Mental Disorders

During the 20th century, sweeping improvements in public health and rapid advances in medical science and technology produced a near doubling of life expectancy in more developed countries. By mid-century, these trends began to incorporate traditional approaches to healing that emphasize the integration of mind, body and spirit. The WHO (1946) constitution, for example, defines health as "... a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity" (p. 18), as does the International Classification of Functioning, Disability and Health, a globally endorsed schema on disease etiology and impact.

The maturing fields of "complementary and alternative" medicine and "integrated" health and medicine have since incorporated precepts and practices from Eastern systems of healing, notably Ayurveda in India and traditional Chinese medicine. Some 2000 years ago, Charaka, an Indian sage, developed Ayurveda, a traditional holistic system of medicine. Ayurveda postulates four etiological factors in mental illness: 1) diet (incompatible, vitiated, and unclean food); 2) disrespect to the gods, elders and teachers; 3) mental shock due to emotions such as excessive fear and joy, and 4) faulty bodily activity. Emphasizing the need for harmony of body, mind and soul, Charaka focused on preventive, curative and promotion aspects of mental health. These tenets of Ayurvedic medicine are consistent with the world-view of most Asian cultures, which is to say that a health system consists of units working together in a symbiotic relationship with the well-being of an individual being who is indivisible from the well-being of community, the land, the supernatural world or the universe.

Picking up on integrated approaches to health and healing, psychiatrist George Engel (1977) proposed a biopsychosocial (BPS) model of illness that featured the independent and interactive roles of biological, psychological (cognitions, emotions, and behaviors) and social

factors in ill health. Engel (1980) was equally if not more influential in his application of the BPS model to clinical care, arguing that any physical or mental condition can be construed solely in biological terms or else as having psychological and social elements that affect one's understanding of the condition and its clinical course. This model helps to account for how biological and psychosocial factors, such as age, co-morbid physical and mental disorders, cultural attitudes, beliefs and behaviors, social supports, and health care systems, can influence the causes, correlates and course of neuro-psychiatric disorders. It also highlights subjective aspects of illness that affect coping practices.

Hollingshead and Redlich (1958) first articulated the need to assess non-medical beliefs about mental disorders using a process of lay appraisal. This term refers to the collateral role of family, co-workers and others in identifying signs of mental disorder and deciding a course of action. Jorm et al. (1997) later introduced the similar concept of mental health literacy, defined as the “knowledge and beliefs about mental disorders which aid their recognition, management or prevention” (p. 182). Again, emphasis is on the role of persons with the disorder *and* members of their social networks in identifying and managing symptoms (Jorm, 2000). A growing body of work on mental health literacy shows that lay beliefs about mental disorders affect patterns of help-seeking, types of treatment sought and used for specific disorders, and stereotyping of persons with the condition (Werner, 2005). Two prominent formulations of lay beliefs in health are “illness representations” and “explanatory models”.

Social Cognition, Illness Representations and Explanatory Models

Most of the theoretical advances in psychosocial aspects of physical and mental disorders are rooted in work on self-regulation of illness by Leventhal and colleagues (Leventhal, 1984; Leventhal, 1997; Leventhal, 2003). Variations with similar underlying features are the Illness

Perceptions Model, Illness Representations Model, Self-Regulatory Model, Parallel Process Model and Common Sense Model of self-regulation. Herein, I refer to the model in its simplest terms as the Common Sense Model (CSM). The main idea of the CSM is that people integrate their lay beliefs about illness in order to help them to make sense of symptoms and to guide coping actions (Nerenz & Leventhal, 1983). These beliefs, or illness representations, reflect cognitive responses to symptoms and illness, and parallel emotional responses (Leventhal, 1984).

The original CSM posited four dimensions of understanding illness: identity, cause, time-line and consequences. Identity refers to how an illness is labeled and its apparent symptoms; cause addresses beliefs about the likely etiology of the condition; time-line concerns perceptions about likely duration (acute/short, chronic, or cyclical/episodic); and consequences means beliefs about the severity and likely impact on physical, social and psychological functioning. Lau and colleagues (1989) added a fifth element, i.e., beliefs about cure and controllability of a condition. These five dimensions of the CSM are dynamic and can exert specific or joint effects on coping efforts and health outcomes. For instance, there may be direct links between identity and consequences or between cause and control.

In the CSM, illness representations begin with symptoms, but change with progression of a disease, emergence of new symptoms and treatment responses. Williams & Healy (2001) found that lay interpretations of first-time presenters to mental health services did not represent a coherent set of beliefs; but included a range of explanations that were held simultaneously or taken up and rapidly dismissed. Transient beliefs make it difficult for clinicians to distil a single set of causal accounts for a given outcome. Standardized instruments for monitoring change can be useful here. The Illness Perception Questionnaire (IPQ) (Weinman, 1996) and the revised and

expanded IPQ-R (Moss-Morris, 2002) contain the 5 dimensions of the CSM, and both versions are well validated using a range of methods across various clinical conditions (Skelton, 1991).

Contemporaneous work in medical anthropology also focused on social cognitive aspects of illness, but emphasized the role of cultural context. Arthur Kleinman (1980), whose work is central to this line of inquiry, refers to patient accounts of illness experiences as “explanatory models” (EMs). In a major paper on culture, illness and care, Kleinman, Eisenberg and Good (1978) distinguished between disease, which they define as “abnormalities in the structure and function of body organs and systems that cause symptoms and signs in a person who is sick,” and illness, or “the human experience of sickness,” meaning changes in social function and states of being that an ill person experiences.

Similarly, EMs that attribute illness to physical causes differ from those that assign it to psychosocial causes (Kleinman, 1979; Kleinman & Gale, 1982; Shweder, Much, Mahapatra & Park, 1997). Kleinman (1995) explains: “In the biomedical definition, nature is physical / knowable independent of perspective--the psychological, social and moral are only superficial layers of epiphenomenal cover that disguise the bedrock of truth of the real stuff.” (p. 30) Psychosocial frames, on the other hand, credit illness to one’s own or others’ thoughts and emotions, typically in response to social factors. Indeed, in a classic ethnography of 139 non-industrial societies, Murdock (1980) found most illness was attributed to psychosocial causes, usually involving social relationships.

Kleinman, Eisenberg and Good (1978) devised 8 questions to elicit EMs of illness. The items are intended to facilitate cross-cultural communication, ensure patients’ understanding of their condition and identify conflicts with biomedical accounts. Their wording and number, which may vary by patient, problem and setting, include: 1) What do you think has caused your

problem? 2) Why do you think it started when it did? 3) What do you think your sickness does to you? How does it work? 4) How severe is your sickness? Will it have a short or long course? 5) What kind of treatment do you think you should receive? 6) What are the most important results you hope to receive from this treatment? 7) What are the chief problems your sickness has caused for you? 8) What do you fear most about your sickness?

The Explanatory Model Interview Catalogue (EMIC) (Weiss, 1997) and the Short Explanatory Model Interview (SEMI) (Lloyd, 1998) were developed, respectively, to elicit and explore explanatory models of illness. Bhui and Bhugra (2002) compare the relative merits and indications of the EMIC, the SEMI and the IPQ (Figure 3.1).

Figure 3.1. Comparison of Explanatory Models and Illness Perception Questionnaires

IPQ (Weinman et al. 1996)	SEMI (Lloyd et al., 1998)	EMIC (Weiss, 1997)
Identity	Naming the condition	Patterns of distress
Causes	What causes it? Is it an illness?	Perceived causes
Consequences	-----	Disease-specific queries
Controllability	Who do you see about it? What can you do about it? What can your doctor do about it?	<i>Seeking help and treatment</i>

The primary goal of early conceptual work on illness representations and explanatory models was to elucidate the dynamics of biological, psychological and social aspects of health and illness. This work gave rise to three decades of theoretical and empirical research, much of it informed by ongoing developments in social cognitive theory. Prominent examples are the Health Belief Model, Theory of Reasoned Action, Theory of Planned Behavior Action and the Transtheoretical Model. These models have subsequently been used to identify personal (e.g., gender, ethnicity, education); psychosocial (e.g., self-efficacy) and personality (e.g., hardiness, optimism, coping, sense of purpose, sense of control) influences on perceptions of health and

threat of disease (Maas et al., 2009). These factors are not universally agreed upon, but their shared constructs often feature in studies of help-seeking. I will integrate these constructs in a discussion the KAP framework after a brief discursive on lay explanations of dementia.

Lay Explanations of Cognitive Impairment

Research on mental health literacy has focused almost exclusively on depression and schizophrenia (Werner, 2005). Very few studies has sought lay accounts of disordered cognition, whether it be dementia, MCI or other types of impairment. In the only study I identified on lay accounts of MCI, Werner et al. (2014) compared help-seeking preferences of physicians and the public for this condition. They found that doctors recommended various types of professional assistance while lay people preferred a specialist, i.e., neurologist. Of the few studies on lay representations of dementia, most use qualitative designs and in more developed countries. Belgrave et al. (2011) used participant observation and focus groups to elicit explanations of AD from 36 African Americans with the disease and their family caregivers. Caregivers reported seeking and using medical expertise, but their explanations for AD were non-medical and characterized as being child-like, a ‘way of being,’ and representing continuity and discontinuity in the life course.

Chung (2000) interviewed 18 family caregivers in Hong Kong about their knowledge of dementia and how they made sense of it. They reported limited knowledge as a result of medical professionals' inadequate explanations of the complexities of the condition, which led them to seek explanations in external events and personal experiences. These and other caregiver efforts to gain control of their situations exemplified adaptive coping strategies. The authors conclude that a strong professional-family caregiver partnership is required to improve quality of care.

In focus groups with 100 family caregivers, health professionals and dementia service providers in Tasmania, Robinson et al. (2008) found that despite endorsing the benefits of having a diagnosis, the term dementia carried strong connotations of stigma and futility. Participants believed that general practitioners have a key role to play in managing the condition, but that they lack diagnostic and treatment skills. Professionals advocated a lengthy diagnostic process, but families wanted a quick diagnosis in order to be able to access dementia-specific services.

Using latent class analysis in a survey of 370 Singaporeans, Tan and colleagues (2012) identified three subgroups of knowledge and attitudes about dementia: good knowledge, good attitude (14.3%); good knowledge, poor attitude (63.8%) and poor knowledge, poor attitude (21.9%). Based on correlates of these profiles, the authors concluded “the public in Singapore may not be ready for screening initiatives and early dementia diagnosis.” (p. 444). They also recommended that public education target low socioeconomic groups, singles, and persons who profess beliefs in the oriental religions of Buddhism, Taoism, or Hinduism.

In another cross-sectional survey, Garvey et al. (2011) adapted the Alzheimer’s Disease Knowledge Test to explore understanding, knowledge and misconceptions of dementia among 174 indigenous adults in Australia. Participants had low levels of understanding of the disease, with indigenous and non-indigenous groups alike holding many misconceptions. Older adults were more likely than their younger counterparts to have at least some knowledge of AD.

Werner and colleagues investigated lay knowledge and interpretations of AD symptoms in the general Israeli population. Over 60% of participants correctly identified warning signs of AD; but, only 47% interpreted repeated and ongoing trouble with remembering the location of glasses or keys as a sign of cognitive deterioration (Werner, 2003). In a more recent telephone survey with a representative sample of 632 lay persons in Israel, Werner, Goldberg, Mandel and

Korczyn (2013) found generally low levels of worry and concern about AD; but women reported greater knowledge, perceived susceptibility, worry and fear than men.

Using the Explanatory Model Interview Catalogue (EMIC), Faure-Delage et al. (2012) explored perceived causes of dementia among 27 older adults suspected of having dementia and 31 of their relatives; 90 cognitively impaired older persons and 92 of their relatives; and 33 hospital workers in Brazzaville, Republic of the Congo. Common EMs of dementia were aging or old age and mental or emotional stress ('think too much', or 'worry' for someone still in shock due to grief, trauma etc.) and general hardships of life. Hospital workers named poverty, social isolation, drinking, and bodily trauma (injury, accident, or surgery) as plausible causes, while older persons with cognitive impairment more often attributed their status to fate or God. Persons with cognitive impairment and their caregivers (but not persons with suspected dementia or their caregivers) also named sorcery as a likely cause.

Beliefs that AD or severe memory problems are an inevitable part of normal aging are common in the lay public (Ayalon, 2004). Indeed, outside of trained medical professionals, the biomedical notion of dementia as a disease is unknown to most people in non-Western countries. Instead, people identify cognitive impairment by its symptoms and their impact on daily life in the context of aging. Responsibility for recognizing and managing exigencies of the condition thus falls to families (Whitehouse, 2005), and lay explanations dominate the limited discourse. Cohen's (1999) ethnography of dementia in Varanasi, India deftly makes this point.

Together, these studies of lay representations of dementia suggest that the general public, persons afflicted with the disease, and their caregivers use a mix of lay and professional concepts to account for their experiences. Some see a role for physicians, ill-equipped as they are. Many think cognitive impairment is due to normal aging, yet they have little concern about their own

susceptibility. Knowledge, attitudes and practices about vary by individual and context, which in turn affect the likelihood and timing of help-seeking and ultimately, the course of the illness.

