Hearing Senility Being Spoken: Aging, Dementia, and Caregiving in Beijing, China

> Shika Card, Department of Anthropology McGill University, Montreal

> > July 2014

A thesis submitted to McGill University in partial fulfillment of the requirements of the degree of Master of Arts

© Shika Card 2014

Table of Contents

Abstract ii

Acknowledgements iii

Introduction 1

An Invitation to Listen 1 Fieldwork in Beijing: Observations on Methods 3 A Brief History of Mental Health Care in China 9 "Too Much in One Word": The Difficulty with Dementia 11 Finding Words for Chidaizheng in China 14 Ethnography in a "Changing Moral Landscape" of Care 18 Aging Anthropologically: Emerging "Geroanthropology" 20 The Anthropology of Senility and Turning Toward the Person 22 Anthropologizing (with) Care 26 Observation as Method for a "Sensuous Scholarship" 29 Outline of Chapters: Taking Up the Invitation to Listen 32

1 Hearing Voices of Difference 35

Songtang Hospital: A Conversation of Very Few Words 35 Theoretical Trajectories: Toward Senility, Voice, and Care 38 The Outpatient Clinic: Unraveling Voices and Hearing Mismatches 42 Taking Communication Seriously, or Listening Ironically 48 Arriving at an Intermediate Area, and Elsewhere 52 At Home with Yeye: Playing with Bottomless Feet 56 When Do We Play? 64 On To Care 65

2 Taking Care to Play 67

Prelude: Following the Logic of Play 67
Interlude: Theorizing Play 70
Act 1: How to Be Serious at Play 76
Act 2: "The Donkey's Head Does Not Fit the Horse's Mouth" 87
Act 3: Psychotherapy as Play, and Taking an Imaginative Leap 98
Coda: Caring About Playing with Senility 102

Conclusion 105

Revisiting the Difficulty with Dementia 105 Taking Care with Ethnography 107 Epilogue: Grandma Barbara, and My Memory 109

Glossary 111

References 113

Abstract

This thesis is an ethnographic invitation to listen to the recognizable difference of the senile voice in a different way, and to rethink the predominant perception of dementia as a condition of degeneration, loss, and disability. Based on ten weeks of fieldwork in Beijing, including thirteen, in-depth interviews with clinicians and family caregivers, as well as observational data gathered in diverse therapeutic settings, this thesis examines how particular modes of communication enable reconfigurations and reaffirmations in caregiving relationships. Putting into question the common impulse to listen primarily for the semantic qualities of speech and language, I argue that alternative and experimental forms of listening and speaking that take the resonances of a senile voice on its own terms make possible a new interactive space between the person with dementia and her caregiver. I take up the notion of play, which can be both creative and serious at the same time, to demonstrate how communication can enact new and transformative practices of care. In this thesis, I show how play enables and empowers a different understanding of senility that primarily takes into consideration not its deleterious effects on the person, but rather its imaginative potential for surprise and joy in relationships of care.

Résumé

Ce mémoire forme une invitation ethnographique à écouter différemment la particularité de la voix sénile et ainsi à reconsidérer la perception dominante de la démence comme une condition de dégénération, perte, et handicap. Ce travail est le résultat the dix semaines de recherche de terrain à Beijing, durant lesquelles j'ai réalisé treize entretiens détaillés avec des cliniciens et auxiliaires de vie et ai eu l'opportunité d'observer différents contextes thérapeutiques. Ce travail examine comment certains modes de communication reconfigurent et réaffirment les rapports construits autour des soins et de l'attention à l'autre. Visant à mettre en question l'impulsion courante d'écouter principalement le discours et le langage à travers leurs qualités sémantiques, ce travail soutient que des formes d'écoute alternatives et expérimentales ouvrent un nouvel espace interactif entre la personne atteinte de démence et la personne qui s'en occupe. J'utilise la notion du jeu, qui est à la fois créative et sérieuse, pour démontrer comment la communication peut générer des pratiques de soins nouvelles et transformatives. Dans ce mémoire, je montre comment le jeu rend possible et donne valeur à une différente compréhension de la sénilité qui a comme considération première non pas ses effets nocifs sur la personne, mais plutôt son potentiel imaginatif pour la surprise et la joie dans les relations de soins et d'attention.

Acknowledgements

I would like to thank the ayi, laoshi, daifu, hushi, nainai, and yeye who took the time to share their stories, experiences, knowledge, and wisdom with me during my time in Beijing. I extend my deep gratitude to Huali Wang, without whose thoughtful guidance my research would not have been possible. I would like to thank Zhao Mei for being the "backbone" of my fieldwork and the team at the Peking University Institute of Mental Health for teaching me so much about aging, care, and medicine in China. I want to thank my graduate supervisor, Sandra Hyde, for her enthusiasm and unwavering support of my research interests throughout my Master's studies at McGill. I wish to thank Lisa Stevenson for inspiring me to take care in thinking, listening, and writing anthropologically. Thanks also to Felicity Aulino, Arthur Kleinman, and Byron Good for their continued mentorship. I am grateful to the Canadian Institutes of Health Research and the Michael Smith Foreign Study Supplements Program for generously funding my research in Beijing. My sincere thanks to Fiona Gedeon Achi for her gracious help with translating the abstract. I would like to thank Josh Eisen, Darcie DeAngelo, and John Mei for their friendship and invigorating discussions. I wish to thank also my writing group, whose support, insight, and shared experiences motivated me to continue writing through the winter months in Montreal. Thanks to Noor Beckwith for being a patiently attentive listener and a wonderful partner in play. I would like to thank my parents, who have continually set for me an example of caregiving that I aspire to. Finally, I wish to thank my grandparents, to whom this project is dedicated, with love and gratitude.

"A voice means this: there is a living person, throat, chest, feelings, who sends into the air this voice, different from all other voices. A voice involves the throat, saliva, infancy, the patina of experienced life, the mind's intentions, the pleasure of giving a personal form to sound waves. What attracts you is the pleasure this voice puts into existing: into existing as voice; but this pleasure leads you to imagine how this person might be different from every other person, as the voice is different."

-Italo Calvino, Under the Jaguar Sun

"Nouns are formed by an accumulation of adjectives. One does not say moon; one says airy-clear over dark-round or orange-faint-of-sky or some other accumulation. In the chosen example, the mass of adjectives corresponds to a real object. The happening is completely fortuitous. In the literature of this hemisphere, ideal objects abound, invoked and dissolved momentarily, according to poetic necessity. Sometimes, the faintest simultaneousness brings them about. There are objects made up of two sense elements, one visual, the other auditory-the color of a sunrise and the distant call of a bird. Other objects are made up of many elements-the sun, the water against the swimmer's chest, the vague quivering pink which one sees when the eyes are closed, the feeling of being swept away by a river or by sleep. These second degree objects can be combined with others; using certain abbreviations, the process is practically an infinite one. There are famous poems made up of one enormous word, a word which in truth forms a poetic *object*, the creation of the writer. The fact that no one believes that nouns refer to an actual reality means, paradoxically enough, that there is no limit to the numbers of them."

—Jorge Luis Borges, Ficciones

Introduction

An Invitation to Listen

"No one really speaks to me anymore," the woman says, smiling. When asked, she does not know what day, month, year, or season it is, or how old she is, and only with some prompting from the young woman asking her these questions does she guess that we are in Beijing. "These are things that I haven't thought about in a long time, and it's been a long time since I've spoken to anyone," she says, chuckling to herself and glancing at the man sitting next to her. "He doesn't really talk to me anymore."

It is two o'clock in the afternoon on July 12, 2013, at the Peking University No. 6 Hospital. One week into my fieldwork, I am sitting in on a mini-mental state examination (MMSE), a 30-point questionnaire used routinely in clinical practice to assess cognitive impairment. A medical student is conducting the MMSE for a woman named Sun¹, who is accompanied by her husband, Zhang. Sun comes into the Dementia Care and Research Center at this hospital every three months for a regular check-up. Taken repeatedly every few months, the MMSE, along with other diagnostic procedures including medical history and MRI scans, can help Sun's doctors assess the extent to which she might be experiencing cognitive decline.

"How old am I?" Sun quietly asks her husband when she is unable to answer the student's question. "81? 85?" Zhang shakes his head both times without saying anything, and Sun chuckles. Eventually, the student determines Sun's age by looking at the birth

¹ All names of individuals, with the exception of doctors and nurses who consented to having their names used, are surname pseudonyms.

year indicated on her medical records, subtracting 1927 from 2013. "Oh, 86!" Sun exclaims when the student tells her, laughing with a toothy smile.

After the MMSE, the medical student asks Sun to self-evaluate aspects of her health.

"Would you say that your current memory is poor, average, good, or excellent?"

Sun ponders the question for a moment, and then answers confidently, "I think it's average."

"How about your mental health?"

"Good," Sun answers, this time without hesitation. Her gaze moves between the student, her husband, and me as she waits for the next question. She sits with her hands clasped in her lap, occasionally brushing a strand of long grey-black hair from her face.

"How about your family and your marriage?"

"They're both good," Sun says, smiling and nodding. The only question to which she gives an answer of "poor" concerns her current ability to handle finances.

Observing the scene, I find myself surprised by the juxtaposition of the noticeable, lingering silence of the student's unanswered questions, signaling the absence of Sun's memory, and the older woman's quiet laughter. Sun seems neither despondent nor distressed when she is unable to answer what day or year it is, where she is, or how old she is. Instead, she gestures toward playfulness—in a sense, playing with the number of her age, as she guesses 81, 85, before happily settling on 86. Sun's matter-of-fact expression of the regular absence of her own spoken voice and the rarity of speech makes recognizable the gap of communication she experiences in her daily life. Her voice is one that is left unheard, unspoken, and unspoken to.

To her listeners—the medical student, Zhang, and myself—Sun's voice is identifiably marked by the loss of memory, one of the primary indicators of what might be considered a senile mind. It is, however, not this sense of cognitive loss, of despair at something unrecoverable, that I am interested in examining. I want to ask a different kind of question here: what does Sun's proclamation call to our attention? In saying that it has been a long time since she has spoken with anyone, Sun can be heard to be calling forth not a lament for memory, but rather a provocation and an invocation for communicative engagement, chuckling and laughter included. The utterance, "No one speaks to me anymore," thus, can be taken as an invitation to critically rethink and reimagine ways of speaking and listening to a senile voice.

Fieldwork in Beijing: Observations on Methods

"For is there not something else going on here, something connecting fieldwork to writingwork, something they have in common? For instance, fieldwork involves participant observation with people and events, being inside and outside, while writingwork involves magical projections through words into people and events. Can we say therefore that writingwork is a type of fieldwork and vice versa?"—Michael Taussig, "The Corn-Wolf: Writing Apotropaic Texts"

This ethnographic thesis sets out to examine the different ways in which care can be enacted as a communicative practice in the context of the growing recognition of dementia in modern-day China. My interest in dementia care grew out of the research I conducted in 2011 in Beijing, the city where I was born and spent the first four years of my life, for my undergraduate thesis on end-of-life caregiving. It was also inspired by my own experiences with my grandparents, with witnessing my grandmother's undiagnosed early-stage dementia when I was a teenager, and later, my grandfather's struggle with terminal lung cancer. In pursuit of these long-standing questions concerning aging,

illness, and death, I returned to Beijing to conduct research for my Master's thesis in order to understand how the relatively recent development of dementia as a biomedical diagnostic category makes possible new forms of caregiving, with attention to interpersonal interaction and communication.

This project has been undertaken with a spirit of commitment to the practice of ethnography as an inquiry into the lived experiences of others. Qualitative social science research, including the ethnographic method commonly used by anthropologists, has been traditionally based on an empiricist view that emphasizes the dichotomies between researcher and subject, self and other, the subjective and the objective (see Davies 2010). Although the discipline of anthropology saw a "reflexive turn" in the late 1970s and early 1980s emerging from a postmodern critique of the authority of the "ethnographic gaze", the question yet remains as to what extent the anthropologist's emotions and personal experiences should constitute her ethnography.

I am inclined to take the position that the ethnographer's subjectivity motivates and deeply informs her research, shaping the ways she might interpret and understand her fieldwork. "Ethnography," writes Sherry Ortner, "has always meant the attempt to understand another life world using the self... as the instrument of knowing... in which the whole self physically and in every other way enters the space of the world the researcher seeks to understand" (Ortner 1995:173). At the same time, however, ethnography also necessitates a careful balance between what Athena McLean calls the researcher's "personal shadows" (McLean 2007:263) and thoughtful and thorough insight into the lives, sensibilities, and experiences of those she has set out to learn about.

In my research in Beijing, I made use of three common elements of ethnographic methodology: interviews, participant observation, and fieldnotes. For ten weeks between July and September of 2013, I collaborated with a team of psychiatrists, medical students, and clinical researchers at the Peking University Institute of Mental Health and its affiliated hospital, the Peking University No. 6 Hospital. Institutional Review Board (IRB) approval was obtained for this project at both McGill University and the Peking University Institute of Mental Health prior to commencing fieldwork.

Most of my research took place at the No. 6 Hospital, a white, square-shaped building with a garden of red roses at its entrance, which provides inpatient and outpatient psychiatric and geriatric care over six floors. The Department of Mental Health comprises a hallway of offices located on the second floor of a smaller building behind the No. 6 Hospital. On weekdays, I would typically arrive in the morning and set up at the cubicle that had been provided for me in the medical students' office. If I did not have an interview scheduled for the morning, I would work in the office, sit in on Mini-Mental Status Examinations and patient appointments in the Dementia Care and Research Center, located on the second floor of the main hospital building, or attend lecture presentations with the medical students.

Under the supervision of Dr. Wang, the Associate Director of the Dementia Care and Research Center, various members of the research team contacted health practitioners and family caregivers with whom they were acquainted and asked if they would be interested in being interviewed for my research project. I conducted 13, in-depth, semistructured interviews in Mandarin Chinese (without the aid of a translator) with two physicians, two nurses, and nine family caregivers. Interviews with family caregivers

took place for the most part at the Dementia Care and Research Center and on occasion in homes, while interviews with health practitioners took place at their place of work, which included the No. 6 Hospital, the Beijing Geriatric Hospital, and the 301 Military Hospital. Interviews were not conducted with dementia patients. Prior to the beginning of an interview, an IRB-approved form in Chinese detailing my research, as well as an oral script by myself in Mandarin Chinese, was provided to the interviewee in order to obtain informed consent. Interviews with health practitioners typically focused on understanding diagnostic criteria and clinical treatments, as well as their perspective on caregiving for patients with dementia from a professional standpoint. Interviews with caregivers often took on the format of a narrative account of their family member's experience with dementia and their own caregiving journey along different stages of the disease progression. With the exception of one caregiver who I interviewed twice, interviews were conducted on one occasion and ranged from one to two hours. Interviews were audio-recorded and were later simultaneously transcribed verbatim and translated by myself into English.

Participation observation, an integral method in anthropological fieldwork, also played a prominent role in my research. Participant observation involves a long-term immersion in the experiences, interpersonal dynamics, social and cultural worlds, and physical settings in which people's day-to-day lives play out. It differs from direct observation in that it is not carried out at an "objective" distance, but rather is "inherently a qualitative and interactive experience and relatively unstructured", generating "free flowing" and interpretive data (Guest et al. 2013:79). In this way, the ethnographer's subjectivity is necessarily engaged in her analysis of her material, without losing the

methodological rigour of the research. In Beijing, I participated in caregiver training sessions and support groups organized by the research team as part of their community health programs. Usually no more than four or five family caregivers attended these weekly sessions, which were led by Mrs. Li, a non-clinically trained member of the Dementia Care and Research team. I also attended the morning activities for patients and families that took place every first Saturday of the month, during which a guest lecturer would present a topic related to dementia care, followed by musical performances by a group of young volunteers. These events were also occasions for patients and caregivers to get together and chat with other families.

A more direct observational method was used when I "shadowed" Dr. Wang in her geriatric psychiatry outpatient clinic at the No. 6 Hospital on four days. I observed her interactions with patients as she took their medical history, reviewed their brain imaging scans and MMSE results, and, on occasion, provided psychotherapeutic counseling. The notes I took during these sessions consisted of my observations of their interactions with Dr. Wang, and no identifiable information about patients was recorded. At the end of each day, I updated a typed document of fieldnotes, written in English, to which only I had access on my personal computer.

Furthermore, the method of participant observation "involves not only gaining access to and immersing oneself in new social worlds, but also producing *written accounts and descriptions* that bring versions of these worlds to others" (Emerson et al. 2001:352; italics original). The intimate link between the participation observation component of fieldwork and what Michael Taussig calls the "writingwork" (Taussig 2010:26) of keeping fieldnotes became increasingly clear to me during my time in

Beijing. I wrote fieldnotes in the format of daily journal entries, in which I recounted the activities of the day, as well as my reflections and feelings, raised questions, and made note of curiosities and moments of surprise or perplexity that arose from events that had transpired. I took care to record in as much detail, and as soon after the fact as possible, not only descriptions and sensations of places and events, but also exact words and phrases that I had heard spoken throughout the day. In the early stages of structuring, organizing, and writing, I relied primarily upon these fieldnotes to provide conceptual and analytical directions, and much of the ethnographic writing featured in this thesis builds on the original "raw" (Emerson et al. 2001:353) fieldnotes I wrote in China.