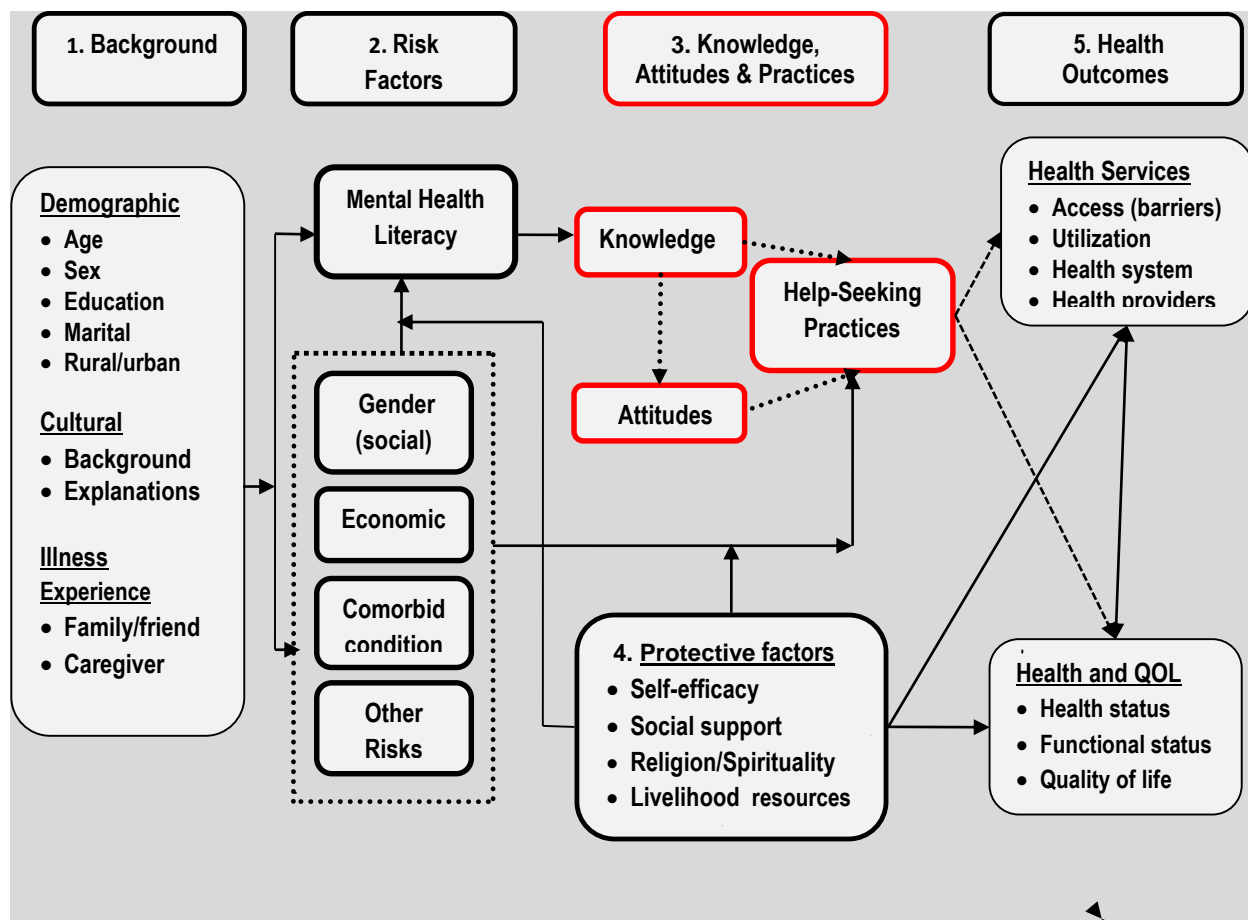
In the rest of this chapter, I will present a KAP schema for framing the current study. I will add to the social cognitive influences on the experience of cognitive impairment by drawing on Obrist and colleagues' (2007) work to extend individual models of help-seeking to include livelihood resources, health policies and systems.

Knowledge, Attitudes and Practices: A Framework for Help Seeking

Research on help-seeking typically uses pathway models, following people who are sick from the point at which they recognize symptoms through their quest for various types of help until they feel sufficiently recovered or at least able to live with their condition. The KAP framework is basically used to assess what a population knows about a condition; what they think about people who have the condition and health system responses to it; and, what they do in terms of seeking care or other actions related to the condition. Grounded in social cognitive theory, the approach postulates that "... individuals first learn about a practice, then develop a positive attitude toward it and, after passing through these stages, engage in the behavior" (Valente, 1998, p. 368). Knowledge can also independently affect help-seeking practices, which are the linchpin in virtually all pathways to early diagnosis and treatment.

Figure 3.2 presents a heuristic schema for integrating concepts from the previous and current chapters in suggesting a pathway of help-seeking for cognitive impairment. The diagram depicts the broader context of help-seeking for cognitive impairment and highlights a subsidiary process that involves background factors (Step 1), risk and protective factors (Steps 2 and 4), the KAP framework, with direct and indirect effects of knowledge and attitudes on practices (Step 3) and health-related outcomes (Step 5).

Figure 3.2 Conceptual Model of Help-seeking for Cognitive Impairment



KAP surveys are especially useful for revealing neglected epistemic values of indigenous knowledge and identifying conditions and patterns that facilitate understanding and action or, alternatively, that create problems and barriers when developing and implementing interventions. Figure 3.3 compares elements of the Common Sense Model and Explanatory Model of illness and shows how I have integrated them in the interview guides to elicit participants’ knowledge, attitudes and behaviors about cognitive impairment and their likelihood and processes of seeking help for the condition.

Figure 3.3 Integration of Common Sense and Explanatory Models with KAP Framework

Knowledge, Attitudes and Practices	
Common Sense Model of Illness (Illness Representations)	Explanatory Models of Illness
1. Identity: How is illness labeled? What are its apparent symptoms?	Is it a disease, an illness? Is it a process of pathological processes, psychosocial factors, both, or neither?
2. Cause: What are beliefs about likely cause(s) of the condition?	1. What do you think has caused your problem? 2. Why do you think it started when it did?
3. Time-line: What is likely duration (acute/short, chronic, or cyclic/ episodic)	1. Will your sickness have a short or long course? 4. How severe is your sickness?
4. Consequences: What are beliefs about severity and likely impact on physical, social and psychological functioning?	7. What are the chief problems your sickness has caused for you? 8. What do you fear most about your sickness?
5. Cure and controllability: To what extent is the condition amenable to cure or control?	5. What kind of treatment do you think you should receive? 6. What are the most important results you hope to receive from this treatment? 8. What do you fear most about your sickness?
	3. What do you think your sickness does to you? How does it work?

A major criticism of KAP surveys is that they treat personal behavior as an outcome of a conscious, rational choice and in doing so fail to capture the complexity of behaviors that are enabled, supported or discouraged by social and cultural contexts of decision-making (Nurse, 2007). Obrist and colleagues (2007) propose a 3-point ‘livelihood’ approach to addressing this problem. The first two ideas reflect the discussion up to this point: 1) individual-level behaviors on the pathway from symptom recognition to help-seeking and attributes of health services (e.g., rates and availability, affordability, accessibility, acceptability, adequacy), and 2) policies to reduce supply barriers, improve service delivery, and offer information, education, and communication campaigns.

The third point adds a livelihood component to access by incorporating the material and social assets and activities people need in order to gain and sustain a living under economic hardship (see also De Haan, 2005). Following Sen (1993), Obrist et al. construe poverty in terms of limited capabilities. To achieve a sustainable livelihood, a group must be able to mobilize the

support it needs to raise income and level of well-being within its own context. Livelihood interventions should target specific needs, and outcomes should be evaluated in terms of the policies and institutional structures designated to meet those needs. Livelihood capabilities weigh heavily in the balance of care accorded to different groups in an economically stratified society such as India, and to different age, gender, caste and disability groups within economic strata.

Summary

This chapter laid the theoretical groundwork for this study on help-seeking for cognitive impairment by older adults and their caregivers. Biopsychosocial theories that emerged in mid-to-late 20th century to account for health and illness perceptions, behaviors and outcomes still resonate, but have been revised in light of advances in studies of social cognition and the effects of economic and environmental hardship on health and illness. I have discussed the Common Sense Model and Explanatory Models of Illness as two of the main biopsychosocial approaches to understanding how people perceive, make sense of, and act on illness and suggested a means of integrating these within a broader KAP framework. I will discuss single and shared constructs from these models further in the context of the study methodology in Chapter 4.

Chapter 4: Methodology

Qualitative designs in social and behavioral sciences are appropriate for three main types of research questions: the *meaning* of events and activities to people who are involved in them; the influence of *context* on these events and activities; and the detailed *process* through which events and activities and their outcomes unfold. The current study poses each of these questions. How do members of three key stakeholder groups, i.e., older persons who screen positive for MCI, their primary caregiver, and physicians/healers, make sense of and act on this experience? How do social, cultural, political and economic contexts in India, Mumbai, local communities influence knowledge, attitudes and behaviors about impairment? About help-seeking? How does the symptom recognition-to-help-seeking process progress? These questions and the use of a qualitative approach are especially fitting for India, where all types of cognitive impairment, regardless of etiology, course or outcome, are referred to generically as “memory problems.”

Study Design

Specific qualitative designs vary depending on the purpose of a study, but all are flexible and characterized by an iterative, reflexive process that defines and drives a project. Interview designs are best suited for soliciting in-depth information about participants’ experiences and views on a particular topic, and are often mixed with other types of data to augment findings. This study used an interview design that combined focus group discussions (FGD) and in-depth interviews (IDI), following Hennink (2007) and Reissman (2008) respectively.

The social, semi-public nature of focus groups shapes the production of data and affords insights into sociocultural dynamics and context. FGDs are thus the preferred means for eliciting information that conveys a gestalt of local perspectives. The group format is also useful for

gaining insight into cultural norms and collective beliefs about sensitive topics (Kim, 2002; Shiu-Thornton, 2005). In-depth interviews, on the other hand, afford opportunities for more intimate rapport and greater depth of information. Because this study aimed to understand individual and collective experiences of cognitive impairment, a combination of FGDs and IDIs was used.

Study Site and Sampling

For recruitment and data collection, I partnered with Silver Innings, a prominent NGO dedicated to preserving the dignity and well-being of older adults with dementia and related conditions in Mumbai, and the Alzheimer's & Related Disorders Society of India (ARDSI). These organizations regularly host 'memory camps' throughout Mumbai to provide education, information and free screening for cognitive impairment. The study team held four camps, two in middle-to-high income areas and two in low-income slum areas.

I used maximum variation sampling (MVS) to select participants. MVS is a rigorous way to obtain a sample with systematic variation on characteristics that are theoretically relevant to the topic and likely to affect outcomes of interest (Hirsch, 2003). The strategy is recommended for samples of at least 30 (List, 2004; List, 2011). I sampled based on three dimensions that were expected to influence KAPs about cognitive impairment and help-seeking (Figure 4.1):

- 1) Stakeholder (3 Groups)
 - a. Persons who screened positive for MCI (PCI)
 - b. Nominated Primary Caregiver
 - c. Health Care Providers
- 2) Socio-economic Status of PCI (2 groups)
 - a. Low income
 - b. Middle to high income
- 3) Provider type (3 groups)
 - a. General Practitioner
 - b. Specialists (neurology and psychiatry)
 - c. Traditional healers

Figure 4.1. Maximum Variation Sampling Strategy

	Focus Groups	In-Depth Interviews
Persons with Impairment		
<ul style="list-style-type: none"> • Low income • Middle/High income 	n = 4-6 (1 group) n = 4-6 (1 group)	n= 2 n= 2
Caregivers		
<ul style="list-style-type: none"> • Low income • Middle/High income 	n = 4-6 (1 group) n = 4-6 (1 group)	n = 2 n = 2
Providers		
<ul style="list-style-type: none"> • Physician: Generalist • Physician: Specialist • Traditional healer 	No focus groups	n = 2 n = 2 n = 2
Total	4 groups	n=14

The final sample comprised 34 people; 20 participated in four focus groups (5 per group) and 14 completed in-depth interviews (4 PCI and their caregivers and 6 providers). All PCI and caregivers were > 60 years of age and 59% of the overall sample was female (14 FGD members, 1 PCI, all 4 caregivers and 1 provider). Gender is an important facet of social life in the highly patriarchic structure of Indian society, however I did not stratify on gender because there was insufficient evidence of differences in how men and women in India experience cognitive impairment or help-seeking. Rather, the study team advised that the more culturally resonant and efficient way to achieve insight into this source of variation was to segregate FGDs by gender.

Screening for MCI: Montreal Cognitive Assessment (MoCA)

The Montreal Cognitive Assessment (MoCA) (Appendix B) is a brief screening tool designed to assist frontline physicians and other health care professionals to detect MCI and early AD (Nasreddine, 2005 www.mocatest.org). There are 30-item and 12-item versions of the instrument. I used the 30-item Version 7.2, which can be administered in about 10 minutes. Of 30 possible points, a score of 26 or above is considered normal. To adjust for lower education, 2 points are added to the total score for persons with 4-9 years of education and 1 point is added

for 10-12 years (Johns, 2010). The range for MCI is 19 - 25.2, and for AD is 11.4 - 21. These ranges overlap slightly and conditions are differentiated by presence of functional impairment.

The MoCA assesses the cognitive domains of attention and concentration, executive functions, memory, language, visuoconstructional skills, conceptual thinking, calculations and orientation. A short-term memory recall task (5 points) involves two learning trials of 5 nouns and delayed recall after 5 minutes. Visuospatial abilities are assessed by a clock-drawing task (3 points) and a 3-dimensional cube copy (1 point). Aspects of executive functions are assessed using an alternation task adapted from the trail-making B task (1 point), a phonemic fluency task (1 point) and a 2-item verbal abstraction task (2 points). Attention, concentration and working memory are evaluated with a sustained attention task (target detection using tapping; 1 point), a serial subtraction task (3 points), and two series of digits forward and backward (2 points each). Language is assessed with a 3-item confrontation naming task of low-familiarity animals (lion, camel, rhinoceros; 3 points), repetition of two syntactically complex sentences (2 points) and the aforementioned fluency task. Lastly, orientation to time and place is evaluated (6 points).

The MoCA is translated in 36 languages and dialects and has been validated in 21. It is used in more than 100 countries and has been tested with people age 49 and older, across levels of education and cultural groups, in primary care and acute care settings, and with a variety of disorders that affect cognition, e.g., AD, HIV, Huntington's chorea, stroke, multiple sclerosis, Parkinson's disease, vascular dementia and substance abuse, and with well older adults.

The MMSE is the most widely used screening tool and it is validated for use in India, but it is ill suited for MCI (Dong, 2012; Smith, 2007). Extensive evaluations of the MoCA find that it compares favorably with a wide range of cognitive screening instruments (Ahmed, 2011). It is gaining credibility due to improved sensitivity in assessment of frontal/executive functioning, is

less likely to be influenced by culture and education. It is also easy to administer in community settings and performs well across diverse ethnic, language and socioeconomic groups.

There is an official Hindi-language version of the MoCA. The 12-item version has been validated with multiple sclerosis patients in India (Kaur, 2013); I did not identify psychometric validation of the 30-item version in Hindi. This version has undergone rigorous translation and has good face and content validity. Figure 4.2 shows cutoff scores, while full normative data on the MoCA can be found at http://www.mocatest.org/normative_data.asp. Absent established cutoff scores for the Hindi version with older adults in India, I used established cutoff thresholds. Nasreddine and colleagues (2005) report 90% sensitivity and 87% specificity for detecting MCI.

Figure 4.2 Montreal Cognitive Assessment Cutoff Scores

MOCA SCORES			
	Normal Controls (NC)	Mild Cognitive Impairment (MCI)	Alzheimer's Disease (AD)
Number of subjects	90	94	93
MoCA average score	27.4	22.1	16.2
MoCA standard deviation	2.2	3.1	4.8
MoCA score range	25.2 – 29.6	19.0 – 25.2	21.0 – 11.4
Suggested cut-off score	≥26	<26	<26ψ
ψ Although the average MoCA score for the AD group is much lower than the MCI group, there is overlap between them. The suggested MoCA cut-off score is thus the same for both. The distinction between AD and MCI is mostly dependent on the presence of associated functional impairment and not on a specific score on the MoCA test.			

It is important to emphasize that the MoCA is a cognitive screening instrument and not a diagnostic tool. Also, as footnoted in Figure 4.2., MCI and AD share a cutoff score of 26, and the conditions are distinguished by the presence of functional impairment. We did not complete a formal functional assessment in screening for this study; however, all persons who were screened were attending memory camps and functioning in the community, and caregivers confirmed that

they had not observed significant decline in their relatives' self-care capacity over the past 6 months (See Schinka, 2010).

Regarding sociodemographic characteristics of participants with cognitive impairment, half (n = 7) were male and the overall age averaged 65.7 (SD 4.1). Fully 57 % of PCI (including 6 women) had fewer than 9 years of formal education. Adjusted for education, MoCA scores ranged from 19-25 (M=22.0, SD=2.1) and were distributed as follows: 19 (n=2); 20 (n=1); 21 (n=4); 22 (n=1), 23 (n=2); 24 (n=2); 25 (n=2). These data suggest that PCI experienced at least mild cognitive impairment, with half the sample falling into the 19-21 range of overlap for MCI and early AD. But levels of formal education are very low among older adults (more particularly women) in India, and education- as well as culture-fair norms and cutoff thresholds are needed.

Inclusion criteria for PCI screen

- Aged \geq 60 years
- In-depth interview: Has a primary caregiver who agrees to participate in the study
- Focus group: Members need not be related

Inclusion criteria for Caregivers

- Interview: Nominated by PCI as primary caregiver, caregiver for at least 6 months
- Focus Group: Caregiver for PCI for at least 6 months

Inclusion criterion for Health Care Providers

- Regular contact with older persons with cognitive impairment in their practice

Recruitment

Memory camp attendees consisted of a mix of local people who either knew about the event or happened by and several members of the small network of dementia providers and advocates in Mumbai. Attendance usually ranges from a half dozen to 20-30. After refreshments,

the executive director of Silver Innings welcomed participants, and a staff member provided a brief education program on recognizing and coping with symptoms of cognitive impairment. After a question-and-answer period, participants were informed of the purpose and requirements of the study and, pending eligibility, were invited to join. Upon completing participation, PCI and their caregivers were paid \$10.00 each, an amount deemed appropriate by the India research team. The Silver Innings and ARDSI staff assisted with recruiting providers. Neither of these groups were compensated, nor were providers.

Training and Materials

Focus group discussions and in-depth interviews were conducted by four bilingual Indian research assistants who have master's degrees in social work and extensive experience with older adults in Mumbai. A physician of Indian origin who is a practicing geriatrician in the U.S. conducted the screening interviews. Using didactic and experiential training methods, a faculty member at the Tata Institute of Social Sciences and I led a mandatory two-day intensive training workshop for interviewers on the purpose and aims of the study, methods of data collection, translation and recording procedures, reporting protocols and cultural and ethical issues. The study was approved by Columbia University and Tata Institute's IRBs.

Interview guides were designed to synchronize with study aims, research questions and theoretical constructs. Some questions overlapped for the three informant groups and others were unique. PCI and caregivers were asked about their experiences with cognitive impairment and their knowledge, attitudes and behaviors, including questions about help-seeking. Interviewers used probes to elicit information about illness representations and explanatory frameworks, e.g., perceptions about etiology, course and expected outcomes. All health care providers, including

different types of traditional healers, identified as ‘doctors.’ They were asked about their training and experience with detection, diagnosis, treatment and management of cognitive impairment. Discussion guides appear in Appendix A.

Interviews, Translation and Transcription

Focus groups were conducted on-site at Silver Innings or at another readily accessible social service or health care facility and lasted on average 1.5 hours. Separate interviews with PCI and caregivers were conducted privately in their homes and also averaged about 1.5 hours. Interviews with PCI were a bit briefer than CG interviews. Experienced bi-lingual interviewers conducted the interviews in Hindi or Marathi, the local language, and trained transcriptionists produced English transcriptions of digitally recorded audiotapes. The standard Hindi version of the MoCA was used. Other data collection instruments were translated from English to Hindi, then back, using standard protocols (Brislin, 1970). This process is typically used in translating standardized instruments in quantitative cross-cultural research. I used it in training sessions to ensure accurate understanding of the study purpose, informed consent and interview protocols.

Data Collection Methods and Procedures

The first three persons and their caregivers who expressed interest in the study and met eligibility criteria were consented to in-depth interviews. Subsequent interested and qualified individuals were consented to focus groups. Small focus groups afford opportunities to explore complex social phenomena that can be clarified more easily in a group discussion than in an individual interview, while the latter allow for deeper rapport and more complex insights. I thus treated these as complementary approaches to the research questions and triangulated the two

data sources and findings from all three participant groups. Triangulation refers to the idea that confidence is improved if data from multiple perspectives, sources or approaches lead to same or similar results. This does not mean that all perspectives should or must converge. Indeed, sources and types of divergence can be most informative.

Focus Group Discussions

Several steps were taken to ensure high-quality data in the focus groups. First, we selected a homogenous sample. Familiarity can impede openness but it can also promote trust, authenticity, self-disclosure, and comfort. Rabiee (2004) describes advantages of existing trust in groups that explore sensitive and personal issues, especially if there is little information on the topic. Second, we thoroughly assessed participants' comprehension of the study purpose and protocols and their ability and willingness to participate, anticipating that the topic might be challenging in a group. Third, we carefully selected and trained group moderators. Finally, to minimize bias in analysis, I used ATLAS-ti to manage the data and followed Krueger and Casey's (2009) guidelines to ensure that analyses were systematic, sequential, verifiable, and continuous.

In-Depth Interviews

In concert with data from the focus groups, in-depth interviews were designed to elicit narrative accounts of participants' experiences with cognitive impairment. Gall, Gall and Borg (2003) describe three standard forms of individual interviewing in qualitative research. *Informal conversational interviews* arise from spontaneously generated questions in the context of natural interaction, usually as part of participant observation fieldwork. At the other end of the spectrum

are standardized open-ended interviews, which use highly structured questions that are asked of all interviewees, but responses are open-ended. I used a middle-ground approach, the *general interview guide*, in this study. Although it is more structured than the informal conversational interview, it retains considerable flexibility for soliciting information from interviewees.

Data Analysis

I used Atlas.ti (ver.7.0), a robust qualitative software program, for data management. Atlas.ti permits the creation of a 'tree' of codes which aid in identifying unique and overlapping thematic units, or frequently occurring sets of explanatory statements (Lewins & Silver, 2007). After coding the data in Atlas.ti, I used Krueger (1994) and Kruger and Casey's (2000) "framework analysis" approach to ensure in-depth analysis along central lines of inquiry in the conceptual model presented in the previous chapter.

Framework analysis involves a clear series of steps, which is very helpful in managing large amounts of complex qualitative data. It is equally applicable for focus group and individual interview data. The analytic process is non-linear and begins with skillful facilitation of the interview in order to generate rich data, which is complemented by observational notes. There are five key distinct but highly interconnected stages:

1. Familiarize oneself with the data by listening to the audiotapes, reading complete transcripts through several times and reading observational notes taken during the interview and summary notes taken afterward. The objective at this first stage is to become sensitized to the interview as a whole before decomposing and deconstructing it. Themes begin to emerge here, albeit in broad strokes.
2. Identify a working thematic framework by jotting memos in the margins of the transcribed text. Use short phrases, ideas or concepts (codes) from the text to develop

categories, which are likely to be later revised and refined. Descriptive statements are formulated and data are subjected to systematic interrogation.

3. Indexing is about sifting the data, highlighting and sorting out codes and text and making comparisons within and between cases.
4. Charting involves lifting codes and quotes from their original contexts and re-arranging them under the emerging themes.

Indexing and charting can be thought of as data management. A key aspect of this task is data reduction, achieved by comparing and contrasting data and cutting and pasting similar codes together. I used the constant comparison method to explore negative incidents and divergent themes (Boeije, 2002; Schatzman & Strauss, 1973). I first explored variation along individual codes across the sample to identify aggregate tendencies toward ‘outcomes’ of interest. This “vertical” analysis de-contextualizes data segments by removing them from the full transcript, permitting examination of code-specific responses across the sample. I then examined individual cases by analyzing how instances of particular factors relate to the larger contexts of meaning, experience and behavior of the individual. This “horizontal” analysis allows one to examine how contextual factors vary along each dimension of diversity.

5. The final stage of analysis involves mapping and interpretation. Here, the researcher must make sense of individual chunks of data and conceptualize their relationships holistically.

Krueger (1994) cites seven well-established criteria for interpreting coded data: words and meaning; context; internal consistency; frequency/ extensiveness of comments; specificity

of comments; intensity of comments; and big ideas. The following excerpt from a FGD with middle-income men serves as an example. (Note: *Participants refer to symptoms of cognitive impairment as “memory loss”*)

-
- R2: Whoever is active, his memory is good.
Int: By active, you mean young age?
R2: One who is active every day. One who wants to work, who knows what he is doing now and what he wants to do tomorrow. In my opinion such a person’s memory remains charged.
R1: I differ. And I have been active throughout my life. I was attending school for four hours daily till the last month. And in the evening I used to visit park, and I am writing stories for a magazine too. I have been so active, still the memory has faded. I don’t know his experience but as far as my experience is concerned, being active is not related with memory.
Int: After a certain age, does everybody face this problem... or only a few people?
R2: How can I say? Old people with whom I have come across...60 – 70% they have said that they have lost their memory. To what level is a different thing, but they do suffer from memory loss.
R3: As far as age is concerned, below 60 it is smoothly running. After 60, memory is deteriorating.
R2: In my opinion, age might be a problem but a few people below 60 also forget at times. Even worse than us... sometimes I tell something to my son, and he forgets. Because of the age, the whole machine of body gets weaker.
R1: But the difference is, occasional loss of memory is something different than the continuous loss. Occasional loss of memory can happen with anybody. Even with her (the group facilitator) also... sometimes people do forget but this is a case of continuously forgetting.
Int: So memory loss is a disease or it is not a disease?
R1: How can we say that?
Int: No... but according to your opinion?
R1: I think it is a disease.
-

Words used and their meaning: With facilitator guidance, three men draw on their beliefs and experiences to judge whether memory loss is in fact part of normal aging. They use mechanistic metaphors to describe the “winding down” of body and mind with age. They reference important dimensions of cognitive impairment in distinguishing between older adults who experience memory loss and those who do not. For example, what are the causes? (After age 60, memory deteriorates); what are temporal dimensions? (Is it occasional or chronic?); is it controllable?

(Can activity help reduce it?). At the end of the excerpt, a group member concedes that memory loss may be due to disease.

Context: The facilitator guided and set the context for the discussion by asking members about possible causes of memory loss. She did not suggest age or disease as possible explanations; but participants engaged in a cycle of argumentation and rapprochement on these possibilities. The context is at once an ideational reflection of personal experiences and a pointed embodiment of dual cultural proclivities for argumentation and harmony in Indian culture.

Frequency and extensiveness of comments: Frequency refers to how often a particular view is expressed, and extensiveness means the number of participants who express a point. All group members described their experience with memory loss at length, both personally and in terms of others whom they have known. Again, there are many references in this transcript to elements of the Common Sense Model of Illness and Explanatory Models (e.g., What causes the problem? Who gets it? Is it inevitable?). Another pattern is tentativeness in responding to direct questions that might in other contexts elicit a declarative statement. Seeking meaning and understanding of their experience, they ask “How can I say?” This is a typical reply to such a question in India.

Intensity of the comments: Emotions are more difficult to detect and track in transcripts than in audio-taped conversations. There is a palpable sense of frustration at several points in this FGD along with expressions of futility and anxiety in other areas. There is an extensive discussion of their fears and anxieties about the future and concern that their families will be unable to care for them if their condition were to become severe.

Internal Consistency: This element concerns changes in opinion or position. A main reason group members gave for joining the study was to learn more about their memory loss. This excerpt is a brief synopsis of a main theme. During the discussion, the group moved from a strong endorsement of the belief that the main cause of memory loss is aging to considering the possibility that it may be a disease process associated with but perhaps not caused by aging.

Specificity of Responses: Far more valence is accorded to personal experience than to hypothetical situations. Indeed, all group members based their ideas, opinions and beliefs specifically on either their own personal experience or that of others they knew.

Big Ideas: This idea refers to broader trends or concepts from evidence accumulated across all components of the study and its contexts. I will discuss the “big ideas” in the data in Chapter 4.