Fieldnotes can be considered to be "a distinctive form of ethnographic writing" (Emerson et al. 2001:353) that offers powerful insight into not only the ethnographic material itself but also the ways in which the ethnographer finds and orients herself in the field. As such, the descriptive writing found in fieldnotes is as much a reflection of moments of meaning- and sense-making for the ethnographer as it is a factual record of places, people, and events (Emerson et al. 2001:353). Because the process of thinking through fieldwork research and writing is inevitably subjective to the ethnographer, fieldnotes are selective in what they include and exclude, and in what they emphasize and how it is framed. "In writing fieldnotes ethnographers face constant choices not only in what to look at and take note of, but also in how to write down these matters. As texts fieldnotes are through and through products of a number of writing conventions, varying not only in content but in style, voice, focus and point of view" (Emerson et al. 2001:365). The descriptive, selective, and personal nature of my fieldnotes is undoubtedly reflective of my own experiences living in Beijing. They provide a textual

mapping of my efforts to navigate the dynamics of being in a place that is simultaneously familiar and foreign to me, and of doing research about an illness that renders the familiar foreign.

Because this research took place over a short period of time—albeit amounting to more than two hundred hours of interviews, activities, lectures, conferences, and shadowing—and made use of a particular set of methods, it poses certain limitations on the kind of findings it presents. James Davies writes, "[M]ethods constrain both what can be discovered and what spheres of subjectivity are viewed as empirically useful in the act of discovery" (Davies 2010:13). With a limited scope in mind, this thesis does not attempt to make generalizable claims on the cultural experience of dementia care in China, nor does it extend its conclusions to propose recommendations for health policy reform. Rather, it is an effort to show through observation, interaction, and attention to words and sensory experiences the ways in which relationships of care can unfold for those whose lives have been altered in one way or another by dementia.

A Brief History of Mental Health Care in China

I want to bring attention to the context of psychiatry and psychotherapy in which the clinical encounters I observed in Beijing are embedded, as well as the historical trajectory that mental care has taken in twentieth-century China. Mental health care has traditionally been viewed as the responsibility of the family and its extended network. The first half of the twentieth century, however, saw the establishment of the Beijing Psychology Institute in 1937 and the introduction and professional development of Western-influenced psychotherapy. Psychologists and psychiatrists were trained in various modalities of psychotherapy, including Freudian psychoanalysis, behavioural

therapy, group therapy, as well as psychopharmacology (Lim et al. 2010). During the Cultural Revolution, between the years of 1966 to 1978, psychotherapy was considered to be counterrevolutionary, and the services provided by psychologists and psychiatrists— effectively, mental health care—were suspended. "Mental illness and other forms of deviance were cast as problems of misdirected political thinking to be addressed through re-education, rather than mental health care" (Gao et al. 2010:75).

Since the political and economic reforms of the 1980s, there has been a reemergence of mental health services, as the "opening to the West" movement in China "promoted the revitalization of Chinese psychiatry and its re-engagement with Western scientific communities" (Gao et al. 2010:75). However, both mental health legislation and mental health care resources remain lacking. Only very recently was the National Mental Health Law passed in 2012, after 27 years of legislative debate. The new law aims to improve the quality of mental health care, shifting the focus from specialized psychiatric hospitals to general hospitals, and to protect the rights of patients by requiring that psychiatric treatment be voluntary (Phillips et al. 2013; Xiang et al. 2012)

In terms of resources for mental health care, a worldwide survey reported that China has a ratio of 1.99 psychiatric nurses, 1.29 psychiatrists, and 10.60 "mental health" beds per 100,000 people (Gao et al. 2010). The overwhelming majority of these services are located in urban areas, such as the No. 6 Hospital where I conducted my research. Furthermore, "the familiar professional disciplines of clinical psychology, psychiatric social work, and occupational therapy have barely been established in China" (Lee 2011:209); I would also include psychogeriatrics in this list (see Wang et al. 2013). At the same time, there is a rising demand for psychotherapy among Chinese people who

have access to mental health care. Anthropologist Sing Lee writes, "Though not affordable for poorer people, the rapidly growing market for talk therapy heralds a new era in the management of emotions and other problems of the Chinese psyche" (Lee 2011:208).

In making this digression into the recent history of mental health care in China, my aim is to provide a social and cultural context to the particular conversations that take place in therapeutic settings between people with dementia and their caregivers, which will feature prominently in this thesis. In taking up the opening invitation to listen carefully, I want to bring attention to the nuances of language and of the spoken voice, including its words, intonations, and utterances, which we might hear unquestioningly as the telltale characteristics of senility.

"Too Much in One Word": The Difficulty with Dementia

"The issue, of course, is one of context and emphasis. Science, for example, requires a highly precise language. Too frequently, the fears and misunderstandings of the public, the needs of science, the inanities of popularized psychology, and the goals of mental health advocacy get mixed together in a divisive confusion."—Kay Redfield Jamison, *An Unquiet Mind*

According to the World Health Organization, dementia is defined as "a syndrome due to disease of the brain—usually of a chronic or progressive nature—in which there is a disturbance of multiple higher cortical functions, including memory, thinking, orientation, comprehension, calculation, learning capacity, language, and judgement" (WHO 2012). With an estimate of 36 million people with dementia in 2010 and a predicted estimate of 115 million by 2050 (World Alzheimer Report 2012), dementia is one of today's most critical global public health issues. The two most common forms of dementia are Alzheimer's disease, representing approximately 50-75% of all cases

globally, and vascular dementia, which accounts for 20-30% of cases (World Alzheimer Report 2009).

The term "dementia," Latin for "being out of one's mind" (Oxford Dictionary of English 2010), is fraught with nosological complications, which has implications for medical treatment and care. Dementia is predominantly taken as an umbrella term for a syndrome that comprises a wide range of generally irreversible signs and symptoms, expressed in distinct manifestations and to varying degrees in different individuals. Although Alzheimer's disease and vascular dementia are the most common subtypes of the senile dementias, this umbrella term also includes frontotemporal dementia (which occurs most commonly in people aged 65 and under), dementia with Lewy Bodies, and dementia that consists of a mixed form of its subtypes. Consequently, establishing diagnostic specificity within this broad, all-encompassing term *dementia* becomes something of a challenging "conceptual mess" (Hughes 2011:13).

Changes in the most recent edition of the American Psychiatric Association's *Diagnostic and Statistical Manual of Mental Disorders* (DSM-5 2013) can be interpreted as a procedural attempt to address this issue of conceptual accuracy and establish another term for the conditions encapsulated by dementia. Previously categorized under "Delirium, Dementia and Amnestic and other Cognitive Disorders," the term "dementia" has been reclassified under "Major and Mild Neurocognitive Disorders" (NCD). Subcategories under Major and Mild NCD then attribute the disorder to a subtype, indicate any behavioural disturbance, and specify current severity (mild, moderate, severe) based on functional capability and cognitive impairment. Diagnostic features for Major NCD due to Alzheimer's can include: psychotic features, irritability, agitation, combativeness,

and wandering (DSM-5 2013:612). These features may or may not be expressed in people with dementia, at different stages of the disease progression, and may be temporary or more central to their experience. In other words, dementia can exist in distinct manifestations that are unique to the individual's biology, personality, personal history, and what anthropologist Lawrence Cohen calls the "therapeutic milieu" (Cohen 2006:2). I take this notion of the therapeutic milieu to include not only the practices of care available to the person with dementia, but also the ways in which such practices are articulated and framed in their particular social, cultural, and institutional contexts.

The frames of reference used in defining dementia occupy a significant role in the ways that dementia is perceived and imagined² as an illness. The most common definitions for dementia reveal a predominant focus on its cognitive aspect, namely on one's functional capacity for language, memory, and recognition (WHO 2012; ICD-10 1992). Julian Hughes, writing about geriatric psychiatry from a philosophical viewpoint, problematizes this cognitive-centered understanding of dementia and claims that such a perspective ignores the "broader reality of dementia," which he argues is an experience of the whole person, and not just of the cognitive functionality of the brain (Hughes 2011:14). In order to clarify the etiology of the condition, Hughes proposes the new, whole person-centered term "acquired diffuse neurocognitive dysfunction" (Hughes 2011:18).

² I use the term "imagined" not to suggest that dementia is an unreal or false health condition, but rather in reference to the sociological idea of the "imaginary" derived from the psychoanalytic works of Jacques Lacan and Charles Taylor's concept of the "social imaginary," which denotes the symbolic and creative dimensions of the social world that make collective life and common understandings possible (see Taylor 2002). I also draw upon Mary-Jo DelVecchio Good's idea of the "medical imaginary," the affective dimension of medicine and science that shapes not only patient experience, but also what Good calls biomedicine's "political economy of hope" and its "biotechnical embrace" (Good 2007:364).

I take this debate around nomenclature to be representative not only of a difficulty with understanding what precisely constitutes dementia as a medical condition, but also of an instance in which we—as scholars, practitioners, theorists, and thinkers, in the broadest sense of the word—find ourselves at a loss for words, and for coherence. This search for a suitable term entails a certain kind of struggle with language and arrives at a semantic impasse in which the limitations of our current logic, language, and their imaginative capacity are made explicit. Perhaps, there is simply, as Hughes remarks, "too much in one word" (Hughes 2011:13). This quality of "muchness" in the word *dementia* is not merely a question of establishing an accurate definition for the purpose of medical classification, but necessarily becomes a direct, experiential issue about care for those whose lives are affected by the illness. In the context of Chinese geriatric medicine and health policy for elderly care, we find just as "much" in thinking about dementia's equivalent term *chidaizheng* and in searching for its alternative.

Finding Words for Chidaizheng in China

"I can never say what I want to say,' continued Naoko. 'It's been like this for a while now. I try to say something, but all I get are the wrong words – the wrong words or the exact *opposite* words from what I mean. I try to correct myself, and that only makes it worse. I lose track of what I was trying to say to begin with.""—Haruki Murakami, *Norwegian Wood*

"[A]pocalyptic gerontology,' the view that the aging of a nation's population will precipitate its financial ruin, is alive and well in China," writes anthropologist Charlotte Ikels (2002:233). The development of dementia care is a crucial concern for China today as it faces a large, rapidly aging population. The National Bureau of Statistics in China shows a population of 184 million that is aged 60 or older, making up 13.7 percent of the total population in mainland China (National Bureau of Statistics 2012). The WHO

estimates a total of 5.4 million people with dementia in China as of 2010, using UN population and global dementia prevalence data (WHO 2012). However, a 2011 article published in China Daily states that there are more than 10 million people with Alzheimer's disease, based on an estimate made by the Chinese Committee for Alzheimer's Disease International (Li 2011). Significant quantitative, demographic and epidemiological research has been conducted by Chinese and international scholars in response to the increased prevalence and public recognition of dementia (see Chan et al. 2013; Feng et al. 2011; Guo et al. 2012; Jia et al. 2014; Prince 2013; Wen et al. 2011; Zhang et al. 2012). Recent studies in gerontology and geriatrics have also examined the challenges faced by dementia caregivers (see Liu et al. 2012; Tang et al. 2013; Wang et al. 2010), as well as the cultural norms and traditions that inform the experiences of dementia caregivers (see Ramsay 2013).

Although the DSM is used selectively in China (see Zou et al. 2008), the predominant diagnostic manual used by Chinese psychiatrists is the Chinese Classification of Mental Disorders (CCMD), now in its third edition. In the CCMD-3, the equivalent of "Neurocognitive Disorders" is categorized as "Organic Mental Disorders." However, the predominant Chinese term for "senile dementia" is *chidaizheng*, which literally means "an illness (*zheng*) of idiotic (*dai*) madness (*chi*)." In my first few interviews with family caregivers, I would use the term *chidaizheng* under the assumption that this was the most commonplace and least medicalized word for dementia. While some caregivers would also use *chidaizheng* without issue, others would speak in terms of "AD" (Alzheimer's disease), "*renzhi zhang'ai*" (cognitive impairment), or "*jiyi zhang'ai*" (memory impairment). Only one caregiver, whose wife had dementia,

told me at the beginning of our interview, "I really discourage the use of that word, *chidaizheng*. That word really offends me."

One of the dangers of using the stigmatizing term *chidaizheng* is a delay in recognizing signs and symptoms and receiving care, as well as reluctance by people with dementia and their family members to seek care. A 2013 large-scale survey study found that caregivers often reported being unaware of the onset of dementia, taking signs such as memory loss, confusion, and personality changes as part of the normal aging process, or denying altogether that the conditions of dementia required medical care (Tang et al. 2013). The study reported that a diagnosis of dementia by a neurologist often occurred more than one year after the initial appearance of signs and symptoms, which likely also reflects the lack of medical specialists trained in dementia-related treatment and geriatric medicine. "I just wish that we had noticed earlier, then the decline would not have happened so quickly," was a statement, a lament, I heard repeated by several of the family caregivers I spoke with.

Moreover, the limited availability of long-term care resources poses additional concerns for people with dementia and their families. In Beijing, for example, although residential care has developed as an alternative option to traditional family care for the elderly (Cheng et al. 2011:366), it is extremely difficult to find a long-term care facility that will provide care for a person with a dementia diagnosis. In my interviews with caregivers, I was told that institutions like nursing homes often consider these individuals too medically and behaviourally complicated to care for, leaving families to find other solutions for care, such as hiring an at-home caretaker. In several of my interviews, family members expressed hesitation and concern about hiring an at-home caretaker.

Most hired health aides, who are typically are migrants from rural areas, receive minimal training in dementia caregiving. Furthermore, people with dementia can be disturbed by the presence of a new and unfamiliar person in their home, which can lead to safety concerns and disruptions in caregiving.

The negative connotations associated with the term *chidaizheng*, as well as the deleterious ramifications it can have for appropriate and timely medical treatment and long-term care, have led to recent efforts by the Chinese government and the public to develop a new, less stigmatizing term. In September 2012, on World Alzheimer's Day, the China Central Television (CCTV) nationally broadcasted the special program, "My Father and Mother" (*"wo de fuqin muqin"*), which brought large-scale, public attention for the first time to issues of terminology and recognition.³ In one segment, the program asked viewers to vote online for a new term to replace *chidaizheng*; over 40% of respondents voted for the more neutral, scientifically oriented term "*nao tuihua zheng*", translated as "cerebral degeneration" (Beijing Today 2012). Clinicians and researchers, on the other hand, argued that this term raised further technical complications, because dementia does not necessarily imply a neurodegenerative process (e.g. in the case of a stroke) and, conversely, neurodegenerative diseases do not necessarily lead to dementia (e.g. Parkinson's disease).

In order to address this potential misnomer, health professionals in mainland China and Hong Kong subsequently proposed the term "*renzhi zhang*'ai zheng", or "cognitive impairment disorder," consistent with the classification of Major and Mild NCDs in the DSM-5 (Lam et al. 2012). *Chidaizheng*, however, remains widely used both in colloquial

³ I was curious about what the lasting impact this program might have made for the Chinese public and was surprised to find very little about the program when entered into the Chinese search engine, Baidu. Instead, the search results shown are those related to a popular television drama by the same name.

speech and in the everyday space of clinical practice. "Even if it has other meanings, it's the term that everyone is familiar with," a nurse I interviewed told me, "and ultimately the conditions of the disease are still the same no matter what word you use, so does the word really make that much of a difference?"

Ethnography in a "Changing Moral Landscape" of Care

"This study is not about China or Chinese people, exactly, though surely, Beijing urban life much resembles that of other Chinese cities and Chinatowns around the world. It is, rather, searching in one place for those specificities that can nuance our sense of the common ground we all must try to occupy."—Judith Farquhar and Qicheng Zhang, *Ten Thousand Things*

Over the course of the ten weeks that I spent in Beijing conducting fieldwork, I became attuned to this struggle for words, evident at two different registers: one, in the discursive search for appropriate nomenclature for the disease, and the other, in the day-to-day efforts by people with dementia to "find the right words" and make sense out of language. During my first week, I attended a training session for family caregivers at the Beijing Science and Technology University. The teacher explained that dementia is marked first by memory loss, followed by the loss of language and the ability to express oneself. On a separate occasion, I sat in on another appointment at the No. 6 Hospital, listening to a woman in her mid-seventies anxiously tell her doctor that she was having difficulty expressing herself through language. "I know what I want to say in my mind, but I'm having trouble finding the right words. Nothing comes out the way I thought, or the way I want," she said. Her doctor reassured her, telling her that she sounded perfectly clear and lucid, and that stressing about the issue might only exacerbate it.

These brief, observational scenes, along with the conversations I had in Beijing with formal and informal dementia caregivers, and older people more generally, take

place at a specific moment in Chinese health policy, law, and public awareness for issues concerning elderly care (Kaufman et al. 2013). In 2012, the All-China Women's Federation and the China National Committee on Aging published an updated, modernized version of the classic Confucian text, "The 24 Paragons of Filial Piety". The Confucian notion of filial piety is one of the major traditional values in Chinese culture that holds together the family unit in providing care for an elder (Ikels 2004). The revised edition, titled "The New 24 Paragons of Filial Piety," offers guidelines that are more relatable to the contemporary social life of Chinese people to encourage them to visit and attend to their aging parents, including teaching parents how to use the Internet or taking them to see a film (Jacobs and Century 2012). In 2013, in a similar endeavour, the Chinese government implemented a controversial, new law on the "Protection of the Rights and Interests of Elderly People," which rules that adult children can be legally sued by their parents, fined, and court-detained if they do not visit their elderly parents regularly (Wang 2013; Wong 2013).