Summary

I used maximum variation sampling to select a sample of three key stakeholder groups: older adults who screened positive for MCI on the MoCA in community memory clinics in Mumbai; their nominated primary caregivers; and a diverse group of physicians and traditional healers. Owing to the study purpose and type of research question, I used a qualitative interview methodology. Specifically, focus groups and in-depth interviews were used to elicit responses to open-ended questions about participants’ experiences with cognitive impairment, including help-seeking for this condition. Questions drew on concepts from the Common Sense Model and Explanatory Models of Illness. I used Atlas.ti to organize and manage the data and Framework Analysis for data analysis.

Chapter 5: Findings

Pathways to help-seeking for mental disorders are structured by a convergence of psychosocial and cultural factors, and have sufficient integrity to be studied directly as unfolding processes (Rogler & Cortes, 1993). Problematizing the experience of cognitive impairment in India, the central argument of this study is that development and implementation of evidence-based policies and practices to improve the lives of older adults with cognitive impairment and their primary caregivers require a contextualized understanding of individual and interpersonal experiences and knowledge of how these experiences figure in the dynamics of help-seeking.

Following on biopsychosocial theories discussed in Chapter 3, I conceptualize help-seeking as a decision-making process shaped by the knowledge, attitudes and practices of key actors—in this case, older adults who have screened positive for PCI, their primary caregivers and a diverse group of health care professionals. I organize the study findings by components of the KAP framework, i.e., 1) awareness and knowledge of the problem; 2) attitudes toward and beliefs about the problem; and 3) resources and strategies, including help-seeking, to manage symptoms and alleviate suffering caused by the problem. I integrate elements of the Common Sense Model and Explanatory Models of illness and, where relevant, compare the two socio-economic groups that were sampled for this purpose.

Knowledge and Awareness: Identifying and Labeling the Problem

Background knowledge is defined as the personal reservoir of information a person has on a particular topic. West, Farmer and Wolf (1991) describe three basic types of background knowledge. *Declarative knowledge* refers to the "what", or content of learning, i.e., concepts, facts, ideas and labels. An example is knowledge of types of cognitive impairment associated

with memory loss. *Procedural knowledge* concerns "how", or what rules one should follow to accomplish a task. Knowing how to care for a person with cognitive impairment is an example of procedural knowledge. *Conditional knowledge* speaks to "when" "where" and "why", or the contexts and circumstances that call for certain procedures. Applying procedural knowledge to prescribe treatment for a cognitively impaired person by staying abreast of best practices is an example.

Participants in the three stakeholder groups were aware of changing cognitive functioning from their respective vantage points. But they exhibited little knowledge of facts, procedures or circumstances about the problem or its care and treatment. Only the few PCI and caregivers who had consulted doctors had heard the terms 'cognitive impairment' 'dementia' or 'Alzheimer's disease.' None had heard of MCI. Rather they referred to the problem in terms of its most familiar and troubling symptom, *memory loss*, and they sought to fill gaps in knowledge with personal experiences and available social and cultural scripts concerning aging.

All three participant groups linked memory loss with aging, describing it as an outcome of age-related deterioration of body and brain. As one man explained in the focus group excerpt cited in Chapter 4, memory begins to falter at about age 60, then steadily deteriorates. As Hindus, members of this focus group described the decline as normal, expected, and synchronous with the cosmic order. Members of the focus group with low-income women agreed. One noted, "This happens to everyone because of age. Just like our bodies, our brains also start aging." Another added, "We start forgetting things with age, as brain capacity also decreases."

Members of this group with low-income women also suggested that menopause further diminishes brain capacity and subsequent memory loss. Men and women otherwise described the experience in similar terms, although consequences were often gendered. Women complained of

being unable to run their kitchens efficiently, for example, while men described difficulty with household repairs and maintaining friendships outside the home if they could no longer drive or move about independently.

A compelling dynamic of awareness and knowledge in the focus groups was how the discussion itself challenged illness-related beliefs of some of the group members. The evolution of discussions on whether cognitive deficits are a part of normal aging processes or a disease is one example. The aforementioned excerpt from the group with middle-income men shows how exposure through even brief social discourse can modify attributions of memory loss to aging, creating space for an alternative account. A revised narrative might be that the aging body and brain are a fertile climate for brain disease, of which memory loss may be a symptom.

Caregivers also lacked basic knowledge about cognitive deficits. They worried about the quality of care they were providing and how they could continue this care into a looming and uncertain future. A geriatric social worker whose mother had been forgetful for several years and was recently diagnosed with early stage AD was knowledgeable about the condition. She pointed out that until recently few people in India survived to old age, so there is little public exposure or personal experience with diseases that predominate in later life. For reasons of safety and stigma, families often sequester affected relatives in the home as symptoms worsen, which furthers low public awareness and pressure to address the condition as a significant health or social problem.

The daughter of an older man with impairment explained, “I haven’t seen this problem much. I have seen very few people who completely forget everything. There can be a little, minor difficulty in remembering things. It would be better to have knowledge about this, as then only we can find more means to help them.” The aforementioned caregiver who is a geriatric social worker thought the public must first be sensitized and educated about the fact that

dementia is an illness. Even in the well-educated colony where she lives with her mother, she explains, “People do not understand when I tell them. They say it happens with aging. They don’t know anyone who has suffered from it, so they don’t know that it is a disease and that it causes deterioration.” This widespread ignorance among persons in their close social networks produces confusion and shame for people who are impaired and deprives their caregivers of much-needed support.

Middle-income caregivers were equally pessimistic about awareness and knowledge among doctors. When asked whether they thought a person with symptoms of memory loss should see a doctor, a spousal caregiver stated, “People don’t go, people don’t know about it, they should be informed that they should visit the doctor so that this problem can be addressed and will not aggravate. People don’t have this information.” Those who had seen doctors were less sanguine. One described how when she informed their family doctor that her mother had been diagnosed with early-stage dementia, he advised her that it is part of aging and to “give her medicines and pray.” Another caregiver reported that her father’s doctor, seemingly perplexed by his increasing memory loss and confusion, simply adjured her to provide him with a restful, calm environment.

Lower-income CG also eschewed medical interventions, but for different reasons. One caregiver daughter stated emphatically, “For memory loss, no, we don’t take them to doctor.” But rather than an indictment of the quality of medical care, her statement reflected livelihood concerns:

Who will take them to doctor? Money is needed to do that. Right? We, neighbors can give food. We may not be able to give money.

Tea and breakfast and food can be given, but who will give money?

If we take them to hospital, it costs around 200 rupees [\$3.00 USD]. Who can pay that much money? We have to take care of a lot of other things in home.

Sometimes we do take her to a doctor. But if a household is as big as ours and only one person is earning, and twelve people are to feed, then what can we do? We have to give preference to food over medicine.

Turning to the experience of doctors, a psychiatrist portrayed the current Indian scenario as “basically an awareness issue—for doctors, family, society and patients.” Virtually all health care providers in the study reported increasing numbers of cases of cognitive impairment in their practices, yet their awareness and knowledge rarely exceeded the procedural and conditional knowledge that many caregivers had acquired from personal experience. Doctors cited training deficits, poor attitudes, low motivation and overwork as barriers to providing high quality care. They described myriad challenges of caring for older persons with cognitive impairment in the current health care system, which they described as overloaded, fragmented, inequitable and ‘sluggish.’ Barely 5% of India’s population has health insurance and most people must wait in lengthy queues, at times for days. There are not enough medications to treat acute conditions, let alone preventive, chronic or palliative care.

Doctors described their medical training as generic, focused on “acute care and common conditions”. None had received formal training in geriatrics or late-life cognitive impairment. Noticing an increase in the number of older patients with the condition, one young neurologist had taught himself to recognize and diagnose conditions of cognitive impairment. Some had attended continuing education (average 2-3 sessions every 5-6 years; “here you get some idea”); seminars (“dementia is at times mentioned, but is never the main topic”); and scientific journals (one person reported this when probed, but could not name a journal). More common means of learning were “on-the-job,” “trial-and-error” and occasional stints with experienced mentors. As one neurologist explained, “You speak to somebody who has done something better and feel that you can learn from them, and that’s how you evolve.”

The majority of Indians ascribe to Ayurvedic medicine, either solely or in tandem with conventional Western medicine. Core features of Ayurveda are the universal interconnectedness of people, their health and the universe, and the body's constitution (*prakriti*) and life forces (*dosha*). Ayurvedic doctors prescribe individualized treatments such as herbs, proprietary ingredients and diet, exercise and lifestyle recommendations. An Ayurvedic doctor in this study described his education as follows: "I trained by nature. I am a clinical person, by God's gift." An older man who had sought help for memory loss through a higher being illustrates the appeal of this cosmology: "God is a great carpenter. It is like an energy that controls our body and mind. That is how; we have to believe that there is some spirit which controls all this."

Shifting Knowledge and Awareness in Evolving Illness Narratives

Reasoning that memory loss is due to biological decline does not necessarily imply a biomedical approach to the condition, but nor does it preclude a role for disease in a biopsychosocial account of cognitive impairment. To explore the fit of these models requires a closer look at participants' accounts of their illness trajectories. The question of whether cognitive deficits are a normal, perhaps inevitable, part of aging was a central theme in descriptions of initial and early experience with the condition. This question was a turning point for PCI, as it requires an awareness of symptoms and their worsening, a search for underlying causes of memory loss and explanations for its progression, and ongoing assessment of effects on functioning. Reflecting on his Buddhist upbringing, an older man who was beginning to search for answers to these questions observed, "We shall see. The wheel is now in motion."

PCI described their growing awareness, and for some, a progression of symptoms. Their realization initially provoked a search for causal agents that might be controllable. Seeking a less deterministic explanation than biological aging of the brain and body, they cited a number of

candidate psychosocial and environmental factors. Though worlds apart in many respects, both income groups cited family and friends as essential to primary and secondary prevention. Several men in a middle-income focus group ventured that staying active and engaged with family, friends and leisure activities could help prevent initial impairment and stall further decline.

Older women in a slum area cited a lifetime of grinding poverty as the main cause of memory loss. As one PCI put it, “This may be also because our mind is filled with a lot of worries and problems, a lot of thoughts and tensions daily. At times one doesn’t realize where one is stuck in one’s own mind.” Endorsing this view, others spoke of the importance of social supports in coping with chronic problems and insecurities that could lead to memory loss. A caregiver described the protective function of family acting in culturally prescribed roles:

Those who have more tensions in life start losing memory at early stages. Others who are happy in family, who have no problem for food and other things, this problem of memory loss starts quite later. Those who don’t have resources or no possibility of obtaining, have many tensions in life, whose daughters-in-law don’t take care, or those who don’t have daughter or son to take care, these people will have the brain problem earlier.

Participants also identified environmental factors as causative agents. Those who lived in slum areas noted the long-term deleterious effects of inadequate sanitation, unclean water and food insecurity. A middle-income respondent worried: “We eat chemicals in our food, even we eat rice and wheat, chemical fertilizers are used, now we see increasing illness, it’s an effect of fertilizers, of chemicals, there is nothing pure available now, everything has chemicals. If we buy milk, they mix water in the milk. We don’t give clean grass for animals.”

To maintain narrative coherence and integrity, participants strived to synchronize these and other causal attributions with their symptoms. This dynamic process required recognition, monitoring and interpretation of symptoms along dimensions of seriousness, stability and intrusiveness. PCI described first recognizing minor symptoms such as misplacing objects,

difficulty retrieving words, and forgetting recent but not remote events. Low-income persons also pointed to non-specific somatic experiences, e.g., fever, headaches, difficulty walking and feeling cold, as sentinel symptoms. Food and hunger were prominent issues across interviews. A homeopathic doctor observed, “Issues of food are a symptom that is very peculiar to dementia.”

The following excerpts exemplify respondents’ early awareness of memory loss and their attempts to normalize the experience by dismissing its seriousness, as seen most pointedly in evaluative clauses (*italicized*) in the following excerpts.

When we forget a very important thing, for a spur of moment we worry about what happened to us. Then we realize about it and tell to ourselves that it is an age-related issue and we have to live with it. *That’s all*

Little, little. Sometimes I forget that I had to get a list of things then I go again and get things. So little problem, nothing much. I have to take something from this room, I come here and then forget and then I go out and come back and start thinking, what was it I looking for. *Nothing much.*

A caregiver described how she first noticed ‘something amiss’ with her mother:

Everything normal.... but like when I dropped her to my sister’s house she went to the wrong block... Then things like in the house she would keep things somewhere and forget where it is, then she would forget people. So that's how we came to know.

Individuals who had experienced more serious memory loss over a longer period of time were more open to the notion of disease. Some of them described “stages” and interpreted their worsening symptoms signaling progression. In an interview, an older man described the vagaries of his condition, noting “There is no thermometer for memory loss. It can move to different levels at different times and different speeds.” Amidst this uncertainty, PCI and their caregivers sought control through symptom monitoring, seeking favorable comparisons between their own current status and past status, their status and the status of age-peers; and their expected status

vis-à-vis age norms and expert opinions. Herewith are examples of these comparisons on key dimensions of symptoms:

There is a small problem. This I realized since five-six years. There are few old people with us, who have forgotten everything. They don't remember their wife, grandchildren and even about their home. I don't have such a problem. I have a little difficulty meaning 5 to 10 percent problem. [stability; seriousness; self vs. age peer; past vs. current status]

I consulted with the doctor also but doctor was also saying that it is not a problem. After a certain age, it is natural. It doesn't affect my daily living. [seriousness, intrusiveness, cultural norms, expert opinions]

It's just that I don't remember things for a long time. I forget things sooner than I used to before. But I am not facing any difficulty because of my memory loss. [past vs. current status; intrusiveness]

But as symptoms worsen, these “aging narratives” that feature memory loss as a common but minor irritation that is normal gradually shift towards “illness narratives” and imaginings of a future driven by progressive, untreatable and incurable disease. One PCI pointed to symptom persistence as an indicator: “Occasional loss of memory can happen with anybody, but this is a case of continuously forgetting.” Another, whose family had sought medical care for him suggested severity as a marker: “I think every person has dementia... only if it is beyond certain limits, then only it causes problems. If I go out and forget my house, forget my address, only then they can say that I have dementia.” A third suggested that novel situations challenge notions of stability: “Whatever the things we do daily on a regular basis will not get affected much. But if there is something to do new then it will be a problem.”