These two official attempts to revamp and make more appealing traditional ideas of filial piety and family reverence characterize a particular instance in the midst of what some consider to be a nation-wide "moral crisis" of traditional values of family and elderly care. The renewed effort to bring attention to issues of filial piety can be seen in light of, and in response to, some of the recent, troubling events concerning the quality of life of older people, including high suicide rates among the elderly in rural settings (Fei 2010), placement of parents in poor-quality residential care facilities, and the phenomenon of *kenlao*—"to gnaw one's elder"—referring to unemployed adult children who live off the financial resources of their aging parents, common especially among the

derogatorily named *jisheng yidai*, or "parasite generation," born under the One-Child Policy implemented in 1979.

The ethnographic snippets and vignettes featured in the following chapters are embedded in these social and cultural currents of what anthropologist Yunxiang Yan calls China's rapidly "changing moral landscape" (Yan 2011:36), which has at its crux longstanding questions of care and familial relationships. I turn now to the anthropological scholarship that informs much of my research, taking up intersecting strands within research on China, aging, dementia, and care. In gesturing toward thinking differently about dementia and what it might mean to be senile, I engage critically in a dialogue with the existing literature on conceptualizing dementia in terms of the concept of personhood.

Aging Anthropologically: Emerging "Geroanthropology"

In recent years, medical anthropology research and writing have seen the emergence of ethnographic works dedicated to thinking critically about aging and old age. Margaret Clark (1967) first called attention to the "ethnographic vacuum" of anthropological exploration into the years of life bookended by one's passage into adulthood and one's eventual death and funereal rites, two of the most widely studied phenomena in classical anthropology (Clark 1967:55). Clark's critique opened a discursive space for scholars to take seriously the topic of aging and old age as an anthropological subject of inquiry. In the four decades since Clark's essay, the growing interest in questions of aging has "[acted] to correct longstanding biases against the elderly as interesting and significant, or as people to be represented in anthropological literature, and against old age itself as a topic of research" (Rubinstein 1995:785).

Lawrence Cohen (1994) provides an outstanding overview of the discipline of "geroanthropology" and its theoretical trends and trajectories. One such trope he points to is the narrative of anger at the neglect and abandonment of old people, "convey[ing] a sense of old age as a state of misery and offer[ing] gerontology and politically engaged fieldwork as responses" (Cohen 1994:142). Another trope posits ambiguity and liminality, to borrow from Victor Turner, suggesting that, at the core of old age, one inevitably finds the ambivalence "both of maximal experience and of maximal debility, simultaneously vaunted and evaded" (Cohen 1994:143). In ethnographies of aging, the topic of growing old and of old age is of central concern, yet it "resists becoming an end in itself" (Cohen 1994:153). These texts not only undertake the difficult task of putting into words the lived experience of old age, but furthermore demonstrate how such a phenomenology of aging is crucially linked with social constructions of old age, imbued with cultural meanings and representations of the older person, and embedded in a local nexus of intergenerational relationships.

Seminal works in the anthropology of aging and old age include (by no means comprehensively) those of: Barbara Myerhoff (1979) on the experience of aging in a Jewish senior center in California; Charlotte Ikels (1983) on Chinese cultural values regarding elderly care; Sharon Kaufman (1986) on the relationship between subjective perceptions of selfhood and age among older people in the United States; Margaret Lock (1993) on culturally specific notions of menopause and aging in Japan; Lawrence Cohen (1998) on the concept of senility and understandings of Alzheimer's disease in India; Sarah Lamb (2001) on gendered experiences of aging in India; Athena McLean (2007) on maintaining personhood in a nursing home in the United States; Emily Wentzell (2013)

on the medicalization of age and notions of masculinity in Mexico; and Annette Leibing (2014) on the link between place and hypertension as disease of aging in Brazil.

The Anthropology of Senility and Turning Toward the Person

Several of the authors cited above, along with numerous others, have contributed to thinking and writing specifically about dementia. The authors of an edited volume on dementia in social science research (see Leibing and Cohen 2006) illuminate two principal theoretical approaches to thinking critically about dementia. The first articulates dementia as a scientific and biomedical diagnostic category (see also Lock 2013) and its subsequent clinical treatment, while the second organizes dementia in terms of personhood, voice, and care. What is critical about this text is its invitation to engage scholars of aging in a conversation about critically re-conceptualizing dementia as senility⁴. Cohen argues that "the study of senility can and must set out to do more than improve the care and treatment of demented persons: it must use senility to understand the critical stakes in persistent and emergent forms of reason, memory, care, aging, medicine, and life itself" (Cohen 2006:3). This shift from the predominant biomedical formulation of dementia (as Alzheimer's disease, vascular dementia, etc.) to a more complex understanding of senility makes possible not only a different future for care and treatment, but also a new horizon for thinking about what it means to be a person.⁵

⁴ The term *senility* can be traced back to the works of Jean-Martin Charcot on the clinical pathology of aging (1866), Ignatz Leo Nascher, who coined the term *geriatrics* (1914), and Georges Canguilhem on the distinction made between the normal and pathological in biology and medicine (1991).

⁵ I use the term *senility* in a theoretical sense, related to questions of voice and care. I use the term *dementia* more generally, both to be consistent with the terminology in the existing literature I cite and to refer to the clinical condition it indexes as a diagnostic category in the ethnographic settings of my research. Similarly, I use the term *chidaizheng* as opposed to the other proposed Chinese nomenclature. In my use of these terms, I am invoking the everyday familiarity we have with the words *dementia* and *chidaizheng* and, in a critical turn, putting into question this familiarity in the ways we recognize and identify markers of senility.

Here, I draw attention to what Cohen and Leibing call the "personhood movement" in the anthropology of dementia. The concept of personhood, which has a substantial philosophical lineage (see Bourdieu 1977; Heidegger 1962; Geertz 1977; Mauss 1985; Merleau-Ponty 2005; Ricoeur 1995) beyond the scope of this thesis⁶, has been written about in terms of the self, subjectivity and reflexivity, awareness and coherence, referring generally to an essence within the person that renders her unique, present, and "alive" in the social world (see Biehl et al. 2007; Good et al. 2008). This hypothetical person is able to recount a life narrative drawn from memories, to express herself coherently through language, to speak, listen, and be able to recognize, which in turn, confers recognition and visibility.

Biomedicine, furthermore, has its own epistemological delineation of personhood as a cohesive, autonomous, rational, and capable self (see Lock and Gordon 1988). The most common perception of dementia, which primarily concerns the loss of these cognitive and functional aspects of the person, runs counter to such configurations of personhood (see Post 2000; Hughes 2011). Hughes argues that "if dementia is mainly a cognitive disorder and if failures in cognitive function amount to a loss of personhood, it follows that dementia must entail a loss of personhood" (Hughes 2011:13). Thus, given this conceptual framework, one's claims to being a person are staked on one's cognitive capacity. Pia Kontos writes, "In this sense, the presumed existential erosion of selfhood with Alzheimer's disease is not simply the result of neuropathology, but is, to a large extent, the consequence of a certain philosophical inheritance" (Kontos 2004:830).

⁶ For this reason, I will use the terms *personhood*, *selfhood*, and *self* interchangeably.

The "turn to personhood" in anthropology⁷, a discipline whose theories and methods often endeavour to critically question assumptions of thought, sets out to reclaim the widely presumed "loss of the self" in the person with dementia. Medical anthropologists would argue that the perception of dementia as a condition that threatens one's personhood is embedded in a set of particular assumptions within Western biomedicine as its own cultural system of knowledge (see Good 1994; Rhodes 1996; Scheper-Hughes and Lock 1987). The analytical shift toward personhood in doing an anthropology of senility argues against the logic that a loss of cognition necessarily entails a loss of personhood.

The distinction is perhaps made most transparent in the context of care. Athena McLean (2007) examines two approaches to care in a nursing home in the United States: 1) *biomedical* care, which "focuses on the objective body and symptoms", and 2) *personoriented* care or "the communications perspective [which] privileges the subjective *person* with dementia" (McLean 2007:39). Janelle Taylor (2008) writes about her experience with her mother's dementia and the question everyone asks her: "Does she recognize you?" In response, Taylor poses a question of her own: "How are claims to social and political 'recognition' linked to, or premised on, the demonstrated capacity to 'recognize' people and things?" (Taylor 2008:315). Taylor circumvents this idea of granting recognition—and thereby, personhood—based on one's cognitive ability to recognize by turning to the notion of care, which holds together her relationship with her mother. Similarly, Elizabeth Herskovits Castillo (2011) proposes a model of

⁷ The focus on personhood as a primary site for rethinking dementia is a popular analytical approach not only in anthropology but also in philosophy and the social sciences more broadly, as well as in nursing and clinical literature. In Chapter 1, I will briefly delve into the literature on communication and dementia care. For the purpose of this thesis, however, I will primarily only engage with the anthropological scholarship on dementia, senility, and care.

"Personhood-Centered Care" in clinical practice to maintain the personhood of people with dementia and improve their quality of life.

To add to the discussion on dementia and personhood in China. Ikels explores the culturally specific experience of dementia (1998) with regard to notions of the Chinese self (2002). Noting in her research that Chinese people, old and young alike, often viewed dementia as a natural part of aging, Ikels argues that deeply-rooted Confucian principles of the self, family relationships, and elderly care shape the contemporary Chinese experience with senility. According to Ikels, "The Chinese concept of the self and of mental function does not prioritize the cognitive domain" (Ikels 2002:249). In the philosophy of Mencius, the Chinese self consists of an affective, pre-rational, "essential" self and a rational, "particular" self. Together, they enable an individual to lead a moral life by fulfilling social roles and responsibilities and to *zuoren*, literally meaning, "to do as a person does." When a person is no longer able to carry out the "correct performance" of social roles" (Ikels 2002:249), it is nevertheless imperative for others to continue to fulfill their own social roles in caring for that individual, such as the case with dementia and filial piety. In the logic of her argument, because the Chinese self is comprised of more than just its cognitive component, the cognitive changes brought upon by dementia do not deprive that person of her selfhood.

Jinhua Guo and Arthur Kleinman similarly address questions of what it means to be a Chinese self through the lens of social stigma against mental illness. They write, "One has to exchange the fulfillment of social obligation for the claim of personhood... [An] individual who is considered unable to fulfill this social obligation will be seen as a nonperson. Nonpersons do not receive social recognition nor are they acknowledged to

be moral agents" (Guo and Kleinman 2011:243). Guo and Kleinman's argument illustrates what can happen when the exclusionary principle of the personhood concept is applied in the context of Chinese mental health care. The denial of social and moral recognition of people with dementia— which, as Janelle Taylor argues, is premised on a cognitive understanding of recognition—can be seen to correspond also to a denial of dementia itself as an illness. Here, the problem of recognition is fundamentally one of care.

Anthropologizing (with) Care

I want to turn briefly to the existing literature on care to highlight certain ways in which anthropologists have grappled with the concept. Rather than ask the question, "What constitutes care and what does not?", anthropologists have been interested in rethinking and troubling traditional associations of care with kinship and with moral values of compassion, charity, and sentiment (see Aulino 2012).

Arthur Kleinman's work on caregiving posits the practice of care as an "existential moral experience" (Kleinman 2010:26) that mirrors the human experience of being a divided self. For Kleinman, caregiving is an embodied practice of giving and receiving care, one that demands "empathic imagination, responsibility, witnessing, and solidarity with those in great need" (Kleinman 2009:293). Caregiving is fraught with ambivalence; it can simultaneously be frustrating and uplifting, desperate and transformative, but it ultimately provides "a clearer picture of our divided condition as the human condition" (Kleinman 2010:17).

John Borneman (1997) argues for a reconceptualization of human relationships grounded in care rather than in terms of classical anthropological categories of kinship

(based on consanguinity or marriage), reproduction, descent, and law. Borneman presents two stories of adoption and marriage in Germany among individuals whose relationships would not otherwise be granted the "social and legal recognition and protection of a particular form of marriage and family" (Borneman 1997:573). One story is that of Bärbel, who is married to her lover Mirka's son, Martin (for legal purposes). Mirka is, then, both the mother-in-law and lover of her son's wife, Bärbel. Borneman writes, "Thinking in terms of anthropological or legal kinship terminology obviously confused the actual relations these people had with each other, yet the legal, theoretical and pragmatic dimensions of kinship were the terrain on which they fought for what was at stake, which, again, was the right to care and be cared for" (Borneman 1997:580). In revealing the limitations of conventional kinship terms to get at the crux of relationships that exceed these concepts, Borneman foregrounds the "fundamental human need" and right to care and be cared for at the heart of anthropological study (Borneman 1997:583).

Recalling Borneman's essay, Angela Garcia (2010) is interested in reframing kinship and practices of care in order to understand how they interweave in different, complex, and ambivalent ways. Writing about how care figures into the everyday relationships of heroin users in New Mexico, she illustrates "how practices of care become reconfigured through heroin, intensified at the kinship level" (Garcia 2010:66). In the story of a mother-daughter pair both addicted to heroin, care is "improvised" and enacted as a commitment to each other's suffering; heroin reaffirms their interpersonal ties in the form of care. Garcia writes, "Kinship operates as a matrix of forms of inclusion and exclusion, through which we derive a particular sense of practice of being and belonging" (Garcia 2010:121).

A significant body of literature also focuses on humanitarian care (see Bornstein and Redfield 2011; Fassin 2012; Fassin and Pandolfi 2010; Feldman and Ticktin 2010) and care at the level of institutions, states, and in global health settings (see Biehl 2013; Ferguson 1994; Nguyen 2010; Han 2012; Hyde 2010). In these contexts, and on this analytical scale, care is critiqued for the exclusionary process it takes part in by denying care to certain groups of people. Miriam Ticktin (2011) brings attention to the unintended consequences of the "regimes of care" of humanitarianism and French immigration policies framed within the rhetoric of compassion. She argues that only certain claims to recognized forms of suffering grant immigrants moral legitimacy, and thereby, legal status and access to care. By problematizing the power relations that currently make up what she calls the "politics of care," Ticktin's argument "is about opening the way to think about how we might care differently, that is, in ways that are... about *not* making exceptions when it comes to questions of inequality, suffering, and violence or when it comes to the possibility of human flourishing" (Ticktin 2011:223).

I have placed these different theorizations of care together both to show how anthropologists have engaged with thinking about the concept of care in various contexts, and to set the backdrop for my own exploration of care and its relation to senility. In writing about care, I am not only referring to the often difficult practices of caregiving for the elderly, which can be fraught with ambivalence, particularly for family caregivers, but also calling attention to practices of recognition—in this case, recognition of the difference of the person with dementia. To add to this anthropological conversation, I also want to suggest a reframing of the notion of care, and of what care can come to entail for a person with dementia, through the conceptual lens of senility. Senility puts

into question both the biomedical, cognitive-based formulation of dementia and, consequently, the ways that we recognize the human need for care, or, as Lisa Stevenson puts it, "the way someone comes to matter" (Stevenson 2014). What would happen if we abandoned the need for a cognitive basis to speech? How then might we listen to the senile voice? What new possibilities of care might arise if playfulness, humour, and creativity entered into this communicative space?

In thinking about dementia in terms of senility, I propose that the idea of play offers an alternative mode of being in the world, and of "caring and being cared for." While there is an extensive body of literature on the play and performance of language (see Austin 1962, Bahktin 1981; Bauman and Briggs 1990; Kohn 2013; Wittgenstein 1953), I engage with the notion of play in terms of its potential for communicative practices of care. In my ethnographic inquiry into playful communication, I deliberately shift away from the notion of personhood and the normative assumption that dementia threatens the loss of personhood. My engagement with different modes of listening and speaking is not an attempt to argue that playful care restores personhood; rather, I am interested in taking up the invitation to listen by attending to interactive relationships of care.

Observation as Method for a "Sensuous Scholarship"

"By why engage in the pursuit of knowledge, I wonder, if not to enrich the quality of life."—Paul Stoller, *Sensuous Scholarship*

In an interview with Chen, whose husband was diagnosed with moderately severe Alzheimer's disease in 2005, she describes the challenges she faced in finding care for him and his gradual decline over the past eight years, including an inability to recognize

her or their son. Chen visits him once a week at the nursing home where he has lived since 2007. I ask her how she communicates (*jiaoliu*)⁸ with him.

"Oh, there isn't really any *jiaoliu*—there hasn't been for a long time," she replies. "Have you eaten? Are you full?' You just ask him some simple questions. They don't have to mean anything. You speak so that he can hear the sound of your voice, and it doesn't matter if he understands what you're saying, because at least your words stimulate him. 'Did you finish your lunch? Did you go to the bathroom? The weather is cold. Wear your coat.' Just whatever comes to mind. He doesn't really speak anymore, and he doesn't give any indication that he can hear me. But sometimes he'll watch you and then smile. He is not completely lost."

With the signals of language and its logical associations no longer located in their usual and familiar places, the words and cues that make verbal communication smooth and uninterrupted can become increasingly difficult, seemingly impossible, when speaking to a person with advanced dementia. For Chen, there is no longer any communicative exchange with her husband, and she speaks to him without the expectation of a response made meaningful by language. Rather, the response involves a smile, his eyes watching her as she talks to him about "whatever comes to mind"; it is how she knows he is not completely "lost."

Here, I have transcribed and translated what Chen relayed to me in our interview when I asked her how she communicates with her husband. From her tone of voice, the way she speaks quickly and sometimes comically, I can imagine how she might speak to her husband, how she might actually ask him, "Did you finish your lunch?" Because

⁸ The word *jiaoliu* is closer to the English word "exchange," whereas *goutong* is closer in meaning to the word "communication." I used both words interchangeably to mean "communication."

Chen has shown me photos of her husband, I can also picture how he might smile and look at her. But my interpretation is, at the most, an imaginative approximation of their particular encounter. The sound of his voice, whatever his utterances may be, their bodily movements when they interact, however small—these moments of caring and of being with another person elude me completely.

Paul Stoller (1997) argues for a scholarly commitment to writing with attention to both the analytical sense of the mind and the sensibility of the body. He writes, "In anthropology... it is especially important to incorporate into ethnographic works the sensuous body—its smells, tastes, textures, and sensations" (Stoller 1997:xv). Stoller's effort to "reawaken profoundly the scholar's body" moves away from the Eurocentric privileging of visual sense and the visibility of text, and toward the other senses, which can be equally if not more central to direct experience (Stoller 1997:xv).

For a similar reason, I write this thesis (albeit in the form of text) in an attempt to bring together words and pronunciations, sensations, movements, and voices. As a result, my ethnography primarily draws upon my observations of unfolding relationships in various settings, rather than the 13 interviews I conducted. In making use of observations that have been recorded in writing, however, one must also be carefully aware of the ethical concerns that might arise from such a method. There is room for messiness in the ethnographic practice of observing people and writing about these observations in fieldnotes, even when stripped of "identifiable personal information," and it becomes further entangled when relying upon memory, however immediate, and translating conversations from Chinese to English. My intention in drawing upon the possibilities offered by the observational mode of qualitative research is to illustrate more

immediately and fully the particular instances that occur in the relational space of care, which I believe could not be accomplished with interviews alone. Anthropologist Mary Ellen MacDonald writes about qualitative inquiry as the "systematic investigation of a given phenomenon, the goal of which is to advance knowledge. As such, this definition of research... requires only an assessment of the rigor of the investigation" (MacDonald 2009:98). Indeed, because "ethnography is more than casually observed opinion" (Angrosino and Rosenberg 2013:154), observation-based research must be carried out with careful and methodical attention. In doing so, I want to use the observations that make up the viscera of this ethnography to awaken the senses and explore "the bodily, emotional, or imaginal modes of learning which can provide entrées into knowing" (Davies 2010:20)—a different kind of "knowing" about what it means not only to live with dementia but to inhabit its lifeworld.

While it might be argued that an analytical focus on the voice and listening is itself a fallacy similar to the emphasis on the visual sense in the Western philosophical lineage, resulting in a disembodied account of "the whole person" (see Cohen 2006; Kontos 2004), I take the stance that careful ethnographic attention to the utterances of the senile voice—be it sounds, words, phrases, fragments of sentences—allows for a new understanding of how care can be enacted and communicated differently through practices of play.

Outline of Chapters: Taking Up the Invitation to Listen

"The problem is that my father is deaf in one ear. My mother wants to talk she's always enjoyed talking—but he can't hear her, so she stopped talking. She just gave up trying to speak to him. Then, she stopped going out, in case she'd wander and get lost, and her interactions with the outside world and her relationships with other people diminished. I think once that happened, she lost her ability to express herself. I think that's part of the reason why she

developed dementia. She used to be so healthy, and she would talk all the time, to everyone. But now, when I speak to her on the phone and she can't respond, I just tell her, 'When you were young, you were so active, so now that you're older, your brain needs to rest.' I tell her that, and she understands."—Mr. Wu, whose 83-year-old mother was diagnosed with Alzheimer's disease in 2012

The next two chapters take up the earlier invitation to rethink new possibilities of care in listening and responding playfully to a senile voice.

The first chapter examines how the vocal utterances of an elderly person are recognized and become construed as markers of senility. Here, I am interested in asking the inverse of Janelle Taylor's repeated question, "Does she recognize you?" I present three distinct conversations that take place in different caregiving settings as an exploration of how dementia itself is recognized at a vocal register, and how these processes of recognition elicit particular responses in the context of care.

In the second chapter, I engage with the concept of play and trace the diverse ways it can unfold as a distinct and experimental mode of communicative care in four ethnographic vignettes. I propose that acts of playful listening and speaking not only have the potential to be therapeutic in a relationship of care, but also critically challenge the ways that dementia is predominantly understood as a condition of loss and incapability. Play provides the possibility for reimagining a new horizon for senility beyond the binary distinctions of language and nonsense, ability and disability, coherence and incoherence.

The ethnographic research that foregrounds this thesis takes place at a time in China when elderly people find themselves neglected and abandoned at home and in residential care facilities, or faced with the stigma and the challenge of finding care for a spouse with *chidaizheng*, and when adult children can procure their livelihood by "gnawing" away at their parents' finances, and at the same time, be legally sued by their

parents for not visiting often enough if they live and work farther away. These current phenomena urgently capture the ethos—or perhaps, the pathos—of a "moral crisis" in traditional Chinese values of familial care.

As disturbed as I am by the occurrence of some of these events, I am also troubled by the idea of what Ikels calls an "apocalyptic gerontology" and the tendency to overemphasize this sense of loss, of demise, of a cultural, moral degeneration that seems to accompany the physical and mental deterioration of the aging person. Likewise, I find myself unsettled by the popular and academic discourse on the "War on Terror on Alzheimer's" (see George and Whitehouse 2012) and the "horror" of the global dementia epidemic. Without minimizing or denying the immense difficulties faced by people with dementia and those who care for them, I want to decouple fear and terror from dementia and turn toward a spirit of play. With this intention in mind, I write this ethnography with a sense of urgency and deliberateness, and with the hope that it inspires the possibility for thinking about senility differently, chuckling and laughter included.

1 Hearing Voices of Difference

"Even knowing what to expect, Nakata found Kawamura impossible to decipher. He enunciated his words poorly, and Nakata couldn't catch what each one meant, or the connection between them. What the cat said came off sounding more like riddles than sentences. Still, Nakata was infinitely patient, and had plenty of time on his hands. He repeated the same question, over and over, having the cat repeat his responses... They'd been talking for nearly an hour, going round and round in circles."—Haruki Murakami, *Kafka on the Shore*

Songtang Hospital: A Conversation of Very Few Words

On my second visit to Songtang Hospital, a geriatric and end-of-life care facility in southeast Beijing, Nurse Yuan called me over as I was about to walk into the hospital's main entrance. She was sitting with an elderly man in the stone courtyard, sheltered from the cloudy morning daylight by a curved wooden roof. Nurse Yuan looked tired and sounded congested, and I noticed the roll of toilet paper next to her. She introduced me to the man, who was 76, and asked me to "help her out" by talking with him while she went to rest. He was sitting on a wheeled walker, and I sat down quite close to him on the stone bench that Yuan had just vacated.

"Hello, *yeye*," I said to him politely. *Yeye*, meaning "grandfather," is an affectionate, honourific term. "What were you and Nurse Yuan talking about just now?" As he began to respond to my question, I quickly realized two things. One, I had forgotten to ask his name at the beginning of our conversation so I could not address him properly for the rest of the conversation (later when I asked Yuan, she also could not remember his name); and two, I could barely understand him. By watching specifically how he moved his mouth, I was able to grasp the general idea that he was telling me about Buddhism, just managing to catch keywords—*fo jiao* ("Buddhism"), *yingguo*

("karma"), *zongjiao* ("religion")—before they slipped away from me and out of the space between us.

A few minutes and several phrases into the story he was telling, which I gathered, from words here and there, was a Buddhist myth, I figured out that it was not a barrier between languages or dialects that made it difficult for me to understand him, but something about the fundamental peculiarities in the motor production of his speech. The words he spoke were barely distinguishable from one another, each syllable slurring into the next without delineation, punctuated occasionally by a few seconds of stuttering, followed by a pause. A medical doctor might call this dysarthria, a motor speech disorder that can be caused by a stroke, neurodegenerative diseases, or brain injury, among others. In the terms of a speech-language pathologist, "The speech impairments of dysarthria relate to articulation, phonation, respiration, nasality, and prosody, and affect intelligibility, audibility, naturalness, and efficiency of spoken communication" (Mackenzie 2011:125).

Whenever he paused, he would have a look of what seemed to me like embarrassment on his face, and I wondered if he knew that I was unable to understand him very well. With time, though, I began to catch the last few words of his sentences, because as he came to a pause, I found that he would enunciate the syllables of each individual word more clearly.⁹ When he stopped speaking, looking embarrassed and chuckling, eyes crinkled, I took this as my chance to say something. I would repeat the last few words I had caught, rephrasing them into a question. He seemed to have no

⁹ Each monosyllabic word in Chinese has its own meaning either as a noun, verb, adjective, or adverb; new words are made consisting of two or three individual words. For example, the word chi - dai - zheng is comprised of three individual words meaning "mad", "idiotic", "illness", respectively; together, they signify the word *dementia*.

difficulty understanding my questions, and would respond, nodding and smiling. Our exchange continued in such a way for at least half-an-hour. It was not so much that I came to understand him more clearly in that short time, but I found myself becoming attuned not only to words that stood out but also to certain patterns of sounds, emphases, and pronunciations of words.

He was very talkative. He explained to me at length the importance of religion and spirituality for the elderly. He pointed to the stack of books on the table beside us, explaining that these were books about Buddhism that he often came downstairs to read.

"Fo jiao shi zui zui zui ... wei da de," he said. "Buddhism is the most most most... powerful." He explained that Buddhism had taught him how to cultivate good thoughts and treat others with respect and compassion. I was unsure whether the repetition on the word *zui* ("most") was deliberate emphasis or an inadvertent stutter. He sighed, smiling, then said, *"Zhe zhi shi wo de kan fa."* "This is only my opinion." I replied with an enthusiastic affirmation and he smiled bashfully, looking down at his hands.

When Nurse Yuan returned, she asked him how our conversation had been.

"Tai hao le!" he exclaimed, shaking my hand and smiling at me. "Excellently."

This conversation, which occurred quite early in my fieldwork for my undergraduate thesis three years ago, left a deep impression on me. I revisit it here as an introduction to this chapter's exploration of distinct voices that might be considered senile and the recognizable vocal difference they represent. Using a theoretical framework built around notions of recognition, voice, and care, I want to examine the ways in which we recognize and identify markers of senility and also gesture toward possibilities of communication as practices of care for a person with dementia. The three

ethnographic excerpts in this chapter point to these possibilities for listening and speaking in different settings and relationships of care. Taking us from this encounter at Songtang Hospital to a geriatric psychiatry outpatient clinic and finally to the home of a family friend, these vignettes bring attention to particular aspects of senility's vocal utterances and expressions, as well as the emergent forms of listening, speaking, communicating, and caring that they engage.

Theoretical Trajectories: Toward Senility, Voice, and Care

I was recently reminded of my conversation with the elderly man at Songtang while reading anthropologist Janelle Taylor's essay on dementia, care, and recognition (2008). The off-repeated question referring to her mother, "Does she recognize you?", prompts Taylor to explore the link between recognition and personhood and its implications. One of the dangers with the concept of recognition in thinking about the person(hood) in dementia is the exclusionary principle it entails. Taylor writes, "You could... draw a clear line between [my mother and me]: place me here, on the side of reality, competence, and personhood, and put her over there, on the side of delusion, incapacity, and the not quite (or no longer) fully human" (Taylor 2008:332). In response to this framework that determines personhood based on one's cognitive capacity, Taylor instead turns her attention toward her mother's own saying: "Keep the cares together!"

Part of holding onto care together involves interaction and the continued effort to communicate, without needing to search for the meanings of the words themselves. Writing about "what passes for conversation" (Taylor 2008:326) between her mother and herself, Taylor claims, "There is, in short, much more to conversation than speech, and much more to speech than the transmittal of information... So much of it really is

procedural, a knowing *how to* interact with people... These communicative practices are, I believe, also practices of *caring*" (Taylor 2008:328; italics original).

The conversation with the elderly man that took place at Songtang Hospital demanded a process of recognition. It took me only a few seconds to recognize that I could not understand him. The dysarthria that impeded clear expression of language, as well as the suddenness of our meeting, pointed to the absence of what are often presumed to be the essential elements of verbal communication. I entered into our conversation without either the usual, familiar markers for intelligible speech or a personal context of "who" he was-I did not even have a proper name to call him by. Nevertheless, our conversation was very much an exchange that existed in the interactive space between us. Although very little was "understood" on my end, I felt fully engaged in what Taylor calls a "communicative practice," marked by the smooth "back-and-forth flow" (Taylor 2008:328) of words and repetitive sounds, as well as by affirmative nods, mm's and *hmm*'s, eye contact, and smiles. The interaction was not without effort—he speaking, I listening—but it was characterized also by a mutual attentiveness that demonstrated a practice of caring. To paraphrase Taylor, there is much more to "spoken communication" than, in a speech-language pathologist's terms, "intelligibility, audibility, naturalness, and efficiency." There is more to speech than language, and more to voice than speech.

Adriana Cavarero (2005) examines the triadic relationship between language, speech, and voice, and its implications in the Western philosophical tradition. What is at stake for Cavarero in her attempt to study the voice as its own phenomenon is an abandonment of the logocentric tendency to privilege language and speech as vocal "destinations" (Caverero 2005:12). She focuses on the simultaneously unique singularity

and relational embodiment of a speaker's voice, making a deliberate analytical move away from *logos* and its derivatives—for example, language and the semantic content of what is spoken. She writes, "[T]he sphere of the voice is constitutively broader than that of speech: it exceeds it. To reduce this excess to mere meaninglessness—to whatever remains when the voice is not intentioned toward a meaning, defined as the exclusive purview of speech—is one of the chief vices of logocentrism" (Cavarero 2005:13).

Cavarero's engagement with the phenomenology of voice offers an invaluable framework for reflecting upon the apparent unintelligibility and unfamiliarity of a voice marked by the juxtaposition of the "nonsense" and "babble" that is heard and the coherence of language that is unheard. Like Cavarero, I do not intend to search for the missing puzzle piece of logic, and instead, I want to call attention to vocal "excesses" beyond comprehensible speech and language. I argue that attending to vocal utterances sounds, syllables, snippets of words, fragments of phrases—offers new possibilities for reimagining senility and its relation to communication and care.

The conversation I had with the elderly man at Songtang required attention to the particularities of his voice that exceeded the limits of comprehensible speech. By attributing the distinctiveness of his voice to the idea of senility as the recognizable difference of age, it is possible to recognize the elderly man's voice as both unique to himself and relational in the way it invoked my listening and my voice in response. According to Cavarero, "Every act of speaking is thus from the start the relation of unique beings that address themselves to one another. They reciprocally expose themselves to one another, in proximity; they invoke one another and communicate themselves to one another" (Cavarero 2005:29). Because he was responsive to me and

CHAPTER 1

our conversation consisted of a smooth back-and-forth flow of words, despite my inability to understand much of what he said, it was unclear to me whether he exhibited the neurocognitive or behavioural signs of dementia.

But there was more to our conversation than speech and language. He was telling me a story about Buddhism, even if I could grasp only a few words here and there. As we continued to talk with each other, both the linguistic "transmittal of information" (Taylor 2008:328) and my effort to assess his cognitive status shifted to the background, their importance replaced by awareness and attention to what Cavarero calls the "proximity... of reciprocal communication" (Cavarero 2005:29). His vocal utterances could be interpreted as those of a senile voice, without necessarily referring to the neurocognitive impairment that characterizes dementia. Here, I work with Cohen's definition of senility, as the "attribution of difference or discontinuity to an old person or to old people as a group, when this difference is embodied as behavior—as actions or utterances—and when it is to some degree stigmatized" (Cohen 1998:33; italics original). My specific use of senility attempts to understand something that recognizably differentiates individuals in old age, but without framing difference strictly in terms of deterioration and decay. Rather, I make the argument that thinking anthropologically about senility as possibility rather than as the degeneration commonly associated with dementia—literally, "being out of one's mind"—opens up an opportunity to thinking differently about care.

I have drawn upon Taylor's ideas of care and communication, Cavarero's concern with the resonance and relationality of the voice, and Cohen's notion of senility as a compelling approach to thinking about dementia care as a communicative practice—an approach that underlies the interactive dynamics observed in the following vignette.

These theoretical trajectories have been pieced together following what I heard being spoken in the field, and it is toward an ethnography of voice and listening that I now extend my inquiry.

The Outpatient Clinic: Unraveling Voices and Hearing Mismatches

Three women, Wang, Xin, and Liu, are seated around a small grey table on a mid-September Wednesday morning, talking.