Caregivers also sought explanations for patterns and changes. When asked in a focus group whether forgetting is an illness, one replied, “Something is there, inside. My daughter-in-law's grandfather was like this.” Others saw changing levels of self-awareness as evidence of decline. The daughter of a woman with cognitive impairment reported that her mother “now only says to everybody that ‘they (daughters) say I have forgetfulness, but I don't know’.” Another

reported that her father used to constantly beseech her, “What is wrong with me? What am I doing? What is happening?” She observed with a mix of concern and relief that he had recently become more withdrawn and had stopped asking.

Caregivers also described a shift in their ability to ignore early symptoms. An older adult with cognitive deficits had left a train in the wrong city, while others were discovered wandering the streets or in a stranger’s home, or neglecting to switch off a stove or other appliance. These safety breaches were a tipping point for symptom tolerance and they provoked a shift in thinking that perhaps the problem is growing more serious, especially if other older adults they knew did not share this experience.

PCI and caregivers alike identified the circumscribing of life with cognitive impairment. An older man experienced this first as curtailed social involvement, then removal of enjoyable hobbies at home.

They stopped me from driving. They say don’t do that... I said Ok...I am happy. But I like to go out ...now driver is not there...my old friends have all become old...we don’t get together...I am just carrying on...day to day activities.

I enjoy repairing instruments (electrical gadgets). If anything goes wrong with toaster, iron...I would repair it... but now these people have stopped me. I even repair the wall clock...but they keep saying don’t do this...don’t do that...

Finally, doctors pointed to patient and family delays in realizing that cognitive decline is a problem as a major barrier to early intervention. A psychiatrist described the pathways taken by people with memory loss and their families, and the conditions that set them in motion:

During minimum cognitive decline, patients themselves show forms of distress, anxiety and depression. Most of the time, they come themselves saying that they are stressed by this particular problem. They ask on their own why they are not like the other days, what is happening? They used to remember properly. They ask these kinds of things.

Later it is memory disturbances and behavioral problems. Most patients with dementia are brought by relatives. Usually they are brought late. Relatives will only bring them in when their memory loss becomes troublesome to the family. Sometimes the cases are

like, 'he got lost last week or four days back', 'yesterday night he urinated in the house, he couldn't find the way to toilet and urinated in the room', 'He just walked out of the home in the night', 'he is asking for food again and again and again.' When these kinds of symptoms become a problem for the families, only then is the time patients approach us.

Another psychiatrist acknowledged that doctors may be complicit in delays.

When we interview people who were here, we realize that even doctors have a feeling that forgetting is related to old age and it is acceptable and should be there and there is nothing wrong with it. That feeling is there even more in the family.

To summarize, knowledge and awareness of late-life cognitive impairment were low in all three participant groups. Early symptoms of forgetfulness instigated awareness and were mainly attributed to normal biological aging. But this narrative shifted if symptoms worsened. More well-off caregivers worried that quality of life and quality of care would suffer, and called for education and skills. Their poorer counterparts struggled with decisions about how to allocate scarce household resources, a calculus in which older adults with cognitive impairment were accorded the least priority. Physicians and traditional healers were ill prepared to identify or intervene in cases of cognitive impairment. Overall, low awareness and the extreme paucity of knowledge seriously hampered participants' ability to identify, conceptualize or articulate their experience as problematic or to foresee and prepare for the eventualities which they may face.

Attitudes... and Underlying Beliefs and Values

In discussing working knowledge, Davenport and Prusak (2000) observe, "The power of knowledge to organize, select, learn and judge comes from values and beliefs as much as, and probably more than, from information and logic" (p. 25). A large body of theoretical and empirical research supports this assertion and clarifies the strong influence of attitudes on health behaviors. Within the KAP framework, "... individuals first learn about a practice, then develop a positive attitude toward it, and after passing through these stages, engage in the behaviour"

(Valente, Paredes & Popper, 1998, p. 368). Moreover, *values* (preferences, often of a religious or moral nature) and *beliefs* (convictions, often of a social and cultural nature) help to shape these attitudes and thereby actions and behaviors. Next, I present findings on attitudes about memory loss and the values and beliefs that imbue these attitudes with form and substance.

Seriousness....

The single overriding attitude toward memory loss in this study was that although it may create problems, now or in the future, for doctors, patients, families, communities and society, it is not a matter that either receives or merits serious consideration. As these excerpts illustrate, all three participant groups expressed this idea. From a PCI:

It doesn't matter so much in the old age. If there is fever or such illnesses then a person has a difficulty, then they run to the doctor as they are suffering. People don't take a problem of memory loss seriously. Everyone has forgetful tendencies. I forget things, but not a serious problem; there are ups and downs, 2 to 3 percent due to memory loss.

Others added: "it should not be looked at with much seriousness," "I take it very easy," and "if one takes it too seriously, then one feels that something is wrong in my body." PCI legitimated these views by noting how closely they are shared by doctors, governments and the general public. For example, one caregiver noted, "Nobody is much bothered about the seriousness of this problem. People take it very casually," and an Ayurvedic doctor suggested, "This is not a big problem in India today. Fast life style like fast food, Chinese food, fermented food is harming people, but not memory loss."

Status changes marked by worsening symptoms and functional decline supply the type of experiential knowledge that can shift conceptualizations of memory loss from a normal aging schema to a biopsychosocial model of disease. These passages can also contribute to changing attitudes. Two cultural attitudes that are deeply rooted in Hindu beliefs and values, acceptance

and duty, suffused accounts of individual and shared experiences of memory loss. Both income groups of PCI believed that memory loss should be accepted, but their reasons differed. Middle-income participants were oriented toward preserving comfort, harmony and the status quo. They often expressed beliefs that their condition was a natural sequela of aging and, regardless of its etiology and course, there is nothing to be done about it.

As one man explained, "...if I am suffering from a certain disease, then we have to go to a doctor. But this particular disease, if it can be called as disease, is not curable. We know for certain that this is going to happen. We should take it positively." This attitude may be deemed passive or even defeatist in the West, but in the Indian context it embodies equanimity, forbearance and acceptance of destiny. Similarly, when asked whether they found it irritating to be told "not to do this...and that," one man replied, "No, I just keep quiet. I say OK. OK." Another said, "I have just accepted that this thing is not to be done." When asked what should be done if a person's memory loss were to become severe and he or she had no family, a focus group member said, "People continue living with a problem, they just pull it on."

Lower-income participants cited duty, social order, fate and lack of other options as reasons for acceptance. This passage from a focus group with caregivers is illustrative:

I: At home, when your mother-in-law forgets things, how you deal with it?

R1: Even if my mother-in-law forgets things, we don't get bothered. We are ok.

I: What difficulties you face because of her memory loss?

R2: We don't have any problem.

I: You don't have any problem?

R1: These people are our own people; where else can we send them? We can't throw them out of home.

R2: That is true.

R1: If she forgets, or makes some mistakes, it is me who will take care. Who else will?

I: So what do you think, where should she stay?

R1: We will take care of her. She is my mother-in-law. Even if she shits or pisses, son and daughter-in-law have to clean it. Even if daughter-in-law has issues, a son cannot have. She is his mother.

R2: This is the reason why people give birth to children, so that in the old age children will take care of them. The condition old people are in will be our condition one day.

This line of reasoning also reflects the values of mutuality, justice, and care that define India's highly allocentric culture and help ensure harmony, order and functionality. At the hub of this dense, intricate web of relationships and responsibilities is the ideology, albeit a waning reality, of the joint family—an ideal that remains vibrant in older age cohorts. I will come back to cognitive impairment and the family in the last section of this chapter. Here, I briefly draw attention to how family attitudes can be marshaled to protect members who have memory loss or alternatively can replicate the stigmatizing attitudes of the larger society. Two related topics which all participant groups raised in this regard were secrecy and disclosure.

Stigma... Shame, Secrecy and Disclosure

Stigma is a significant attitudinal barrier to help-seeking for cognitive impairment (Alzheimers Disease International, 2012). In his classic definition, Erving Goffman (1963) defined stigma as “an attribute, behavior, or reputation which is socially discrediting in a particular way: it causes an individual to be mentally classified by others in an undesirable, rejected stereotype rather than in an accepted, normal one” (p. 2). He identified three types of stigma – bodily abominations, moral incapacities, and tribal stigma, or stigma that is ‘courtesy’ of one’s affiliation with stigmatized others.

A large and growing body of cross-cultural scholarship confirms that persons who experience dementia syndromes and those who associate with them face significant stigma. Liu,

Hinton, Tran, Hinton and Barker (2008) suggest two main sources of this type of stigma in Asian cultures--chronic mental illness and negative stereotypes of aging or the aged. Only one PCI in this study, and only when prompted by the interviewer, mentioned a mental problem, and the point was to deny it: "Nobody has told me like that. On the contrary they say that my illness has come this way. But nobody said to the extent that I have mental problem." The matter of aging-related stigma was more nuanced. Despite cultural precepts that value and revere older adults, few participants described old age as a venerable social status. Several proffered an opposing sentiment, highlighting Machiavellian motivations and utilitarian values in Indian society:

Society is selfish. If there is any benefit from this person, they get closer to such person, if there is no benefit from this person; they keep distance. When a person is earning money, he has respect in the family. But now society is changing. If a person is of no use, everybody ignores him. People always look for their interests. This world is like this.

Perceptions of memory loss as a part of normal aging might be expected to lessen stigma through normalization. Equally possible, conflation of these two experiences might intensify the stigma of cognitive impairment and come to discredit older adults. Discussions with PCI and caregivers about how people with memory loss are treated in India suggested both processes, again varying along the lines of income and "good" and "bad" families. Members of a middle-income focus group of PCI echoed the experience of a man who commented, "I have not experienced stigma, nothing like that." But middle-income caregivers were strongly inclined to shield affected family members and, by extension, their families from public scorn and humiliation. A middle-income man notes: "If somebody asks me if I have memory loss, I say yes, I have memory loss. My family members have never told me things like that. But it is possible that general people outside would do that."

People who live in public spaces have more flexible social boundaries and may be more sensitive to the beliefs, values and attitudes of social networks such as friends, neighbors, clergy and the media. In the densely populated communal slums of Mumbai, much of life is on public display. Here, caregivers worked hard to preserve the integrity and reputation of their families--but not necessarily of the person with memory loss. When asked whether they would request help from neighbors for their memory loss, an older woman replied, "No, we would remain hungry, but would not ask from others." Others described efforts to conceal the condition: "We prefer to keep it confidential. If we tell others, they might laugh at us. It is always like that. People ask questions, laugh or comment." In this exchange, we see how the "spoiled identity" of an older adult with cognitive impairment can be used to discredit the caregiver and the family, especially if they lack other ways to 'save face.' The following exchange among low-income women exemplifies the dimensions of 'good' and 'bad' caregivers and families and the potential for social exclusion.

R1: 'These people are old and their memory is weak, so don't listen to them', that's what neighborhood people would say.

I: How do family members behave?

R2: Family members also do the same.

R1: If they are good people, there is no problem. But if their children have some issues with them, then they will tell other people to ignore them. They will also ignore them. They will give them food and will tell them not to bother in other matters.

I: Ok, So these ignoring and such other things happen?

R2: Yes, these things do happen.

R3: Now, see, the relatives would say that 'you are old. You don't understand anything, so keep quiet. You got your food to eat, didn't you? So don't bother in anything.'

R2: Yes, they talk like that.

I: Do you think people mock or irritate these people who suffer from memory problems?

R2: Yes, they do.

R1: Some people do.

R2: Not only others, we also do.

R1: We do.

In the dynamics of stigmatization, the flip side of secrecy is disclosure. This topic was discussed in terms of caregivers disclosing their relatives' condition to people outside the family and doctors' disclosing the condition to PCI. Lacking knowledge themselves, caregivers were unsure whether, what and when to tell people outside their family. Most assumed that others either had or eventually would notice their relatives' condition since it "cannot be hidden." Unless, of course, the impaired person is confined. Several PCI and caregivers gingerly raised the possibility of abuse and neglect, and a physician reported, "In a friend's family I saw the father, he just shouts at his wife to keep quiet, which I felt is not right. I tried telling him also that it's not she and it's the illness because of that she does." This topic also arose in a focus group, but it provoked such a high level of discomfort that it was not pursued.

Opinions about whether doctors should inform patients about possible dementia were mixed. Some people endorsed disclosure, e.g., "Doctor should tell the patient what is the secret behind this problem. If it is kept secret, then it is a big problem for us." Others disagreed: "There is no difference if he tells or does not tell. If a person keeps on hearing this then he will keep on thinking about this and after a point he will get irritated with the things he does. It will not be a success." Still others favored disclosure, although within certain parameters and even then with a measure of ambivalence.

I think he should tell. Now it is beginning of memory loss for me. Now I can recite 'vishnusahasranama' without looking at book. I recite it every morning. Now it is almost in my memory. But if somebody is telling me that after two years my condition will be worse and I will go to extreme extent, then I am ready to go to a doctor. I will go only when I am convinced that he can help me.

Yes of course, of course, the doctor should tell such things to patients. So doctor can give proper treatment. But as I told you, patients don't take doctors seriously.

Doctors themselves were at once perpetrators and objects of stigmatizing attitudes. They consistently objectified persons with cognitive impairment, referring to them as “those people” and “this kind of people.” These dismissive attitudes were reflected in their comments:

Though it (“senility”) is growing, doctors are not aware of it. They consider it to be part of normal aging and are very laid back and not aggressive; most choose to ignore it.

I don't think (doctors) are that much sensitive...they will probably not even attend them with that much care that is needed and they are more comfortable referring it to someone else because it is more like a task for them.

Physicians in India are very happy actually because there is not much concern of taking care of such people. Most neurophysicians will be happy not to have a ‘dementia patient’.

Though troubling, such remarks should be judged in the context of prevailing conditions of high workload (hundreds of patients per day; very time-consuming problem); lack of training (in chronic care, geriatrics or age-related cognitive problems); lack of treatment options (home care, medications, occupational therapy) and few back-up services (psychoeducation, social support; chronic and/or palliative care). Doctors also expressed major frustration about delayed presentation and lack of follow up. A general practitioner of twenty years explained it this way:

Basically what I have observed in India is after age of 60, a patient's relatives get tired of giving treatment because of multiple problems. Poverty is one of the problems. Secondly the work, people are working in India. They are not able to put that much money behind treatments. Probably these are the main key factors. Most patients are undiagnosed because they don't go for investigation, they don't go for the specialists further.

Younger doctors were more charitable. Asked if he wanted to add anything after his interview, a newly-minted neurologist reflected on the difficulty of defeat:

It is very painful...that is what I can tell you. To see a patient developing dementia and then when I send them back... I tell them that both of us have to live with it... there is no help. It pains a lot as you can't do anything more about it.

Similarly, attitudes of PCI and caregivers about consulting doctors for memory loss ranged from dismissive to distrustful, but for most participants it was simply not an option. Both lower- and middle-income participants struggled with access. A member of the latter group explained:

It depends on person to person, financial conditions. Today health care is very costly. If you have to visit a doctor, you have to pay 400 Rupees. Only as a consulting fee, if you meet a big (specialist) you have to pay 800 Rupees. A person whose earnings are nil, whose family background is poor, from where this person will get money to pay for the doctor? That person gives back seat to problem such as memory loss due to other significant issues such as financial problems.

Dismissive comments ranged from agreeable disregard to outright hostility:

I don't give attention (to doctors). I feel myself...and I am OK.

I don't expect anything more (from Dr. P.). If I think there is nothing wrong with me...and they are telling it looks like dementia... dementia ... dementia. So I say Ok (laughing). I just ignore it.

I don't think myself to have memory problems. Doctors are trying to force me to believe.

Finally, emotions operate in close concert with cognitions in the formation and change of attitudes. In the previously described spirit of acceptance, one PCI noted: "Actually, there is no point in getting afraid. This disease is going to that extent where I can't figure out who really I am, so it will then be a matter for other hands." But fear and anxiety, at times manifest and other times thinly veiled, were generally high among PCI and their caregivers.

PCI feared most for their personal safety, loss of dignity and disintegration of sense of self. Concerns about safety already constricted the social and spatial parameters of many of their lives. Several PCI had been lost and others were robbed of money and jewelry while walking or traveling; they feared being outside their homes alone. Caregivers likewise described shrinking

social networks and constricted activities. They voiced concerns about their growing inability to engage in routines of daily life, including work, without consuming concerns about the safety and well-being of their relative. The few who had a better understanding of the condition also worried about their ongoing capacity to provide adequate care.

Practices: Social, Cognitive and Behavioral Management

Low levels of awareness and knowledge and dismissive and stigmatizing attitudes were major barriers to help-seeking for cognitive impairment among PCI and their caregivers. In the rest of this chapter, I present findings on help-seeking as a way to overcome these and other barriers to coping with exigencies of late-life cognitive impairment (see Banerjee & Roy, 2007).

In India, any measure, any mention of coping begins and ends with family, the fulcrum of personal and social life since antiquity. Traditionally, this ideology has taken the form of the “joint family,” a configuration of multiple generations of blood-related males and their wives, mothers, single daughters and widowed relatives, all living together and bound by the common (sapinda) relationship and ancient legal and religious texts. Respect and responsibility for elders are likewise codified and enacted through the family. These values are particularly embodied in the concept of *dharma*, which designates the behaviors necessary to maintain a divinely conferred natural order of things, and are thereby deemed appropriate, correct or morally upright. Conceived of as duty or propriety, *dharma* espouses that justice, social harmony and happiness compel people to discern and live in a manner that is appropriate to requirements of that order.

The joint family structure is vanishing and its capacity to fulfill traditional functions is diminished in much of India, especially its large urban centers. Middle-income study participants continued to cherish the symbolic value of this longstanding social arrangement, but they were cognizant of change. Indeed, despite their strong allegiance to core ideals inherent in traditional

institutions such as the joint family, a number of participants had migrated internally or abroad, as had their children. As the fabric of society loosens, *de jure* models of family care will cohere only if all the requisite players have sufficient motivation, capacity and resources to enact the letter as well as spirit of the law.

Capturing the sentiments of many PCI, an older woman observed, “Family support is one of the best cures, along with medical treatment; sometimes it’s even better than medical treatment.” Close familiarity and comfort of intergenerational care is authentic and it is carefully, continuously calibrated to need. Again, referencing the theme of food as sustenance and nurture:

I go with the flow. I know that (kitchen) is her domain and I don’t interfere unless she needs me. In between she was not well so I used to do everything but when she got better she was back to her own. And she started keeping things her way again. Because she feels it’s like her temple, her space. So I let her be. (A middle-income caregiver)

Right now we don’t have any problem. We are living nicely, cooking our food, eating our food, managing ourselves. (Husband of a couple, both with cognitive impairment).

An initial read of interview transcripts conveys a strong, unconditional confidence in family support; however, closer scrutiny reveals perceptions of troubling realities and anxieties.

In response to the question of how important family members are in their care, a PCI stated:

Hundred percent. They take us easily saying that 'he is an old and respectable man. He has forgotten, but no problem, we will remind him'. As far as I am concerned I have hundred percent support of all members of my family, including my daughter-in-law.

And, from two middle-income PCI whose sons had immigrated to the United States:

Our son has told us, if there is any problem, you can come anytime here, when you feel that you can’t stay alone, that very same day, you should come.

Now also our son was saying, you stay for some more days and then in year, I will get citizenship for you. They say come soon, come tomorrow. Such things are not available for all, but we are in a good condition.

Lower-income participants had little formal schooling. Illiteracy and other forms of social exclusion limit their exposure to changing social conditions and the resources that are needed to accommodate change. Consider this exchange about the alien concept of “caregiver burden”:

I: You tell me, she is your mother-in-law who has started losing memory and it is you who provides care to her every day, what problems and difficulties do you face?

R: What difficulty are you talking about?

I: If you face problems, tell us about them.

R: What problems?

I: Problems in caring for your mother-in-law.

R: I do not understand your question. This is a duty, not a problem.

Middle-income families have resources that afford them options to supplement family care, typically hiring a “helper woman” (maid). As one man explained, “If (the family) has money, then it is all right. They keep one or two servants for you or they can keep you in hospital. They will pay.” This statement stands in stark contrast to that of a lower-income woman who states, “They will visit a hospital only if their daughter-in-law gives them money. If they don’t get money, then it is not possible for them to go to hospital.”

Discussing such contingencies, conversations moved quickly and at times painfully to the possible limits of family care among middle-income PCI. As a focus group member commented, “family members have their own lives, their own work. I don't find fault with them. How can they come to us for 12 hours a day? They cannot!” Another woman who was caring for her mother described the types of challenges she anticipated based on a recent encounter:

I recently met a friend’s mom who is maybe in the third stage. When I was there in her house for two hours she chewed my brains by repeating, repeating. I was just saying a silent prayer that I hope I will never have to see my mom like this. But I am prepared.

Caregivers also discussed how caring for kin with cognitive deficits has changed their daily lives, creating social constriction, inconvenience, and financial concerns. Some worried about personal physical and mental health strain that may come with time. One man alluded to depression in surmising, “those who have got very serious problems in remembering things must be feeling very low and very negative about life. This whole thing must be affecting the entire family environment.” For PCI, the possibilities of future disruptive behaviors and functional impairment were a somber presage to the finite capacity of family, as these men discussed in a focus group with middle-income men:

R1: See, even your wife would reject you. Not to talk about the other members. If this is the disease and it is going to the extent that a person is forgetting to take bath and wear clothes, then nobody will be there to support that person. Support will come only from lips. For one month-two months. Not afterwards!

I: That means you all say that if you get some problem like this, your family members won't give much support but some lip service?

R2: There will be a limit for their help.

R3: Whether they can help or not depends. .

R1: That it where the mercy killing comes.

R2: And the whole life spent for this!

A sizeable cadre of other informal supports, including friends, neighbors, communities, religious organizations and servants, supplement and substitute for family care in middle income families. Offering the example of a friend who appointed a servant to do all the work his wife used to do, an older man mused, “If a person is poor, then who will take care of this patient?” The experience of a woman with no family supplies an inspirational reply to this rhetorical question. Her neighbors in the slum where she had spent her entire life essentially “adopted” her. Motivated by necessity, not altruism, they endorsed the ethos that, regardless of what happens

(‘she keeps on complaining,’ ‘she asks for food soon after lunch, forgetting that she has had it,’ ‘she sometimes uses a lot of bad words’, ‘she has walked all Indira Nagar to find her home, we have to retrieve her every day’), they will continue to care for her because “there is no choice.”

This sense of compulsory obligation, of duty, also served to create and sustain a sense of community, affording those who are poor a modicum of comfort and security, as illustrated in an excerpt from an interview with an older woman in a slum area:

I like speaking to my neighbors. When I start feeling uncomfortable/ nervousness /panic (*ghabarahat*), I visit the doctor. Sometimes because of severe headache, I have even slept at my neighbor’s place. I feel better when I talk to them. Whenever I feel stressed or scared, I get up and go to them.

Another resource that participants used to cope with challenges of cognitive impairment was membership in a religious organization or faith community. Both income groups referenced religious cosmology to explain memory loss and its consequences. In reply to a question about how best to handle the situation of older people who have no one to care for them, one man explained: “To me this is all about destiny. If for someone, if there is somebody to look after them, then in the last phase of life it is good; but if there are some who are alone and don’t have anyone to take care of – they have to suffer.” This sentiment reflects the Hindu concept of karma, the law of cause and effect through which each individual creates his/her own destiny through his/her thoughts, words and deeds.

Although less than 5% of the population of Mumbai is Christian, this religion was prominent in a focus group with older women in a slum. Asked whether they had ever consulted a doctor for memory loss, one replied, “No. Our doctor is Jesus Christ. We don’t go the doctor.” Another added, “I used to go earlier. When I didn’t believe in Jesus, I used to go to the doctor. But then I started forgetting and up till now I only pray on Jesus. Now I rely only on faith because I keep forgetting. Our doctor is Jesus Christ. We don’t go the doctor.” At this point, a

call to prayer sounded, prompting focus group members to engage in an emotionally charged prayer for their protection and well-being and the care and keeping of families and loved ones.

These types of ritualized behaviors afforded study participants solace and community. A middle-income PCI spoke of her participation in a devotional music (bhajan-kirtan) group. Asked how this helps her, she explained,

If you look at the world, it is full of good and bad things, when you start devoting your life in the god's path, then you don't have to worry about anything. I do one thing, that whatever trouble I have; I directly converse with the gods. Whatever I speak, the god understands my feelings. We just have to depend ourselves on the god and things will be alright. If you depend on human beings, then there is a problem.

In addition to social and religious networks, PCI engaged in various activities to improve their cognitive status, e.g., crossword puzzles, jigsaw puzzles, reading, listening to and playing music and watching television. They described mental exercises they believed would stave off memory loss. A PCI enjoined fellow focus group members to recollect their daily activities in minute detail each evening. Another used a series of Hindu chants to "discipline" his memory. Still others invoked compensatory behaviors, e.g., asking friends to remind them of events, having someone to organize their activities, and using memory aids such as diaries, e.g., "If diary is lost then everything is lost. My life is there in the diary."

There was also an important distinction between perceived and evaluated need. PCI who had just begun to notice memory problems readily dismissed their seriousness, as did their doctors. The needs of those whose conditions had worsened were more difficult to ignore. They monitored symptoms through the routinized rhythms of daily life, mostly at home. Could they recall where they had put objects? Whether they had completed tasks? Had they eaten? How much effort was required of them to follow conversations on television or *in vivo*?

Familiar, mundane features of domestic life lent comfort and guidance. But caregivers of older adults with more serious symptoms expressed concerns that their efforts would be exhausted and inadequate in the face of mounting needs and that they would have to turn to health and social services. When pressed about who they would see should they decide to take this action, PCI and caregivers alike uniformly named their family doctors. But they are likely to confront formidable structural barriers that hinder access, use, treatment and favorable outcomes. Professionals are generally ill prepared and there are few sources of support and no financial support outside the family.

The general feeling among middle-income PCI and caregivers was that NGOs that sponsor activities and outings might be of interest, but most services should be reserved for older adults who did not have families. Their low-income counterparts expressed a keen interest in any and all types of social services, from self-help groups to job assistance to caregiver aid. Unable to articulate specific needs or services, they repeatedly asked interviewers to decide for them. Both income groups strongly endorsed day care for older adults with memory loss, although several middle-income men judged this an outright abrogation of family responsibility. Finally, in noting that they specifically joined the study to learn more about memory loss and potential resources, participants in both income groups repeatedly asked interviewers pointed questions about the nature of cognitive impairment, e.g., what did they think caused it? What is their future likely to hold? What sorts of support services are available and how might they access them?

Summary

The experience of ill health is shaped by independent and interactive effects of patient, condition and context. This chapter presented findings on the knowledge and attitudes of persons who screened positive for MCI, their caregivers and a group of doctors and healers about

cognitive impairment and how these may factors may influence health behaviors, including help-seeking. Persons with impairment and their caregivers had very low levels of awareness and knowledge of the condition, which they uniformly referred to as “memory loss.” Several doctors and all traditional healers lacked basic knowledge, which led to pervasive lack of confidence and pessimistic views of doctors and the health care system. All three stakeholder groups expressed the view that this condition is not taken seriously and, in the words of one person with cognitive impairment, “there is no good reason to see a doctor.”