"So originally," Wang says to Xin, "She bought this sweater, but now she's forgotten it, so she thinks—"

"I didn't forget," Liu interrupts. Liu's voice is quite a bit deeper in register, grainier in tone, slower in articulation, which gives it a quality of deliberateness and intention.

"You didn't forget," repeats Wang affirmatively, her voice soft and neutral.

Xin, sitting next to Liu, explains, "After a while, she'll look at the sweater and start thinking that it looks just like the one she bought. And then other times, she'll look at it and think, 'this is definitely not like the one I bought."

Liu looks straight ahead of her, attention directed at Wang. "But the things I bought, honestly, they're not there anymore. They've disappeared. Including my medications. There's much less medicine for my high blood pressure in the container now."

"But it's not less!" protests Xin. Her face has a look of confusion and embarrassment.

Liu turns to Xin, who is sitting to her left. "I watch it very closely. Before I leave the house, I'll count how many pills there are, and then when I come back, there are fewer pills."

CHAPTER 1

"But they're always packaged. I've made sure that they're always packaged neatly for you in your container. How could they disappear?" Xin asks Liu, speaking quickly, her voice expressing frustration.

"I understand how you feel," Wang says to Liu. "When you see that something of yours is no longer where you put it, of course you'd be worried, right?"

"It's not just that they've disappeared," Liu explains. "Someone has substituted them with something of worse quality. I used to have really good ones, but they're replaced now with something else."

"When you find that your things have been replaced, are they a different colour or a different size?" Wang asks Liu.

"Colour," Liu replies after some thought. "Colour," she repeats, with emphasis.

"What about the quantity? How much is inside? Has that changed too?" Wang asks.

"I don't know. I didn't notice. But the effects of it are different now, and the colour is different," says Liu. She brings up the lost sweater again. "I bought the sweater a year ago, in the winter, for my younger daughter. She's tall so I bought a sweater that I thought would fit her well. But the other day, I discovered that the sweater had been replaced with another one. The sweater I bought had thick stripes, but someone replaced it with another one with thin stripes, and the size is smaller."

"Mm. So something's changed, right? It's different, and so you're not *manyi* about this." Wang uses the word *manyi*, which means "satisfied" or "content."

"I'm not *manyi*, because when I look at it now, it's completely different," says Liu, her voice expressing anger and indignation, contrasting with Wang's neutral tone.

"Ok. If you're not *manyi*, then let's find you something that will make you happy," says Wang. "Maybe the pattern and the colours will be different, but as long as you're *manyi*, that's what matters most. Maybe when you look at the one you bought your daughter last year, you don't like it anymore and you're not *manyi*. So how about we find you a new one for this year that you can give her? Is that ok? How about that?"

After a moment of hesitation, Liu replies softly, "Yes. Thank you."

Xin, Liu's older daughter, who has been quiet for the past several minutes, notes that her mother's hands are shaking. "They shake when she's upset. Doctor, sometimes she'll say that there's another woman in the house. I'll ask her, 'did you see something?' She'll say, 'No, but I heard sounds. I heard her voice.'" Dr. Wang is entering notes into the electronic medical record template she uses for every patient. She nods and continues to type her notes.

"Yes, it really affected me," Liu pipes in. "What happened was my son-in-law left for work in the morning, then I saw him come back home during his lunch break. Then, after he was at home for a while, I heard another person—another woman's voice from the front door entrance. My son-in-law was talking with my daughter... I mean, no, my son-in-law was talking with the other woman. And it really had an impact on me, because I really didn't know who that person was."

"I've never seen anyone like that," Xin says to her mother, her voice muted, as though not to disturb Dr. Wang's note-taking.

"Then who changed my medication?" Liu asks. Her voice is quiet but there is a sharpness to it. "Honestly, I think if you wanted to catch her one of these days, it would

be very easy. If you came home from work early one day, then I'm certain you could find her in the building."

"But I've never seen anyone like that!" Xin protests in a hushed tone. The syllables of the computer keyboard fill the silence as Dr. Wang types. In the hallway, the computer-automated system announces the next appointment for one of the other doctors in the outpatient clinic.

At this point, Dr. Wang prints out a slip of paper for Liu's prescription for *meijingang*, or memantine, a drug commonly prescribed for patients with moderate-to-severe Alzheimer's disease or dementia with Lewy Bodies. Because Liu is leaving in just two weeks to visit her younger daughter in the U.S. for six months, Dr. Wang encourages Xin to fill up her mother's prescription before she leaves.

"Is it expensive to see a doctor in the U.S.?" asks Liu, but it seems that her question goes unheard by her two interlocutors.

"That's why you need to get her medications prepared before she leaves," Dr. Wang is saying to Xin, using a blue pen to sign her name on the prescription slip.

Xin gets up from her chair, swinging her purse onto one shoulder and helping her mother stand up from her seat. "Thank you, Dr. Wang," she says, opening the door.

"No problem," replies Dr. Wang.

"Thank you, Doctor," says Liu, following her daughter out the room and closing the door behind her.

This conversation occurs during one of the Wednesdays I spend shadowing Dr. Wang in the outpatient clinic at the No. 6 Hospital, where she sees mostly elderly patients in her role as a geriatric psychiatrist specializing in dementia care. On these days, I sit at

CHAPTER 1

a 45-degree angle behind Dr. Wang, facing the patients and their families and observing their interactions. The twenty-or-so minutes Dr. Wang spends with Liu and Xin this morning cover the steps of a typical patient-doctor encounter; she follows up with the patient a few months after her previous appointment, provides some psychotherapeutic counseling, enters notes into the computer, and renews the patient's prescription. However, in this clinical setting where patients fill the waiting room from seven in the morning until six in the evening, and where time is at a premium, I have rarely seen such detailed attention dedicated to eliciting and characterizing the patient's paranoid delusional and hallucinatory claims, which are common symptoms of dementia.

As I sit through Liu's appointment, I become puzzled by the exchange of language and speech between the patient, her medical provider, and her family caregiver. As an observer of the scene, it is evident to me from the beginning of the encounter which individual embodies which particular role in this clinical context; for each role, there is a neatly corresponding association that matches assumptions of age, competence and coherence, and caregiving. In her mid-seventies, Liu is undoubtedly the dementia patient, but the obviousness of this fact is quickly put into question by a perspective that takes into account difference differently. Although she speaks slowly, Liu retains all the components that constitute intelligible speech. There does not appear to be any cognitive issue with her capacity for using language to reason deductively through her own thinking. The words that she uses, strung together, make logical sense, and furthermore, her words and expressions are, in psychiatric terms, "mood-congruent," meaning that her affect matches the feelings she is experiencing.

What is unsettling, however, is that what Liu is describing with such conviction has no objective referent; they are not factual happenings that index anything "real" in the world. In psychiatry, delusions are defined as "fixed beliefs... which are based on unsound reasoning and are maintained even in the presence of evidence to the contrary... In dementia, delusions of theft are common and often relate to misplacement of objects" (Rodda and Walker 2011:114). A hallucination, on the other hand, is "a perception in the absence of an external stimulus and may occur in any modality (auditory, visual, tactile, olfactory, gustatory, somatic)" (Rodda and Walker 2011:114). For Liu, her belief that someone is replacing her clothes and medications would be medically categorized as a delusion, whereas her perception that there was an unknown and invisible woman in her home would be considered an auditory hallucination. In the clinical setting, both signify notable indicators of a disturbed senile mind. Here, in this small grev room, the nonsense of dementia produced by Liu's voice is contrasted with her daughter's muted protests, which attempt each time to bring her mother back to reason, and with Dr. Wang's neutral-sounding yet authoritative, medical-rational voice.

What is perhaps more unsettling to me than this sense of the unrealness of Liu's words (without denying that they are very real to her own experience) is the unquestioning ease with which the three other people in the room, myself included, recognize that Liu is speaking about delusions and hallucinations. What exactly is not reasonable about Liu's voice? Or rather, in what ways might her voice actually "make sense" and thereby disrupt our normative presumptions of the relationship between age, senility, and speech? Liu possesses a clear command of speech and language, unlike the elderly man at Songtang, and she speaks with conviction and confidence. In the process

of identifying a voice marked by senility, what then are we listening *for* and *how* can we listen to its difference? If we were to strip away the parameters of the clinical setting and imagine a space in which the boundaries between the normal and the pathological were not so much at stake, how might one then listen and respond to Liu's utterances?

Taking Communication Seriously, or Listening Ironically

"My mother can't communicate. She lives in her own world." –The daughter of one of Dr. Wang's patients, when asked how they communicate

In order to untangle the implications of these questions, I turn for a moment to selections from the existing literature on communication and dementia care. Much of this scholarship takes up the work of Thomas Kitwood (1997), who argues that recognition of the uniqueness of the whole person in dementia is a crucial step toward improved communication and care. Liz Forbat (2003) uses the method of discourse analysis to explore both perspectives in a care dyad of a woman with dementia and her daughter, identifying points of unresolved contention in their relationship. Because talk can "be understood as constructing understandings, identities, relationships and even dementia itself" (Forbat 2003:71), she argues that taking discourse seriously is crucial for understanding how personhood can be maintained in dementia.

Adams and Gardiner (2005) expand Forbat's idea of the care dyad to consider what they call the "dementia care triad," consisting of the person with dementia, her informal caregiver, and a health care professional, and how the social roles and positions taken up by each individual in the triad affects communicative exchange. They identify two types of communication: enabling and disabling. Enabling dementia communication occurs when caregivers "either help the person with dementia express their thoughts, feelings and wishes or represent the person with dementia as someone who is able to make

CHAPTER 1

decisions about their own care" (Adams and Gardiner 2005:190). Disabling communication, on the other hand, occurs when caregivers essentially do the opposite, preventing the person with dementia from expressing themselves and representing them as "unable to participate within decisions" (Adams and Gardiner 2005:190).

Taking a phenomenological approach in their research, Walmsley and McCormack (2013) observe how facial expressions and bodily gestures come into play in verbal and non-verbal communication between a person with advanced dementia and her family members. Using dance metaphors, the authors describe two contrasting modes of interaction: in-step and out-of-step. In-step interactions occur when "family members appeared to interact harmoniously, spontaneously and reciprocally. Timing of interactions flowed easily, with or without speech, and there was a sense between the interactive members that 'meaning was understood'" (Walmsley and McCormack 2013:6). In contrast, out-of-step interactions are characterized by disharmony, syncopation, and vulnerability. "Discordant relational patterns were observed when delays, distressing noises, or interaction appeared to be overshadowed by past negativity" (Walmsley and McCormack 2013:9).

It is important to note that the two latter studies feature a positive versus negative dualism in the types of communication they propose for dementia care. The idea of enabling versus disabling communication, as well as the concept of in-step versus out-ofstep interactions, are framed within binary distinctions of good versus bad, ability versus disability, and inclusion versus exclusion. In this thesis, I engage theoretically with the anthropological delineation of senility precisely to avoid such dualisms in thinking about good versus bad care, or person-oriented care versus biomedical care.

It is for this same reason that I also shift away from the notion of personhood as the basis for thinking about dementia. Cohen (2008) provides a cogent commentary in response to Taylor's essay on dementia and caring, and on the personhood turn in anthropology more broadly. He claims that the concept of personhood, even when founded on care rather than on recognition, is a category that perhaps inevitably entails a principle of exclusion that considers individuals as either persons or non-persons. "I wonder if through such pedagogies of attention we are enabling a return to personhood for only those persons with dementia fortunate enough... to have caregivers with the resources to attend with some relative sufficiency," he writes, going on to ask, "Does the hermeneutic power of the personhood turn at its best evade the demand that the person with dementia be positioned on one side or the other of the binary between a comprehensible and an incomprehensible form of life?" (Cohen 2008:337-338). It can be argued, then, that in using the concept of personhood to foreground senility, there arises a risk of reproducing the aforementioned dualisms, whether the concept is oriented around recognition or around care.

I return for a moment to revisit concepts of senility and voice in order to provide an alternative route for thinking about communication in dementia care that lies outside of the theoretical framework of personhood. Cohen (2003) writes that, for its listeners, the senile voice becomes "troubled when it turned the *order* of language... inside out" (Cohen 2003:125; italics original). Cohen posits an alternative mode of listening which he terms *ironic listening*, in which the utterances of the senile voice do not "correspond to the expected referents... (that is, are coherent) nor are they necessarily radically beyond coherence" (Cohen 2003:127). Concerned with how people might hear, listen, and

respond to the differences of the senile voice differently, the process of ironic listening offers new possibilities for enacting care as a communicative practice.¹⁰

Cavarero's notions of *logos* and vocality similarly provide a useful approach to imagining how an engagement with the senile voice may unfold differently in the absence of language and other conventional indicators of interaction. According to Cavarero, logos, signifier of the realm of order and knowledge in the Western philosophical tradition, risks becoming devocalized, universalized, and depersonalized when it problematically prioritizes the visual over the auditory. By concerning itself "with saying, but not with the human world of singular voices that, in speaking, communicate the speakers to one another" (Cavarero 2005:43), logos relegates the relational plurality of voices outside of its intellectual domain. In response, Cavarero shifts the philosophical focus from language to speech, "in order to listen... for the plurality of singular voices that convoke one another in a relation that is not simply sound, but above all resonance" (Cavarero 2005:178-179). Rather than be obligated to convey normative semantics, interacting voices instead can be heard in their own tones and registers. Together with the possibility of listening ironically to a senile voice, the idea of vocal resonance-which conveys a reverberation of prolonged sound, of something sustained and shared—sparks the potential for reflecting on and practicing communicative modes of care.

¹⁰ The concept of ironic listening can be observed in the film, "Complaints of a Dutiful Daughter" (1994), directed by Deborah Hoffmann, which documents her mother's struggle with Alzheimer's disease. The film demonstrates the evolution of communication between Hoffmann and her mother, from frustration at her mother's loss of recognition to a different mode of listening that reaffirms their relationship with love, care, and a sense of playfulness. Hoffmann "learns to listen and to relate to her mother in a different way, without the surety of fixed positions in language" (Cohen 2008:336), making possible new communicative practices of care in their relationship.

Arriving at an Intermediate Area, and Elsewhere

The slow disclosure narrative strategy that I have used in describing this scene in the outpatient geriatric psychiatry clinic is a deliberate attempt to reflect the feeling I sensed of something being unsettled. As I listened to the dialogue unfold between Liu, Xin, and Dr. Wang from my vantage point—as both an observer of the scene and a listener unfamiliar with psychotherapeutic techniques of communication—I became puzzled by the way that Liu's utterances seemed to disturb and disrupt the familiar, and elicited different responses from her two interlocutors. What I found striking about this encounter in the outpatient clinic was the series of mismatched correspondences that became unraveled throughout the conversation. Firstly, there was a mismatch in Liu's words between what was assumed by her listeners as delusions-and conversely, what was assumed as real and factual—and what Liu herself felt and experienced as very much real. Additionally, there was also a mismatch between the different ways that her two interlocutors took up and responded to her speech. Whereas Xin was intent on correcting her mother's speech, Dr. Wang's responses entailed a different kind of communication. By not playing into what is deemed true or false, real or imagined, how did Dr. Wang's listening and speaking enact other possibilities for care for Liu?

Writing on child psychology, Donald Winnicott proposes the idea of "an intermediate area of experience" between subjective (inner) and objective (outer) reality that goes unchallenged (Winnicott 2005:18). For children, this intermediate area is that of play, where the delineation between imagination and reality is left unquestioned; parents intuitively recognize that transitional objects and phenomena, like a teddy bear, are necessary for their child's development (Winnicott 2005:18). He argues, "Should an adult

CHAPTER 1

make claims on us for our acceptance of the objectivity of his subjective phenomena we discern or diagnose madness" (Winnicott 2005:18). In this manner, Liu's utterances can be diagnosed as madness—the madness of *chidaizheng*—if we interpreted her speech as "making claims on us for our acceptance of" the reality of her subjective experience.

Here, drawing upon this idea of the intermediate area, I want to suggest that Dr. Wang's interaction with Liu can be understood as an instance of ironic listening. She did not attempt to correct Liu's speech so that it conformed to its expected correspondences; rather, she allowed Liu's voice to resonate on its own terms, in its anger, irritation, frustration, and confusion, and it is on these terms that Dr. Wang communicated with Liu, her patient. Although, in her role as a geriatric psychiatrist, Dr. Wang most likely recognized that Liu was speaking about something that was not factual in reality, she neither challenged the intermediate area nor participated in making the distinction between true and false. Instead of "refusing the specificity of a voice by hearing only its sickness, madness or course," Dr. Wang attended to the singularity of Liu's voice and allowed it to invoke her own by "hear[ing] language and its correspondence... work in unexpected ways" (Cohen 2003:132; italics original). Because the frame of the clinical setting is such that Liu's status is that of a patient with Alzheimer's disease, what is at stake for Dr. Wang is the care of her patient, for whom it is most important that she is manyi. The therapeutic "back-and-forth flow" between Dr. Wang and Liu are what Taylor calls "communicative practices of caring."