Both PCI and caregivers experienced memory loss as a trajectory of gradual decline, punctuated by symptom-related critical incidents. Less impaired persons attributed memory loss to normal aging, while those with greater impairment were more inclined to consider the possibility of disease. Attitudes of participants in both income groups reflected cultural norms of acceptance in the service of harmony and equanimity, but other reasons differed. Lacking resources and access to medical and social service interventions, low-income people accepted their condition as fate and sought support of family, community and religion. Middle-income persons, regardless of the availability of material resources, also turned to family first. Even PCI who estimated high odds of their condition worsening were dismissive and disdainful of doctors’ willingness and ability to help. Taken together, these findings, conceptualized in terms of the KAP framework, support the widely-studied symptom recognition-to-help-seeking process that is central to social cognitive concepts in Illness Representation and Explanatory Models.

Chapter 6: Discussion and Conclusion

By 2025, the population aged ≥ 60 years in India is expected to reach 150 million, second in size only to China. This demographic trend brings rising rates of non-communicable diseases, the need for rapid changes in basic social institutions, including inadequate systems of health and social care. Against this backdrop there looms the daunting prospect of an epidemic of cognitive health problems, including but not limited to diseases that cause dementia. There is a dire need for the development and effective implementation of policies and practices that will help prevent cognitive disorders, slow deterioration in cases that are progressive, and preserve and improve quality of life. To accomplish this goal will require the appropriate uptake of services. It is thus important to understand how impaired individuals and their care providers experience and act on these conditions.

This study used focus group discussions and in-depth interviews to solicit this type of information from 34 individuals in Mumbai: 14 older adults who screened positive for MCI on the 30-item MoCA, their nominated primary caregivers, and a diverse group of 6 physicians and traditional healers. To guide data collection and analysis, I drew on social cognitive theory and more specifically on elements of the Common Sense Model (Illness Representations) and Explanatory Models of Illness, organized within a KAP framework. In this final chapter, I discuss the main study findings and suggest potential directions for policy, practice and research. I organize this discussion in overlapping sections on awareness and knowledge, attitudes and beliefs, and practices (including behaviors and policy and programmatic resources).

Awareness and Knowledge

The literature on dementia and studies on other types of late-life cognitive impairment in LMIC emphasizes uniformly low levels of awareness and knowledge about these conditions. Until emergent health problems are accorded sufficient public health attention, the lay public and professionals alike tend to rely on indigenous knowledge systems for understanding and guidance. In times of rapid social change, if avenues of communication are sufficient, traditional and current sources of knowledge and information may become mixed. This syncretic model aptly captures the understandings, attitudes and actions of study participants about cognitive impairment in contemporary Mumbai.

Low levels of accurate knowledge contributed to lack of awareness of possible resources for some, to inability to access these resources for others, and indifference or outright aversion to help-seeking for others. PCI and their caregivers were keenly aware of cognitive decrements, which they uniformly referred to as ‘memory loss.’ Indeed, most had joined the study for this purpose. With few exceptions, PCI and their caregivers attributed all types and levels of memory loss to normal aging and described it as a ‘running down’ or ‘wearing out’ of the body and brain. Lower-income persons blamed physical exhaustion due to cumulative tension and stress, while their better-off counterparts believed root causes were advanced age and religious cosmology. Both income groups strived to parsimoniously organize and catalogue their knowledge and experience to support sense-making and present-focused problem-solving rather than attempt to formulate long-range views of the condition, its course or its likely outcomes.

General practitioners, neurologists and psychiatrists readily recognized symptoms of neuropathology in their patients, but admitted to lacking even basic knowledge about whether or how the conditions might be prevented or treated. Traditional healers saw cognitive impairment

holistically as an environmental and behavioral casualty of modernization, e.g., diet and stress, and they prescribed life style changes, meditation, Ayurveda and other traditional approaches.

Low knowledge and awareness of cognitive impairment, and multiple interpretations of its causes and effects suggest a need for a multi-pronged approach to information and education. Properly designed, targeted, and executed public education campaigns can be low-cost and far-reaching and may help reduce stigma and increase help-seeking (Niederkrotenthaler, Reidenberg, & Till, 2014). To maximize reach and effectiveness, all stages of campaigns should meaningfully involve key stakeholders. Ideally, accurate and sufficient information could be available to entire populations (Riva, Caratozzolo, Zanetti, et al., 2012). Knowledge can also be tailored, perhaps more effectively and affordably, to the needs of specific high-risk sectors, e.g., low-income persons and older women in this study. Public education for non-literate individuals and those who live in more remote areas could be delivered on television or other non-print media.

Public education might also be enhanced by working through existing inter-sectoral linkages. Governmental and non-governmental organizations could partner, for example, on campaigns in schools, communities, religious organizations and workplaces. The 10/66 Dementia Research Group estimates that at least at least one-third of people with dementia worldwide live in three-generation households that include children under age 16 (10/66 DRG, <http://www.alz.co.uk/1066/public.php>). School-based programs could help children understand and cope with cognitive impairment of household members. Similarly, workplace education could sensitize employers and co-workers to the demands of caregiving. Other viable avenues to be further developed for education and support are mobile health applications (an estimated 91% of Indians have mobile phones) and internet blogs and social media. An example of such a resource is “Dementia Care Notes.” <<http://dementia-care-notes.in/resources/india/>>

Dias and Patel (2009) identify the paucity of well-trained human resources as the primary barrier to closing the mental health treatment gap in India. General practitioners, specialists and traditional healers in this study discussed their lack of formal training in geriatrics and low knowledge of age-related cognitive impairment. These circumstances appeared to court negative attitudes and in some cases, an objectifying and shunning of patients. Doctors opined that older people with cognitive disorders were time-consuming, and their needs incompatible with the ethos and skills of their training. PCI and caregivers reciprocated by rejecting doctors as either unnecessary or unwanted. The singular exception was a strong and unanimous endorsement of primary care physicians as their first and most important resource.

Existing training and resource centers include an MD in Geriatrics at Madras Medical College in Chennai and a 1-3 year post-graduate diploma in Geriatric Medicine at Indira Gandhi National Open University in Delhi. The government also offers 6-month, full-time certificate courses in geriatric care for non-medical and para-professionals, e.g., a course at Tata Institute of Social Sciences in Mumbai. However, study participants were quite pessimistic about the will or the ability of the government to bolster knowledge or improve attitudes.

A widely preferred strategy in low-resource settings is to synchronize mental health services with existing health systems, with primary care as the first, most frequent and favored point of contact. These settings are more familiar, more physically and financially accessible and less stigmatizing than mental health services. Doctors advised that local primary health care centers were better equipped, with government funding, to take on the care of persons with cognitive impairment. And as noted, despite their criticism of primary care, PCI and caregivers expressed a strong preference for their primary care doctors.

India has an extensive community-based primary care system staffed by doctors, nurses and community health workers (Accredited Social Health Activists (ASHAs)) operating through the country's National Rural Health Mission (NRHM). This vast network is a logical locus for patient and caregiver education in local languages and at appropriate education levels. But the NRHM does not include mental health services and the performance of the National Mental Health Program (NMHP, 1982) and the District Mental Health Program (DMHP) (which covers only 20% of districts nationally) is uneven at best (Kumar, 2011).

Memory Clinics are another option for educating persons who have memory loss and their families—especially in anticipation of or if and when the disorder worsens. These hospital based, out-patient, multidisciplinary services provide detailed assessment, management, and advisory service for individuals with dementia and their caregivers. *ARDSI Dementia India* reported 100 memory clinics nationwide for a population of over 100 million older adults. The report recommended at least one memory clinic be attached with a dementia day-care facility in each district. But insufficient infrastructure makes expansion to that scale unlikely. It might be more practical to draw on the expertise of memory clinics in primary care settings (Lee et al., 2010) and public hospitals. The use of research diagnostic criteria to categorize cognitive deficits could yield useful data for developing other clinics (Nair, van Dyk, Shah, et al., 2012) and could dovetail well with surveillance and monitoring of cognitive impairment, which I discuss below.

With respect to professional education, a helpful start might be to incorporate minimum core content and clinical skills on screening, diagnosis and referral mechanisms in medical, nursing and other health care profession curricula. As the linchpin in the care process, primary care doctors might also participate in refresher trainings on a regular basis. Kakuma, Minas, van Ginneken et al. (2011) review a growing body of evidence that shows that with brief training and

appropriate supervision by mental health specialists, non-specialist health professionals, lay workers, some affected individuals and caregivers can detect, diagnose, treat and monitor individuals with mental disorders and reduce caregiver burden. This model of care emphasizes long-term patient and family support through in-home assessment and management of chronic diseases and outreach, and it can be delivered effectively in primary health-care settings through community-based programs and task-shifting.

A decentralized, semi-professionalized approach would fit with a general practitioner's creative suggestion to establish a small number of multi-disciplinary "centers of excellence" for cognitive health. Using a public health model, these centers would serve as referral and training hubs for health care providers and provide services ranging from basic education to referrals for palliative care. A strong emphasis would be on counseling, psycho-education and psychosocial care of patients and families. For case-finding and early intervention, a trained para-professional or nurse could use a validated, user-friendly tool for routine screening. Mitchell and Malladi (2010) present evidence of the diagnostic validity of single-domain cognitive tests in community, primary care and specialist settings (see also Bordaty, Low, Gibson & Burns, 2006).

Finally, study participants with cognitive impairment and their caregivers also described system-level knowledge barriers to help-seeking. Many lacked even basic knowledge of what to ask for, from whom and how. This was especially the case for lower-income people, who repeatedly asked the interviewers to send or help them access any and all available resources. Several caregivers reported hearing of potential resources but did not know how to determine their eligibility or whether these resources were actually available, accessible, acceptable and appropriate for their needs. It is thus important when designing education and information and

referral programs to realize that service use is a learned behavior and to be familiar with barriers, including misconceptions and negative attitudes, to access and effective use.

Attitudes and Beliefs

In the KAP framework, knowledge can influence behavior either directly or indirectly through changing attitudes. In this study, lack of knowledge about cognitive impairment affected service use through three related attitudes: the condition is not serious, prevention and treatment are futile; and impairment is a source of stigma for those afflicted, their families, and physicians.

PCI and their caregivers relied mostly on familiar sociocultural scripts to make sense of their experiences with cognitive impairment, yet they readily stated that the problem is due to brain and body dysfunction. To resolve any antagonism in these perspectives, they explained cognitive impairment as a part of normal aging, which implies that it is like other age-related physiological changes--an expected and inevitable outcome of a long life. Incorporating religious beliefs such as karma and destiny further enabled this narrative to accommodate any observed variations among individuals they might know personally or through others.

In what seemed more an observation than an indictment, all three participant groups repeatedly noted that the whole of Indian society, from the highest level of government to their most intimate neighbor, rejects the notion that 'memory loss' is or ought to be taken seriously. This belief is consistent with the overarching explanation that the condition is part of normal aging, but at the same time it may negate perceptions of need for resources or services, whether medical, psychological, social, financial or spiritual. This turning away from services and resources also reinforces the cultural belief that the family is fully responsible for care.

Several doctors suggested that to acknowledge the seriousness of cognitive impairment would obligate the government to respond, which it can ill afford. Some participants seemed to deny or rationalize their memory problems, perhaps to ‘save face’ or to avoid the disappointment of identifying a need that in all likelihood could not be met. In other words, without sufficient education and information, available scripts for help-seeking were limited to those legitimized by existing norms, e.g., family caregiving, expectations of professional competency and existing service structures. For some PCI, these norms included seeking help from traditional healers. These practitioners play an important role in many communities, particularly in rural India, but their services are unregulated and unaccepted by the modern health care sector. The healers interviewed in this study appeared to be dismissive of scientific explanations or remedies for memory loss. However, models that integrate traditional forms of healing into conventional medical care appear to hold significant promise (World Health Organization, 2008; 2013).

Another major barrier to help-seeking was social stigma, especially among people who regarded cognitive impairment as a mental illness. Virtually all participants mentioned stigma as a barrier to care—including doctors who pointed out that physicians who treat “those people” may be subject to ‘courtesy stigma’ by association. PCI and caregivers also described strong stigma associated with seeking help outside the family, which discredits both patient and family. Several family members had begun to confine relatives whose symptoms had worsened. This practice afforded the caregiver and the family a modicum of protection from public scrutiny and judgment, but at the high price of social interaction and stimulation for their impaired relative.

It is interesting to note the interpretation of cognitive impairment as a normal eventuality of aging alongside this experience of stigma, as they might appear conflictual. One explanation for such a disjuncture may be that the impairment signifies mental illness. Another possibility,

since not all older adults experience cognitive impairment, is that the absence of impairment is the standard against which the experience is being assessed. A third explanation may be that the impairment, especially if it progresses, can involve behavior that is socially awkward, difficult or embarrassing. Finally, along with other social and cultural changes, the status of older adults may be diminishing and cognitive impairment may signal and reflect this general decline.

To address the common attitudes that late-life cognitive impairment is not serious, cannot be prevented, cured or controlled, and that it constitutes a source of stigma and shame are likely to require multilevel and multifocal intervention. Following on the KAP assumption that knowledge influences attitudes, accurate information and education targeted to the general public and professional and continuing education might be helpful first step. Examples of key messages are that cognitive impairment is not inevitable, impairment does not invariably progress, some symptoms can be controlled and improved, and early detection and treatment are essential.

This education is of little value, and may in fact instill or exacerbate fear and stigma, if it is not accompanied by explicit information on accessing assessment and treatment. PCI in this study expressed well-founded fears of safety and security, of whether and how their condition will worsen, of whether they will lose their sense of self and become a burden for their families. Caregivers worried that they do not know how to be most helpful, do not know about or cannot access or afford treatment, and may eventually exhaust their capacity for care. Doctors lamented the lack of knowledge and skills and of supports in professional education and the health care system for older adults with cognitive impairment, and worried about futility and stigma.

In a climate of stiff competition for scarce resources, within and beyond health care, a strong advocacy movement might well be paired with public and professional education efforts to promote adequate resources, perhaps beginning with one or two services that are efficient and

effective. Older adults with and without impairment and their families and communities could push this agenda in policy circles. NGOs, social workers, health workers, village level workers and others are highly active in Self-Help Groups (SHG) throughout India. There are two main types of SHGs, one for education and support and another a microfinance forum. These are small (usually < 20 members) voluntary association of poor people who join forces to solve shared problems or to promote small savings among members. The latter type of SHG could help address livelihood concerns or other caregiving needs, especially in low-income communities.

The current cohort of older women in India have minimal or no education and they are most affected by cognitive impairment, as patients and as caregivers (Lee et al., 2014). The lives of rural women are even harsher, they are discriminated against in land and property rights and in access to medical care and finances, and their nutritional status, literacy rates and labor wages are lower than those of men (44 rupees/day vs. 67 rupees/day) (<http://www.alz.co.uk/starting-a-self-help-group>). In early 2014, the Ministry of Rural Development announced Rs 1,400 crore allocations in subsidized loans to women self-help groups in rural India, an amount that promises to benefit 3 crore (30 million) women in 25 lakh (2.5 million) SHGs.

In urban and rural areas, a “collaborative recovery model” (CRM) that assists clinicians to use evidence-based skills with consumers in a manner consistent with the recovery movement in mental health is one appropriate approach (Oades et al, 2005). An adult day-care collective, for example, could be an important resource for patients and caregivers, and could employ local citizens familiar with consumers and their cultural preferences. Intergenerational programming might be another effective, efficient and culturally congruent approach and one that could help reduce stigma.

Societal Initiatives and Responses

Policies, programs, legislation and research are essential to develop, sustain and advance knowledge and practice to improve the well-being of older adults with cognitive impairment and their caregivers. Although mild forms of cognitive impairment do not always lead to dementia, the Alzheimer's and Related Disorder Society (ARDSI) of India is a strong advocacy umbrella for the broader family of conditions of cognitive impairment. ARDSI is the most vocal and powerful lobby calling on government and policy makers to recognize dementia as a health and social welfare priority and to develop a 'National Dementia Strategy'. In this spirit, Alzheimer's International produced the *2010 National Dementia Strategy*, which also addresses milder types of impairment. The purpose of the document was to persuade the government to create a national plan to hold itself accountable for accomplishing specific objectives and policy changes, and for taking leadership on relevant issues, even if they are accomplished in collaboration with NGOs.

The Government of India does not currently sponsor services for people with cognitive impairment or their caregivers. The country also lacks basic infrastructure for service delivery in public and private hospitals and throughout the general health care system. The few available services are through NGOs, e.g., ARDSI, Silver Innings Foundation and Nightingales Medical Trust. ARDSI (Shaji et al., 2010) lists the types and numbers of NGO services nationally as follows: day care centers (10), residential care facilities (6), domiciliary care services (6), support groups (unknown), memory clinics (100) and telephone help lines (10). But, NGO capacity is limited by its urban locale, restricted missions and low resources. Moving or co-locating services to routine health and community settings, as suggested, could improve access and reduce stigma.

There are also important human rights issues for people with cognitive impairment. The Government's 12th Five-Year Plan, which is now in force but still pending approval, references

neurological disorders, including dementia and other types of cognitive impairments, under the purview of the Ministry of Health. This improves visibility, but recognizing them as a group with disabilities would open further options in terms of Social Justice and Empowerment. Grant in aid to support day care, respite care, long-term care and home-based care are prominent examples.

There is also a great need for improved monitoring and research on cognitive impairment in India. The capacity for prevention and control of non-communicable diseases, including national surveillance operations, is limited. A surveillance framework comprising a minimum set of exposures and outcome indicators is needed for policy development and to assess and monitor disease trends and public health. Technical, human and fiscal resource constraints tend to impede effective prevention and control programs. Alwan et al. (2010) suggest a useful surveillance framework for quantifying and monitoring non-communicable diseases and their determinants. They argue for integrating disease surveillance into national health information systems, with regular monitoring of actions that are designed to prevent non-communicable diseases. India does have an operational integrated policy on non-communicable diseases and a dedicated office within its Ministry of Health. Diseases that cause cognitive impairment should be included in basic health information systems and high-risk population groups might be surveyed routinely. Primary care providers or their designees, once trained to detect cognitive impairment, could be charged with this type of monitoring.

There is a great need for high quality research that can contribute to monitoring, building an evidence base, and informing policy and advocacy in the country and the region (Dias et al., 2008). Studies on the prevalence, course, outcome and impact of health problems of older adults, including cognitive disorders, are needed in primary care settings. There is also a need for research to guide the development, implementation and evaluation of services. Strengthening

linkages between academic settings and day-to-day practice could facilitate the generation, dissemination, and effective application of research in education and advocacy. There is also a need for funding mechanisms for participatory and implementation studies in which researchers collaborate with individuals and families and with community-based and non-governmental organizations (see National Institute of Mental Health and NeuroSciences (NIMHANS, 2014).

PCI and caregivers in this study worried a great deal about their uncertain futures. Of particular concern was the possibility that memory loss would worsen and whether they would have the capacity and resources to manage the situation over the long term. Middle-income PCI worried that if they reached this stage, their families would have no choice but to give up care. But since their relatives were mildly impaired, most caregivers were guardedly hopeful that they would be able to manage. Lower-income participants were more present-focused and showed by example how their community is obliged to care for them—meaning to ensure safety, food, and shelter. As one psychiatrist described it: “Somehow they manage to learn and they learn to manage.”

Individuals who had exposure to older adults with cognitive disorders were less sanguine. They specifically expressed grave concerns about behavioral and psychological symptoms of dementia (BPSD), i.e., agitation, aggression, repeated calling, sleep disturbance, wandering and apathy, which typically occur in the middle of the disease trajectory, as well as depression and psychotic hallucinations and delusions. To know that they would have access to necessary means for self-care and the ongoing care of their family member could go far toward assuaging present anxieties. The Disease Control Priorities Project (DCP) compiles best available information on interventions to prevent or manage significant diseases in developing countries (Chandra et al., 2006). A section on mental, neurological and substance use disorders (Patel, forthcoming) in the

third edition (DCP³) will update information on cognitive impairment, including evidence-based therapies for psychological symptoms, e.g., anxiety, depression, agitation, delusions and hallucinations, for more advanced disease. Training family caregivers and paraprofessional aides in behavioral management techniques can help reduce agitation and anxiety. Treatments that target stress and depression of caregivers may also be beneficial.

Finally, with regard to the need for a continuum of care for persons with progressive cognitive impairment and their caregivers, there is a strong palliative care movement in the state of Kerala that could be incorporated into this service sector (Sivaraman, 2005). Knowing this service is available could lessen the anxiety which PCI expressed about euthanasia as an option to spare families the burden of care and could mitigate the concerns of caregivers that they may not be able to manage the care of their relative over the long term.

The three participant groups in this study brought unique perspectives issues of memory loss in India, yet their knowledge, attitudes, values, beliefs and practices were remarkably similar. This concordance likely reflects common sociocultural and environmental substrates that give rise to and reinforce individual and shared perceptions and responses to ill health. Going forward, the question will be whether barriers to detection, diagnosis, treatment and quality care for patients and their family caregivers can be sufficiently identified and addressed. It is a matter of population health, which in turn is a matter of human rights and social justice.

Summary

There is a widespread if not universal tendency of people in India to attribute problems of age-related cognitive impairment to normal aging processes. To correct this common conflation of correlation and causality requires an effort to first understand its origins and how it functions. The purpose of this study was to discover how three groups of people in Mumbai who are

intimately involved in this issue make sense of and act on it in ways that help them to preserve the integrity and dignity of their lives.

The challenges faced by older adults with cognitive impairment in India are substantial and extend across sectors. Policies and services would do well to exploit existing linkages of the health, mental health and aging sectors to increase awareness and knowledge and promote healthy attitudes. Areas for potential focus are prevention, accurate and timely diagnosis, quality of care, caregiver support, workforce training, monitoring and surveillance, and research. In the face of limited resources, governmental and non-governmental strategies and services should target the most vulnerable groups, such as the poor and those who lack access to care. Finally, legislation and regulation are needed to reduce stigma and discrimination and promote respect for human rights.

Study Limitations

Although generalizability is not a goal of qualitative research, it is important to note that the small size of the sample, and their selection from public memory clinics in Mumbai, potentially limit the findings. Use of the MoCA is another possible drawback. There is an official Hindi-language version of the MoCA, it is often used in India, and its performance in this study suggests good face validity. But it has not to my knowledge been validated for use in India. This is an important task for future research given the multiplicity of languages and cultures within the country. Thirdly, persons with cognitive impairment appeared to be functioning well and their caregivers reported no recent decline. We thus did not perform a formal functional assessment, which might have permitted us to better distinguish levels of cognitive impairment.

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Appendix A: Discussion Guides

Wording adapted by participant group (PCIs, Family Caregivers)

Focus Groups

Introduction: We would like to talk with you today about the experience of cognitive impairment, which is more common as people get older. [Moderator will describe CI in lay terms as involving memory loss, confusion]. We would like to learn more from you about how you and other people think about this issue, what you think are the biggest challenges and best ways to cope with such challenges.

Q. 1 What do you think of when you hear about cognitive impairment? What do you think causes it? Who does it happen to? What happens once someone has it? What can you do to treat it or make it better?

Q. 2 What do you think [people who are close to you, such as your friends, family, and others in your community] [health care providers, such as doctors, nurses, and social workers] [people in the general public] think about this condition?

Q. 3. How do you suppose these views might influence someone who has cognitive impairment in terms of their willingness and ability to seek help to manage it?

Q. 4. If you could develop a program to help people and their families manage this condition better in your community, what would it look like?

Q. 5. What sorts of things would make you more likely to participate in such a service? Less likely?

In-Depth Interviews: P-MCI, Family Caregivers)

Q.1 When you think about someone who had cognitive impairment, what comes to your mind? What do think causes it? Who do you think gets CI ? What happens to a person once they have CI? What can you do to treat it or make it better?

Q. 2 How do think others [close networks / health care providers/general public] see this condition ?

Q. 3 Could you tell me a bit about how you came to find out you [family member] have this condition?

Q. 4 How have things been going for you [family member] since the diagnosis? Challenges? Strengths?

Q. 5 What sorts of things have you done to cope with these challenges? What has worked best? Not?

Q.6 Looking ahead, how do you see the future unfolding for yourself / your family member?

Q. 7 If a program for persons experiencing cognitive impairment and their caregivers was established in your community, what should it look like?

In-Depth Interviews: Physicians and Traditional Healers

Q. 1 Do you often see patients for cognitive impairment that is serious enough to be considered mild cognitive impairment or early stage dementia? Does it seem to be a growing problem in your practice here in Mumbai? Under or over diagnosed?

Q. 2 Based on your knowledge and experience, what would you say is an ideal screening and treatment program for dementia?

Q. 3 How are these patients typically managed in clinics, hospitals, emergency rooms and other health care settings? How do you think they might best be managed?

Q. 4 Could you describe for me what types of training, if any, you have received to prepare you to work with persons with dementia, either in your school curriculum or in courses or training since then?

Q. 5 What would you say are the main challenges you face in treating patients with dementia?

Q. 6. What sorts of resources do you now have or need to effectively manage the care of these patients?

Q. 7. Could you please select one patient with dementia whom you have or are currently treating and describe how you have managed his or her care? What has been most effective? Least?

Q. If you had 15 minutes with the Minister of Health to discuss what is needed most to improve the future care of people with dementia in India, what would you tell him?

Appendix B: Montreal Cognitive Assessment

MONTREAL COGNITIVE ASSESSMENT (MOCA)
Version 7.1 Original Version

NAME : _____
Education : _____ **Date of birth :** _____
Sex : _____ **DATE :** _____

VISUOSPATIAL / EXECUTIVE							POINTS
		Copy cube	Draw CLOCK (Ten past eleven) (3 points)				
[]	[]	[]	[]	[]	[]	[]	[]
		[]	[]	[]	[]	[]	___/5
NAMING							
						[]	___/3
		[]	[]	[]			[]
MEMORY		Read list of words, subject must repeat them. Do 2 trials, even if 1st trial is successful. Do a recall after 5 minutes.					No points
		FACE	VELVET	CHURCH	DAISY	RED	
		1st trial					
		2nd trial					
ATTENTION		Read list of digits (1 digit/ sec.). Subject has to repeat them in the forward order [] 2 1 8 5 4 Subject has to repeat them in the backward order [] 7 4 2					___/2
		Read list of letters. The subject must tap with his hand at each letter A. No points if ≥ 2 errors [] FBACMNAAJKLBAFAKDEAAAJJAMOFAA B					___/1
		Serial 7 subtraction starting at 100 [] 93 [] 86 [] 79 [] 72 [] 65 4 or 5 correct subtractions: 3 pts , 2 or 3 correct: 2 pts , 1 correct: 1 pt , 0 correct: 0 pt					___/3
LANGUAGE		Repeat : I only know that John is the one to help today. [] The cat always hid under the couch when dogs were in the room. []					___/2
		Fluency / Name maximum number of words in one minute that begin with the letter F [] _____ (N ≥ 11 words)					___/1
ABSTRACTION		Similarity between e.g. banana - orange = fruit [] train - bicycle [] watch - ruler					___/2
DELAYED RECALL		Has to recall words WITH NO CUE					Points for UNCUED recall only
		FACE	VELVET	CHURCH	DAISY	RED	
		[]	[]	[]	[]	[]	
Optional		Category cue _____ Multiple choice cue _____					
ORIENTATION		[] Date [] Month [] Year [] Day [] Place [] City					___/6
© Z.Nasreddine MD www.mocatest.org Normal ≥ 26 / 30		TOTAL			___/30		
Administered by: _____		Add 1 point if ≤ 12 yr edu					