There was, however, something disrupted and disturbed in this space as well. Though it never quite spilled into spoken conflict, underlying tensions existed between Liu, Dr. Wang, and Xin. While Dr. Wang practiced ironic listening as a form of care, Xin

heard predominantly in her mother's senile voice the loss of reason. There was a clear sense of discomfort that Xin expressed either vocally or facially as her mother spoke to Dr. Wang. For Xin, her mother's beliefs that someone was stealing her clothes and changing her medications indicated a delusion, a false perception irreconcilable with reason, logic, sense, and factuality.

Using discourse analysis as her interpretive method, Forbat (2003) illustrates the tensions between a care dyad of Mavis, who has dementia, and her daughter Barbara, who also provides care for her mother. Forbat notes the discrepancies and differences in each woman's narrative as they provide an account of their family history, personal relationship, and their current relationship of care. She writes, "Their accounts suggest longstanding tensions which, although not caused by dementia, do seem to be exacerbated by it. The relational difficulties... can be seen as a function of malignancy that has a historical basis in their earlier relationship" (Forbat 2003:73). In particular, Forbat points to Barbara's negative descriptions of her mother and her disregard for her mother's confused speech (Forbat 2003:72). Forbat claims, echoing Winnicott here, "Barbara's response seems to be one of challenge to her mother's confused presentation, rather than trying to understand or accept her perceptions... This is described as being an interaction style whereby there is a failure to acknowledge the subjective reality of the other person's experience" (Forbat 2003:79).

Although the space of this brief Wednesday morning encounter in the outpatient clinic offered limited context about Liu and Xin's particular mother-daughter dynamic and family history, the disturbance of reason in Liu's speech most likely signified also a disturbance in the trajectory their relationship had taken as a consequence of Liu's

dementia. The communicative practices upon which their relationship was previously hinged, thus familiar to both women, had been disrupted. Liu's troubled and troubling utterances represented what Cohen calls the "contested speech" that emerges from an "intergenerational conflict over the authority of interpreting the word" (Cohen 1998:121). If a deeper narrative of their relationship were to be explored, as in Forbat's discursive analysis of Mavis and Barbara, it might be possible to argue that the dynamics of conflict between Liu and Xin surrounding the older woman's contested speech were also a conflict over understanding the relation between senility and illness.

Attending to the discursive interactions between Liu, Dr. Wang, and Xin in this clinical encounter deliberately moves away from logocentric tendencies to privilege language and allows for other ways of listening to take place, namely hearing the senile voice on its own terms, in its own resonance, and as its own phenomenon. The impulse to diagnose and to question to what extent Liu's words were representative of factuality versus delusional speech is superseded by a curiosity of the possibilities of difference. Rather than identifying mismatches between expressed imagination and so-called objective reality, how might we listen if we took seriously—and playfully—the possibility of care when a person's words do not fit neatly into their assumed and expected correspondences?

At the same time, in my exploration of the potential of ironic listening in caregiving, I am also not making the argument that this mode of communication simply restores those expected correspondences at a different register. Listening and speaking differently in response to a voice of difference does not entail a search for coherence or for a new "language." The key here is a shifting of conceptual frames that allows one to

grapple and engage ethnographically with possibility, messiness, uncertainty, and questions left unanswered. I am interested not so much in the *what* being uttered, but in the *how* and, in the words of Hannah Arendt (1958), the *who* in listening and speaking. In the following vignette, I continue to take up the idea of communicative practices of care and explore how play can enter into and reconfigure relationships of care in the midst of listening and speaking.

At Home with Yeye: Playing With Bottomless Feet

"He has lost logic. He is unable to distinguish between his own fantasies, his own imagination, and reality."—Xiaoyi

"[A]n uncanny effect is often and easily produced when the distinction between imagination and reality is effaced, as when something that we have hitherto regarded as imaginary appears before us in reality..."—Sigmund Freud, "The 'Uncanny"

"The university won't accept four music students." *Why?*, a woman's voice playfully asks. "Because they don't have soles on their feet." Lying on the bed, resting during the hot afternoon, Yeye is certain about the bottomless foot condition of these four students. In the bedroom with him, his daughter and son, and my mother and I are casually arranged in different spots around the room. Yeye's daughter Xiaoyi is sitting next to him on the bed, holding his hand, her older brother Shen leaning against a dresser. Xiaoyi, which means "auntie," is my mother's childhood best friend. Mom is seated next to me, and I am sitting next to a bookshelf, where I find a photo of Yeye, his wife, and Shen from the 1980s.

"That was taken when my parents visited Shen in Finland," Xiaoyi tells me, pointing to her smiling father in the photograph. In it, he is wearing a black suit and a white shirt, and his hair is black and longer than the buzzed style he sports today. At 82, Yeye is a retired astrophysicist for the China National Space Administration. In early 2010, he and his wife were concurrently diagnosed with cancer—he, gastric, and she, primary peritoneal (cancer of the cells lining the abdominal cavity). She passed away a year later. Today, Yeye is still recovering from the surgical procedure that removed his cancer and, along with it, a portion of his stomach. He also appears to have moderate-to-severe dementia. Xiaoyi first noticed the beginning of what she calls her father's "loss of logic" prior to his cancer when he had claimed that a friend had called him about coming to visit when, in fact, there had been no such phone call. However, his most notable cognitive, as well as physical, decline seems to have occurred after his surgery.¹¹ Just a few months ago, it had become difficult for Yeye to eat, and he became malnourished. Xiaoyi and Shen thought their father was at the end of his life.

Though he has lost a considerable amount of weight, Yeye has recovered a great deal since then, after having taken a daily protein powder drink over the past couple of months. Lying in bed, holding onto his daughter's hand, Yeye is quiet and smiling. He is thin and dressed in summer cargo shorts, and I can see his bony legs, knees knobbed, spotted, frail-looking. Yeye speaks the nonsensical "babble" of what would be attributed to a senile voice. Today, between briefly referencing family friends and remarking how closely my mother and I resemble one another, Yeye tells us about Japanese spies, Indian tourists in China, and these four musicians without soles. Yeye's speech, however, is heard in a particular context of care, here at home with his family. It is not interpreted as delusions in the clinical context of neurocognitive impairment and behavioural

¹¹ Post-Operative Cognitive Dysfunction (POCD) is "used to describe a decline in cognitive performance from pre- to post-surgery... [People] in the very early stages of dementia, as yet undiagnosed and possibly unnoticed, may be more vulnerable to developing... POCD because of the changes already going on in their brain. They may go on to be diagnosed with dementia at a later stage" (Alzheimer's Australia 2007:1-2).

disturbances, and is instead listened and attended to with humour and playfulness. His utterances are just that, utterances—and imaginative ones at that—not symptoms fulfilling diagnostic criteria. Here, in this small, cramped bedroom, attempts to maintain the order of logic and reason evaporate into the hot afternoon air. Something else comes into the room, perhaps a spirit of play that makes its presence felt, shared, and enjoyed.

"The university won't accept these four students because they don't have soles," Yeye repeats, looking up at us from his pillow. We all nod and agree, but we cannot help laughing. There is something extremely funny about the word for "sole" in Chinese, consisting of a combination of the words for "foot" (*jiao*), and "board" (*ban*) and at the end, the distinctive *-er* suffix that Beijingers like to use liberally. It comes out all together as a flurry of rounded vowels and comically exaggerated sounds, deliberately slurring sloppily into one another, dipping down in intonation before rolling back up the throat.

"But if they don't have *jiao bar*, how would they be able to walk?" Shen asks his father jokingly. "*Baba*, do you think they would walk like this?" Shen, in his sneakers, stands on his toes and in rapid motion, tiptoes across the small room, arms extended in front of him as though mimicking a wooden puppet. We laugh, Yeye included.

Heh heh, is what it sounds like when he laughs. It is a soft, breathy chuckle that escapes quietly between his unevenly toothed grin.

After a little while, the four of us migrate to the living room, allowing Yeye to take a break from the commotion and rest.

"Please make yourselves feel at home," Yeye tells Mom and I as we leave the bedroom. We thank him and tell him that we will.

"I wonder how he came up with the idea of people without soles," Mom remarks.

"It's nothing new," Xiaoyi says. "He's mentioned it before. Maybe he had a dream about it and now he's unable to distinguish between his dreams and illusions and reality."

The air conditioning is turned on in the living room. We are drinking leafy green tea and eating watermelon, looking at some of the family portraits in the room, and tuning in once-in-a-while to the television program that is playing. A few minutes later, Yeye quietly appears in the doorway and very slowly maneuvers himself around the furniture, one hand against the wall. We shuffle around to let Yeye sit in one of the armchairs. His thin arms rest comfortably on the cool leather. Xiaoyi sits on the sofa next to him, holding and patting his hand. Mom and I are sitting on the bed against the wall, and Shen is by the window, taking pictures of the watermelon on his phone.

"Baba, what's this?" he asks his father, showing him the picture of the watermelon. Asking a person with dementia to recognize common objects—a watch, a pen, a feather, a spoon—is a common practice in medical diagnostic procedures, but the context and purpose of the question here is different. When Shen shows Yeye the picture of a slice of watermelon and asks him what it is, we are witnessing not a mini-mental status examination, but something different. It occurs to me that no one in the room expects a matched correspondence between language and object in Yeye's answer, leaving room for surprise, for delight.

"Watermelon," Yeye responds without hesitation or uncertainty. Xiaoyi and Shen, in turn, enthusiastically praise their father. A couple minutes later, as we are watching the television, Yeye points out that the people on the screen do not have soles. It is not posed as a question, but stated as a fact. This is again followed by a burst of laughter among the four of us, and Yeye joins in also—it seems that *jiao bar* is the recurring topic of the day.

"But what would that look like, do you think?" Xiaoyi asks her father. "What do you think it would look like if they didn't have *jiao bar*?"

Yeye slowly traces a rectangular shape on his arm. "It... it looks like a *chang*... *chang fang kuar*," he says. "A rectangle."

"Chang fang kuar?" The exaggerated *-er* suffix of the last word, *kuai*, rolls up into the question mark.

"Yes, like this." He traces the shape again on his arm.

Xiaoyi has a mischievous look in her eye. She turns to her brother, and says to him in a sneaky and hushed voice, "Hey, you should take a photo of a foot and ask him what it is." We are all giggling. Yeye is smiling, watching us. Xiaoyi takes off her shoe and points her foot in the air, a chubby and pinkish foot, and Shen, doubling over in the laughter, comes around to take a photo of it, holding his phone at arm's length for a close-up. "Make sure you get a good angle," she suggests, chuckling. Yeye quickly catches on.

"You're taking a picture of her *jiao bar*," he remarks matter-of-factly as Shen is still trying to capture the perfect angle of his sister's foot. Caught red-handed (or rather, red-footed) in the middle of mischief! We all laugh. There are actually tears in my eyes. *Heh heh*, a soft and slow chuckling sound, Yeye is laughing with us.

I first met Yeye two years ago when I was in Beijing doing research for my undergraduate project on end-of-life caregiving. It had only been three months since Xiaoyi's mother had passed away. Those months prior, Yeye was recovering from his own surgery just as his wife underwent surgery that unsuccessfully attempted to remove multiple tumours from her abdominal area. She was admitted to the intensive care unit,

where she died ten days later. After her death, Yeye felt helpless, confused, and *xinli bu'an*—"without peace of heart"—according to Xiaoyi, and became increasingly "difficult to care for." He blamed himself for causing his wife's illness and constantly raised protests against his children, blaming them for leaving him alone at home with a *baomu* (a female at-home caretaker), for the surgery that removed part of his stomach, and for not taking good enough care of him. In an attempt to placate and console him, Xiaoyi explained to her father that his decreasing mobility, slower speech, and declining cognitive abilities were a part of an illness.

"I told him that he wasn't just getting older, but that he was also sick," Xiaoyi told me then. "It was easier for him to accept the reality of his situation after admitting to himself that he had an illness."

When I visited his home three years ago with Mom and Xiaoyi, Yeye was able to move around by himself. Though thin, he was twenty-or-so pounds heavier. Then, there was a different *baomu* looking after him. As we sat in the living room, messier then, cardboard boxes everywhere, Yeye quietly observed our conversation, occasionally speaking, slowly but comprehensibly. His gaze shifted between watching Xiaoyi and Mom chatting and the intermittent flashes of light and sound on the television.

"His brain has become kind of illogical, you see," Xiaoyi explained, when Yeye could not quite keep up with the current conversation. "Even when he tries to say something, he can't say anything related to the topic. I think he's lost this ability."

When Xiaoyi told her father that we were leaving briefly to buy a phone card on a main street nearby, Yeye rose from his seat on the bed.

"Let me go with you. You don't know where the store is. Only I know which store to go to," he said.

"There's no use for you to come," Xiaoyi told her father assertively, despite his protests. "We'll be fine by ourselves. Don't get up." Yeye slowly agreed, hesitating, and sat back down in front of the television.

At that time, their interaction marked a moment of surprise for me. Without knowing more about the particular dynamics of their father-daughter relationship beyond what Mom had briefly described to me as we were leaving for Xiaoyi's earlier in the day, I found myself at a loss for how to make sense of their relationship without any other context or background. Because of my unfamiliarity both with being in the intimate space of their family home and with their personal history, I was struck by the sudden change in Xiaoyi's voice when she spoke to her father. Loudly and quickly, she spoke in a tone that was neither condescending nor argumentative, but lacked the gentle, comforting quality that in my mind, and in the context of my relationship to her as her "niece," characterized her. Later, when I asked Mom if Xiaoyi had been angry or annoyed with her father, she replied, "No, that's just how they are. That's how they've always been."

That tone of Xiaoyi's voice, which had me wondering what she meant and how she felt, is not heard today. Despite his obvious cognitive decline, it seems as though Xiaoyi is relieved that her father is comparatively healthier than he was a few months ago, and even a few years ago when he had cancer. Rather than exacerbating previously existing tensions, perhaps Yeye's senility has actually smoothed over certain difficulties in their relationship. Perhaps Yeye is less "difficult to care for," less argumentative and more easygoing. Perhaps the idea that "that's how they've always been" no longer holds; there is something new in their relationship today, emerging as a new kind of care in the spirit of play with which they speak, and listen, and respond to each other's voices. Though there might also be an unspoken sense of loss for all three—of a past together, of the lifelong familiarity with one another's personalities—there is undeniably something different that was not present three years ago, something that entails imagination and laughter, and peace of heart.

When I ask Xiaoyi whether Yeye has been medically diagnosed with dementia, Xiaoyi shakes her head. "When he was really sick a few months ago, the doctor told us he probably had dementia," she says. "But he doesn't want to go to the doctor anymore, so we haven't been to a specialist. He's happy now and doing much better, and he doesn't want to take any more medications."

I am not attempting to make the argument here that dementia left undiagnosed is better or worse than in a situation in which a person with dementia receives neuropsychiatric care. Rather, I am interested in a question of framing that moves beyond the binary distinction between person-centered care and biomedical care. Xiaoyi, Yeye's primary caregiver, sees her father not only as an elderly person (*laonian ren*) but also as a sick person or patient (*bing ren*) who "probably has dementia." How does Xiaoyi's recognition of the particular difference in her father's speech—as simultaneously progressively senile and more peaceful—make it possible for a distinct space of response and communication to open up? How might the spirit of play reconfigure their relationship of care?

Listening to Yeye talk repetitively about musicians without soles produces a bizarre and somewhat uncanny feeling, in the sense that "the distinction between imagination

and reality is effaced" (Freud 1919:243). Hearing Xiaoyi and Shen play along with their father's utterances adds to the feeling of surreality, but the tone that is evoked is not one of discomfort or disturbance, but rather of playfulness, lightness, and the joy in being together. The distinction between fantasy and reality, between imagination and logic, is clearly defined for Xiaoyi and Shen, and yet, at the same time, blurred for Yeye. The loss of this distinction serves as the primary explanation Xiaoyi has given over the past three years about her father's cognitive decline. However, she leaves the intermediate area between Yeye's imagination and their shared reality unchallenged. For Xiaoyi, the fact that her father is now "unable to distinguish between his dreams and illusions and reality" is a phenomenon that does not need to be questioned. She listens to the mismatches in Yeye's utterances without needing to search for semantic coherence. As a result, I am able to enter into the interactive space of their family home without feeling compelled to ask whether or not *jiao bar* exist. Yeye's voice is neither contested nor uncomfortable for his listeners, and it gives rise to the possibility for something unexpected and playful.

When Do We Play?

After we leave Yeye's home, Xiaoyi says, "It makes him so happy to have visitors. You could tell he was in a good mood today."

I wonder how one *tells* with senility. How exactly does Xiaoyi tell that her father is happy today? Avery Gordon writes, "How can we tell the *difference* between the symbolic, the imaginary, and the real...? How can we *tell* the difference between one story and another's? It will all hinge, as we shall see, on that double modality of telling—to recount and to distinguish" (Gordon 1997:38). The problem of telling, which could be rephrased as a question of recognition, seems most often directed as a problem of the

senile person. Recall, for example, the question "Does she still recognize you?" that Janelle Taylor constantly grapples with. I want to know what happens when we turn this question of recognition on its head. How do we recognize senility—its differences and its demands, its affect and its needs—such that we are able to both recount and distinguish it? With Yeye, how do Xiaoyi and Shen recognize that their interactions with him are instances that demand playfulness, not solemnity?

Enter play. It might be impossible to pinpoint the moment that play entered into the dynamic between Xiaoyi and her father, but the initial moment seems secondary to the fact that play has evolved as a communicative practice and now figures essentially into their relationship today, a relationship weathered by cancer, death, and dementia in only the past three years. There is jubilance and delight in their interactions with one another today, genuine pleasure in the way that Xiaoyi pats Yeye's hand and the way that Yeye smiles as he quietly watches his children. Xiaoyi plays with her father's imagination and speech, which express the blurred distinction between his dreams, fantasies, and reality, and through play, their communication takes on a new form of care in their relationship—one that is different than "how they've always been."

On To Care

From Songtang Hospital to Dr. Wang's outpatient clinic, and finally to Yeye's home, these ethnographic vignettes have been placed with one another in a kind of three-part harmony. Their distinct voices resonate in their own tones and terms, yet they also share what Cavarero calls the relational plurality of voices marked by senility as an embodied and recognizable difference. Together, they illustrate different aspects of what it means to recognize and interpret difference—a person, a voice, a body—differently.

The disruption of Liu's frustrated voice in the clinic with Xin and Dr. Wang. despite her capacity for language, has an altogether different quality than the speech of the elderly man at Songtang Hospital, whose incomprehensible utterances nevertheless allowed for a smooth "back-and-forth" conversation. At the same time, Yeye's obscured voice, deficient in the motor functionality needed for speech and the cognitive ability needed for the logic of language, is neither troubled nor troubling. Even when it speaks the apparent nonsense of senility, it elicits something different—humour and play—from Xiaovi and Shen. Each voice here is specific to its speaker, but each voice also undoubtedly occupies a space with those it speaks to and engages in conversation. The harmony of these voices does not necessarily need to "make sense" as semantic correspondences that match normative assumptions of language. Rather, in invoking the listener and the listener's response, these voices marked by the difference of senility make possible something new, something previously gone unheard and unnoticed, something even playful. In the next chapter, I explore this interpersonal space of interaction in the context of communicative care in order to demonstrate the possibilities of play for attending to voices of difference that require new and unexpected ways of speaking, listening, and being together.

2 Taking Care to Play

Prelude: Following the Logic of Play

"Never try reasoning with a person with dementia, because there is no reason in their world."—Li

Li holds regular caregiver training sessions in different parts of Beijing, as part of the Dementia Research and Care Center's community health outreach programs. Today, she is teaching the first of three sessions to a group of four caregivers at the Beijing Science and Technology University, all of whom have a spouse or parent recently diagnosed with dementia. Li is in her early forties, sporting a short haircut with dyed reddish-brown hair and make-up. She collaborates with Dr. Wang and her research team to carry out these training sessions for caregivers. Li begins the session by introducing herself and speaking about her own experience with her grandmother's prolonged illness, and her expertise in dementia care complements Dr. Wang's clinical knowledge. Together, they co-authored a book titled "Smart Caregivers" (*congming de zhaoliaozhe*) which provides detailed guidelines for giving care at different stages of dementia.

In her presentation, Li uses several personal anecdotes to give examples of possible scenarios that could occur "somewhere down the line" as the disease progresses, and much of her lecture on the illness experience of dementia focuses on the loss of memory and recognition. She tells the caregivers that people with dementia will eventually forget how to carry out basic tasks—putting on clothes, using utensils, brushing teeth—and they will gradually lose the ability to recognize people, even loved ones.

"There's no right or wrong in the world of a person with dementia. Don't reason with someone who has dementia, but don't lie either," Li says. Her voice is sweet and high-pitched. "What we have to do is establish a new way of communicating. We have to understand how they feel before we're able to communicate. Once we empathize with them, then we'll be able to guess what they need or want." The first step to communication (*goutong*), Li says, comes with patience. By smiling, nodding, maintaining eye contact, and gently touching, the caregiver asserts to the person with dementia: "I am listening to you. I am giving you my attention. What you're saying is important to me."

Each of the caregivers is provided with a package of written materials with information on the logistics and daily challenges of caregiving for a relative with dementia. Among the materials is the small, brightly coloured, spiral-bound manual, "Smart Caregivers."

"Caregiving for someone with dementia doesn't just require physical labour, but it also demands creativity and flexibility—that's why we want to teach you smart caregiving," Li tells the group. To give an example of smart, adaptable, and creative caregiving, she recounts the story of a man who covered all the mirrors in his home with blankets and towels when his wife no longer recognized her own reflection in the mirror and suspected that he had brought another woman into their home.

In these training sessions, caregivers are taught that the first step to smart caregiving is skillful communication through attentive speech, gestures, and touch. Here, techniques of communication—verbal, non-verbal, bodily—are enacted as techniques of care. Li's approach to caregiving for a person with dementia is delineated in terms of care

as communication, and within this framework, there is a particular style of caregiving-

even a logic.

In her exploration of the logic of care, anthropologist Annemarie Mol writes:

There is a risk in using a word like 'logic' when talking of practices. It might seem to suggest that those practices are so coherent that everything within them is firmly defined by everything else. Let me insist that this is not the case. Unexpected things always happen. A lot of creativity is involved in any practice... I am after the rationality, or rather the rationale, of the practices I am studying. Here the term 'logic' helps. It asks for something that one might also call a style. It invites the exploration of what is appropriate or logical to do in some site or situation, and what is not. It seeks a local, fragile, and yet pertinent coherence. [Mol 2008:8]

I find Mol's use of the concept of 'logic' here especially helpful to think about the possibilities for understanding rationales behind practices of caregiving for a person with dementia. In her role as both a teacher and a confidante for caregivers, Li essentially "translate[s] a logic into language... mak[ing] words for, and out of, practices" (Mol 2008:8). In her training course, there are certain techniques of communication that are considered appropriate and inappropriate—and "smart"—when caring for a relative with dementia, whose senile voice is presumed to exist in a world without reason. The logic of care in Li's approach is based on this assumed illogic of senility; it imagines the lifeworld of dementia as often unpredictable and recognizes the consequent demand for a particular kind of communicative care. At the same time, built into this logic of care is the need for adaptation and creativity—such is "smart caregiving." This rationale is not inflexible by virtue of being a rationale; rather, it integrates flexibility into its logic and its corresponding practices.

I am, moreover, interested in making a conceptual parallel between a logic of care and a logic of play. By adding the component of play to Cohen's notion of ironic listening as a possible practice of care, I want to suggest that communicative play follows a logic of its own, without necessarily seeking to restore coherence or reason. Play is neither always about creativity and flexibility nor always spontaneous, fun, and openended; it can be serious, intense, fragile, and risky in its experimentation. "[I]t creates order, *is* order," writes the historian and play theorist Johan Huizinga (1949:11). How does this order, or logic, of play operate when faced with the apparent disorder of senility? In this chapter, I explore a rethinking of the concept of play and a reconsideration of its multiple dimensions and demonstrate ethnographically the various ways that play can be played out in the communicative space of care. Using Li's community health-oriented caregiver training session as a starting point, I trace the logic of play throughout its diverse sensibilities, forms, styles, and practices in different contexts of care—at home with Xiaoyi, Shen, and Yeye; in the dementia care unit at the Beijing Geriatric Hospital; and in Dr. Wang's outpatient clinic at the No. 6 Hospital.

Interlude: Theorizing Play

"The cadences of play skip through a vast number of situations in everyday life... Play is evident in moments of dreaming and daydreaming and fantasy... We hear the jest of play in riddles, jokes, puns, gossip, wordplay. We find play at work in beauty contests and white-water rafting, in hobbies and gambling, at parties and in psychotherapy... Play is as basic to human functioning as eating or dreaming. Indeed, rather than think of play as being bound within certain situations only, it makes sense to conceive of it as an elemental feature of people's lives."—Robert Desjarlais, *Counterplay*

The different ways in which the concept of play has been theorized in anthropology, psychology, philosophy, and the social sciences merit attention here. A recurring theoretical model for thinking about play juxtaposes it with something that is not-play. In sociocultural anthropology, for example, play has been conceptualized in contrast to the concept of work. In this distinction, work is understood as productive labour that has high stakes, whereas play, being associated with social activities like games, is seen merely as non-work, and thus non-productive and lacking the seriousness of high stakes—in the words of play theorist Roger Caillois, "an occasion of pure waste" (1961:5). However, as the anthropological study of play has expanded over the course of the twentieth century, "[i]t has become difficult to deny that play is often productive... Along the way it has also become more difficult to sustain claims that play is essentially about 'fun,' 'pleasure,' or other positively charged sentiments" (Malaby 2008:1).

The trope of play as pleasure—"fun and games"—is often contrasted with the seriousness of not-play, a dualism that Huizinga puts into question in his seminal text on play, *Homo Ludens* (1949). He writes:

[The] contrast between play and seriousness proves to be neither conclusive nor fixed. We can say: play is non-seriousness. But apart from the fact that this proposition tells us nothing about the positive qualities of play, it is extraordinarily easy to refute. As soon as we proceed from "play is non-seriousness" to "play is not serious", the contrast leaves us in the lurch—for some play can be very serious indeed. [Huizinga 1949:5]

For Huizinga, play is a primary category in human and animal life, fundamental to the experience of being alive. He posits, "[W]e might call it a free activity standing quite consciously outside 'ordinary' life as being 'not serious', but at the same time absorbing the player intensely and utterly" (Huizinga 1949:13). Because both humans and non-humans are capable of engaging in play, he argues that play is not grounded in "any rational nexus" (Huizinga 1949:3); rather, the fun of play resists logical analysis and interpretation in the human domain of reason. "The very existence of play continually confirms the supra-logical nature of the human situation. Animals play, so they must be more than merely mechanical things. We play and know that we play, so we must be more than merely rational beings, for play is irrational" (Huizinga 1949:3-4).

The co-existence of fun and seriousness in play, particularly among animals, poses something of an intellectual conundrum among scholars of play. Anthropologist David Graeber asks the question: how can we know if an animal's form of play is not ultimately intended to carry out some practical purpose? Graeber problematizes the way that animal behaviour is understood in the biological sciences in terms of means and ends calculations; in the Darwinian evolutionary framework, animal activity is rationalized as an expenditure of energy in order to fulfill some kind of goal, be it reproduction, survival, or dominance. He argues, "[E]thologists have boxed themselves into a world where to be scientific means to offer an explanation of behavior in rational terms-which in turn means describing an animal as if it were a calculating economic actor trying to maximize some sort of self-interest" (Graeber 2014; italics original). According to Graeber's argument, the fact that we—as thinking humans—are so mystified by certain kinds of animal play, and find ourselves at a loss for explaining these behaviours, reveals our intellectual limitations for thinking about this aspect of life. For Graeber, the "play principle" offers an explanatory possibility that science cannot; play can explain why pleasure is fun and why something serious and not nice can also be fun. What is powerful about the concept of play is that it "gives us ground to unthink the world around us" (Graeber 2014).

But what happens when play not only becomes serious but actually slips into something that is not play? A critique by the philosopher Alva Noë in response to Graeber ponders the undefined and unpredictable threshold between play and something other than play. "Fun itself... has the curious quality that it threatens to be a pretty serious business," writes Noë (2014). He goes on to say that playing with others entails

CHAPTER 2

the risk of loss, the danger of being disappointed and hurt. On the other hand, winning can also happen, which can involve pleasure and fun. "But pleasure is often hard-won, and the risk of loss and failure... are always just as much in the offing as that of pleasure itself... [O]nce we've divorced play from pleasure, play doesn't look all that different from... work" (Noë 2014). According to the logic of Noë's argument, even if play were not simply a means to an end but rather an end in its own, as Graeber claims, once it is decoupled from pleasure, it slips into something entirely different, into what Gregory Bateson would call a slipping of psychological frames (Bateson 2006:326). The question then becomes: what is play without pleasure?

Perhaps part of the difficulty in conceptualizing play without falling into the trap of reducing it to what it is not—which, as Huizinga argues, "tells us nothing about the positive qualities of play"—is because we imagine it in the form of activity, rather than as experience or sensibility. Thomas Malaby proposes thinking about play instead as a disposition, or "an attitude characterized by a readiness to improvise in the face of an ever-changing world" (Malaby 2008:2). The association of play with improvisation and spontaneity is not an uncommon characterization and exemplifies what the play theorist Brian Sutton-Smith terms the "rhetoric of the imaginary," in which *rhetoric* refers to a "persuasive discourse, or an implicit narrative" (Sutton-Smith 1997:8) reflective of a way of thought. The rhetoric of the imaginary frames play in terms of: "imagination, fancy, phantasmagoria, creativity, art, romanticism, flexibility, metaphor, mythology, serendipity, pretense, deconstruction, heteroglossia, the act of making what is present absent or what is absent present, and the play of signifiers" (Sutton-Smith 1997:127). Play is simultaneously characterized by an attitude and experience and also involves "its

own distinct performances and stylizations" (Sutton-Smith 1997:219). The rhetoric of the imaginary can be characterized by its light mood and playful attitude, as well as its underlying belief "that some kind of transformation is the most fundamental characteristic of play" (Sutton-Smith 1997:127). At the same time, Sutton-Smith argues that play should not be defined only as a fun and voluntary activity, which reflects "restricted modern Western values" (Sutton-Smith 1997:218) that are historically contingent and cannot be universalized.

Thinking of play not only as an activity but also as a sensibility for the imaginary provides a particularly useful framework for understanding how play might unfold in the communicative space between a person with dementia and her caregiver. Bateson (2006) explores the evolution of play as non-verbal communication when both human and non-human organisms are able to recognize the "mood-signs" of those they are playing with as signals carrying a message. He writes:

I saw two young monkeys *playing*, *i.e.*, engaged in an interactive sequence of which the unit actions or signals were similar to but not the same as those of combat. It was evident, even to the human observer, that the sequence as a whole was not combat, and evident to the human observer that to the participant monkeys this was "not combat."

Now, this phenomenon, play, could only occur if the participant organisms were capable of some degree of metacommunication, *i.e.*, of exchanging signals which would carry the message "This is play." [Bateson 2006:316]

According to Bateson, participants must possess the ability to correctly recognize the meanings behind one another's signals in order to play through communication. I find this idea of play as a metacommunicative exchange of signals suggestive of the significant yet troubling role of recognition and the exclusionary principle it entails when thinking about dementia and personhood. Is play restricted to those who are able to engage in this activity of recognition? It seems that yet another exclusionary distinction

arises given this formulation of play. Because the signals of play are referential to other events—for example, the dog's playful nip "denotes the bite, but it does not denote what would be denoted by the bite" (Bateson 2006:317)—there is the constant possibility that play might slip into something not-play that "threatens to be a pretty serious business." Again, we find ourselves in another turn of the wheel of the play conundrum that inevitably pits it against something it is not. Despite these two points of critique, however, what I find most compelling about Bateson's theory is his idea that "the evolution of play may have been an important step in the evolution of communication" (Bateson 2006:317).

I take up these different theorizations of play as pieces of a larger discourse that come together, clash, refute each other, and speak to one another in unexpected ways. I am interested in thinking about the activities, words, sounds, gestures, expressions, experiences, and attitudes that play makes possible in the specific context of giving care for a person with dementia. With this focus in mind, I deliberately uncouple play from the assumption that it must be associated with creativity, flexibility, fun, games, humour, and laughter. Like my conversation with the elderly man at Songtang Hospital, play can require attentiveness and effort; it is possible to strain, to exert oneself intensely in play. To avoid making conceptual dualisms—fun versus seriousness, play versus work—I want to put forth the idea that the experimental messiness of play need not denote its failure, and consequently, a failure of care.

Furthermore, I am not attempting to make the argument that the notion of play *in* and *as* care is a practice of recovering coherence or rediscovering the self thought to be "lost" in dementia. Rather, the potential of play as a sensibility to and practice of care has

the power to disrupt common binary distinctions made in conceptualizing dementia. To echo Graeber, play "gives us ground to unthink the world around us" and how such a world has been configured with the presupposition that the capability to recognize, remember, and reason ultimately determines personhood. Though play can be seen to follow a logic of its own as it plays out in different ways, it does not need to operate in the domain of rationality (Huizinga 1949), nor does it need to be explained or analyzed according to a fixed definition. Play communicates something different: it allows for a rethinking of senility not as deterioration but rather as possibility, and it is this trajectory of thought, and of the unfolding of relationships of care, that I follow ethnographically.

Act 1: How to Be Serious at Play

"Senility does not so much turn the actual order of things inside out as trouble our desire for and identification with such an order."—Lawrence Cohen, "Senility and Irony's Age"

Every weekend, Xiaoyi visits the farmer's market near her house to stock up on a week's worth of groceries for her family and for her father. On a late Saturday afternoon in September, cool enough to wear long pants, I am walking behind Xiaoyi, pulling along the fold-up grocery cart that grows heavier with every melon and gourd she loads into it, especially because she buys two shares of everything.

"Yeye won't be able to eat all of these in a week, so let's give him the smaller bag and we'll take the larger one," she says when we are back at her car, allocating and dividing two bags of white peaches. On our way to visit Yeye, we stop at a convenience store where Xiaoyi buys several bottles of Russian kvass soda, and then we pick up Shen, who is waiting outside his apartment building. In the ten-minute drive to Yeye's, Shen talks about buying a motorcycle, and Xiaoyi teases him about being more of a homebody than a motorcycle adventurer.

It is dark by the time we get to Yeye's. He has just finished eating dinner, sitting at the small dining table as the *baomu*, or at-home caretaker, washes the dishes in the kitchen. He is dressed in a long-sleeved, checkered, button-down shirt and khaki-coloured pants. The *baomu* unloads the groceries from the cart, and Xiaoyi pours some of the kvass soda for everyone.

"Have you had this drink before?" she asks her father. Yeye shakes his head. "I bought it for you before, you must've forgotten. Do you like it?"

"I like it," Yeye says, nodding, sipping the bubbly soda. Kvass tastes like sweet rye bread.

Xiaoyi sits across from Yeye, Shen is on the sofa seat behind him, and I am seated on a wooden stool against the wall opposite the dining table. As Yeye quietly drinks the kvass, Shen asks Xiaoyi what brand of motorcycle she thinks he should buy.

"Is it a Japanese brand?" Yeye asks, turning his head around to look at Shen. "You shouldn't buy Japanese products. They're coming to China to take China's money." Yeye's suspicion of all things Japanese is something he has repeatedly mentioned before. Shen tells him that no one is coming to take China's money and reasons that, in today's globalized world, it is practically impossible not to buy Japanese products.

"Where do you think the components of your fridge come from?" Shen asks his father. Yeye replies with something incomprehensible to me, stuttering for a few seconds, then pausing mid-phrase, or stopping altogether, with just a smile on his face. He and

Shen debate for a few more minutes, but I cannot catch more than a few words of what Yeye says. Xiaoyi listens to the exchange, looking amused and content.

"Come on, come on," she says to her brother, chuckling. "Don't worry, *baba*, we definitely won't buy any Japanese products," she reassures her father when he pauses between words and sentences. "You have to *shun zhe ta lai* when you talk to him," she tells me. "Just go along with him," it means.

"We have to fight fascism," Yeye says seriously, looking at me. I nod and agree, not sure how else to respond. Meanwhile, the topic of fascism has spurred Xiaoyi and Shen into boisterously singing old Chinese revolutionary songs from the 1930's, songs they learned as children, songs whose lyrics they have now forgotten and are comically struggling to remember as they humour their father. Yeye watches them with a toothy smile on his face.

After the death of his wife in 2010, Yeye was "afraid of being alone" and insisted on living with Xiaoyi and her family. Xiaoyi lives with her husband, who is in his seventies, and her teenage son, who is attending middle school, in a three-bedroom apartment not far from her father's home. At the time, she did not think that having Yeye move in with her family was a feasible living arrangement. Instead, she hired a *baomu* to take care of him in their old family home, and she and Shen visited him together once a week.

Over the past few years, Xiaoyi has been primarily responsible for looking after Yeye. Shen comes to see his father only when accompanying his sister. When I visited Yeye with her three years ago, she expressed how challenging and burdensome (*fu dan*) it was to care for him. At the same time, she told me, "But I just have to be patient, because

there is nothing else I can do but continue to care for him. Once you've accepted your role as a caregiver, you have to just accept the reality of your situation and endure this difficult time." When I visited Yeye with her then, I heard a firm edge in her voice; she spoke with a slightly impatient rhythm that echoed the ambivalence and frustration she felt toward her father and about her role as his caregiver.

Until recently, Yeye often complained about his children not coming to see him enough. A few months ago, Xiaoyi retired from her job at Ericsson and decided to take a less demanding position with Shen's software design company. Since the company's office building is conveniently located a ten-minute drive from Yeye's home, Xiaoyi and Shen are able to visit their father every day during their lunch break, joining him for a meal cooked by the *baomu*. Xiaoyi notes that, in addition to his weight and mobility, Yeye's mental health and overall energy level have improved a great deal recently. Just a few weeks ago, she says, he would lie in bed all day, without enough energy even to sit and watch television in the living room. "He's happy now that we see him every day," she says.

Back in the dining room, Yeye talks to me about the importance of offering equal educational opportunities for my son and daughter, and not favouring one gender over the other. I do not tell him that I do not have children. Instead, I nod, straining to understand him in the hopes of catching a few words here and there. As he stumbles over his words, he pauses, formulating thoughts and gathering words, or perhaps just taking a break from the demands of speech. He opens his mouth, stuttering, and just as he is about to utter something, in the passing of these few seconds, Xiaoyi and Shen interject with an unrelated topic, spontaneously moving the conversation in another direction. When this

CHAPTER 2

happens, Yeye smiles and watches them joke around, and so flows the back-and-forth of their voices. Eventually, he speaks what I presume he meant to say minutes ago—usually there seems to be a sort of recurring topic of the day—and the conversation once again changes direction.

"It's important to make sure your children have a Chinese education," he says, directly addressing me. "You see, both my children are *guo chan*." Translated literally, this means "domestic products," but Yeye is referring to the doctorate degrees his children received from Chinese universities.

"What do you mean we're *guo chan*?" Shen asks his father. "I got my degree in Finland and my sister went to Norway. Those are international degrees." Shen's tone is neither antagonistic nor condescending, but his statement is nonetheless a correction, a moment of logical reasoning.

Yeye looks confused. "Where do you come from then? What kind of *chan* are you?" *Chan* means "product."

"Wo men shi ni chan de!" Shen responds loudly without missing a beat. "We're your products!" is what Shen has retorted, playing with double meanings, and the four of us burst into laughter. Yeye looks around at each of us as he laughs. *Heh heh*.

A few minutes later, as Yeye is again talking about how best to educate my children, Shen rubs his abdomen and complains that his stomach hurts. His complaint does not sound particularly serious to me, and I wonder if he is growing bored or impatient since it is past dinnertime and trying to suggest that we leave.

"What's wrong with you?" Yeye asks him.

"I'm dying," Shen replies without hesitation. *Where did that come from*?, I wonder. As Yeye slowly registers what this might mean, I see Xiaoyi give a vigourous shake of her head from across the table, frowning and silently mouthing, "Don't say that!" to her brother. "I'm sick. I have an illness. My stomach hurts," Shen corrects himself, picking up on his sister's cues. Without waiting for a response, he casually wanders over to the living room.

Shen's claims to a stomach illness do not seem to perturb Yeye much longer, and the moment passes. Nonetheless, Shen's speech has introduced into the atmosphere an element of something other than the light-heartedness of play, however fleeting. As Yeye turns his attention back to me, continuing on with his ideas about children's education and gender equality, Shen saunters back into the dining room.

"I think you've already made the point," Shen interrupts, his tone teasing.

Yeye turns to him and says, "I'm not talking to you. I'm talking to her." His assertive statement is spoken not only with clarity, but also with a confident intensity that I have not heard from him before.

"Wow! You're so mean!" Shen exclaims, laughing and feigning indignation, once again leaving the room.

What I experience as an instance of conflict—an apparent moment of disorder that seems to interrupt the smooth-flowing order of play—passes by without any more commotion or attention. When Xiaoyi tells her father that we should get going, Yeye stands up from his seat, assisted by the *baomu*, and Xiaoyi notices that he is wearing the new shoes she bought him. Yeye happily and proudly shows off his brown, leather sandals.

"Don't you think they look nice?" he asks. Xiaoyi and I compliment him on his shoes as he walks with us to the door. We wave goodbye before Xiaoyi quickly closes the door behind us so that mosquitoes do not sneak in. Shen is already outside in the courtyard, waiting for us, and the three of us walk over together to the car.

"Yeye seemed happy today," I suggest to Xiaoyi.

"He's happy to have company," Xiaoyi says. "Most of all, he's happy to have people listen to him. It makes him feel respected. You know, he used to be an academic leader, so he still has this sense of wanting people to listen to him when he talks. It's important that he feels respected. And you have to just *shun zhe ta lai* when you talk to him."

Xiaoyi's notion of "just going along with him" is a logic of care and a style of play that occurs in alignment with the light mood and the playful attitude—characterizations of what Sutton-Smith calls the rhetoric of the imaginary—that she has established with Yeye over the past few years. In addition to her involvement in the logistics of her father's daily life, which include buying weekly groceries and carefully monitoring his health, Xiaoyi takes care to listen to him, recognizing that by going along with his speech, whatever it might be—Japanese motorcycles, children's education, Chinese nationalism, bottomless feet—it makes him feel respected, content, and cared for.

What struck me about this particular encounter at Yeye's compared to other visits was the moment in which it seemed like the activity and attitude of play shifted into something else, and specifically, when the use of particular language disrupted the otherwise smooth back-and-forth flow of playful listening and speaking. How did Shen's spontaneous and abrupt proclamation, "I'm dying," disturb Xiaoyi? How was Yeye

provoked to say to his son, "I'm not talking to you," and how did this moment of clear speech and intention from his father provoke Shen to leave the apartment and wait outside for fifteen minutes? Although these were but brief instances that were glossed over without any further deliberation or dispute, like the initial moment of surprise I felt when I heard the sudden change in Xiaoyi's tone three years ago, insignificant in the larger picture of their family dynamic, they were nevertheless noticeable moments of dissonance, of contradiction, and of tension in a space of communication that was built upon a sensibility of play at the boundary of logic and imagination.

Perhaps it is not such a rare occurrence when it appears that play slips into another framework, into that of not-play, and that the logic of play is held together by what Mol would call a "fragile coherence." One approach to take in answering the questions above is to examine the easiness with which play can seem to slide into not-play. "The precariousness of play," writes Winnicott, "belongs to the fact that it is always on the theoretical line between the subjective and that which is objectively perceived" (Winnicott 2005:68), and in Yeye, Xiaovi, and Shen's situation, between the imagination evoked by the senile voice and the observed reality of its non-senile, reason-oriented listeners. Bateson argues that the actions of play are intimately linked to and denote those of not-play, using the metaphor of framing to better understand how the phenomena of play are perceived and interpreted. He writes, "The frame around a picture, if we consider this frame as a message intended to order or organize the perception of the viewer, says, 'Attend to what is within and do not attend to what is outside" (Bateson 2006:323). Play, according to Bateson, "occur[s] within a delimited psychological frame" (Bateson 2006:326). In Yeye's home, it could be argued that play takes place within the delimited

frame of senility and its associated assumptions, namely that Yeye's voice utters nonsense that has no referent in the world of logic and reason. However, something odd happens when Shen says, "I'm dying," a statement that unsettles Xiaoyi and surprises me. In this moment, it was Shen's voice that uttered nonsense. It "becomes that which is irrelevant to context, that to which context is irrelevant... Nonsense becomes a negative language" (Stewart 1978:5), falling outside the lines of the operative frame at play here. Does play fail when the lines demarcating the edges of that frame are effaced?

A language of failure, of that which happens when play devolves into not-play, mirrors the language of ability and disability used in describing dementia—a binary that I have set out to rethink. The notion of failure also implies that play is carried out as a means to an end, as though Xiaoyi and Shen are taking part in an act of play only as a technique to achieve some practical, end goal in the form of caregiving. Instead, I want to argue that the critical question is not so much about how play succeeds or fails, but rather about the communicative space it makes possible in what Winnicott calls the "intermediate area of experience." I draw upon Bateson's idea of play evolution as having an important role in the evolution of communication to propose that we listen to Yeye and Shen's so-called "nonsense" speech differently. Rather than focusing on the words of language in themselves, I am interested in the relational resonances of these three voices as they speak to one another and how care is entwined with their communicative practices, with a particular focus on Yeye's interactions with Xiaoyi, his primary caregiver.

In the previous chapter, I wondered whether it was be impossible to know when play entered into Xiaoyi's relationship with her father. Play, however, is dynamic; it does

not just appear and disappear, exist and not exist. If we are to take seriously Huizinga's notion that play is a fundamental part of human experience, then we would be able to imagine that play has always been a part of Xiaoyi and Yeye's relationship. What I find more important than determining the instance that play took on the more prominent role that I witnessed during my visits in 2013 is understanding how play has evolved throughout their relationship, alongside Yeye's developing senility, and what it has come to mean for them as an experience of care.

It is not that play is all about fun and laughter, nor is it about appeasement and avoiding conflict, by merely nodding along and smiling quietly as I did when Yeye spoke to me. Play, in any case, is not always denoted by laughter. Huizinga writes, "Laughter, for instance, is in a sense the opposite of seriousness without being absolutely bound up with play. Children's games, football, and chess are played in profound seriousness; the players have not the slightest inclination to laugh" (Huizinga 1949:6). The kind of play that Xiaoyi engages in with her father is not simple and mindless fun, even though Xiaoyi's demeanour is usually laidback and easygoing. She is constantly aware of the interactive atmosphere, attuned to moments that might disrupt the smooth back-and-forth flow with her father, and makes the effort to "*shun zhe ta lai*" and go along with her father's mood and senile utterances. Play is serious business here for Xiaoyi and Yeye because of what is at stake for them in their relationship of care.

In his now-classic essay "Deep Play" (2005), Clifford Geertz writes about the Balinese cockfight, a cultural event where the stakes are incredibly high for its participants. The phenomenon of deep play has its roots in the philosophy of Jeremy Bentham, who refers to "play in which the stakes are so high that it is, from his utilitarian

standpoint, irrational for men to engage in it at all" (Geertz 2005:71). In Bali, however, Geertz argues that in the activity of deep play that takes place during the cockfighting event, "much more is at stake than material gain: namely, esteem, honor, dignity, respect—in a word, though in Bali a profoundly freighted word, status. It is at stake symbolically" (Geertz 2005:71). By bringing into focus what is at stake in everyday social life, the deep play of the Balinese cockfight "could be called a paradigmatic human event" (Geertz 2005:84).

There is a sense of deep play at stake for Xiaovi and Yeve, one that critically affirms their relationship despite the tragedy and illness that they have faced in their family life in recent years. Yeye's senility can be seen as a condition that has made play possible in ways that it might have been otherwise impossible at an earlier stage in their relationship. Xiaoyi and Yeye's serious engagement in play, often "an experimental action... of an evolving system of interaction" (Bateson 2006:327), highlights what is important for them: dignity, respect, communication, accompaniment, and a sense of continuity—as Kleinman might say, "what really matters." It is not that play does not have a purpose in their interactions, but rather that it does not serve some other purpose; play is not carried out as a means to an end that could be categorized as "good" caregiving or "good" communication. It is instead characterized by the sensibility toward improvising and being open to change, to adapt and to be imaginative, to be at ease in the intermediate area between one's own and another's-specifically, a loved one'ssubjectivities. What play accomplishes is play itself, and at the same time, as it moves through its own evolving trajectory, play brings along with it tangible experiences for those involved in its communicative practices of speaking, listening, and caring.

Act 2: "The Donkey's Head Does Not Fit the Horse's Mouth"

Two o'clock in the afternoon marks the time for daily recreational activities for the patients at the Beijing Geriatric Hospital's Psychiatry and Psychology Department (*beijing laonianren yiyuan jingshen xinlike*), formerly named the Dementia Unit (*chidaike*). Nurse Yu, one of the head nurses, who shows me around the unit, notes that the name change is confusing because some people assume that it admits people with mental illnesses when it actually provides care specifically for people with dementia. The staff still use the name *chidaike* because it is what people are most familiar with, she says.

The hospital is located at the outskirts of Beijing, and it takes me two-and-a-half hours by subway and bus, from metropolis to rural landscape, to arrive at the hospital gates. Following the path of the long driveway that winds into the hospital grounds, I notice the dark green arrows on signposts pointing the way to the "Infections Area," the "Inpatient Unit," the "Outpatient Unit," and "Staff Dormitories," labeled in both Chinese and English in bold white letters. Soon, I come to a beautiful green area, the afternoon sunshine and heat shaded by a canopy of trees. I notice magpies in the grass, and it is quiet, but for the sounds of birds and cicadas. I see people reading on benches, others walking around, some pushing wheelchairs, along narrow stone paths in this expanse of green, cooling themselves with paper fans. I ask a woman in a staff uniform for directions to the *chidaike*, and soon find it situated between a complex of white buildings. Nurse Yu meets me at the entrance, dressed in the head nurse's uniform of all pink—cap, shirt, pants. The dementia unit provides acute and long-term care to 34 patients, all of whom have been diagnosed with some form of brain-related disease resulting in cognitive

impairment. Most patients are diagnosed at the No. 6 Hospital and come to the Beijing Geriatric Hospital when family members feel that they are unable to take care of them at home. The unit has two floors of rooms of two to three patients arranged down the narrow hallway. There is a *hugong* (hospital-hired caretaker) assigned to the care of the patients in each room. At the end of the hallway is the Recreation Room. It is now almost two o'clock and Nurse Yu suggests that I observe their afternoon games and activities session with patients.

Today is different because there is a photographer from a health magazine present, and only three of the patients, whose families had given prior consent for their photographs to be taken, are brought to the Recreation Room for the photo-op. The room is organized around a long, yellow, conference-style table. There are cheerfully bright stickers and drawings taped to the walls and windows. Nurse Yu and two other nurses who have arrived at the scene take out an assortment of colourful plastic fruits and vegetables, toys, balls, drawing utensils, and illustrated children's books from the closet, placing them on the table. Nurse Yu turns on the CD player and a medley of hybrid traditional-pop Chinese songs begins to play, making the mood in the room festive and lively. Soon, three elderly patients, one man and two women, enter the room, each accompanied by their hugong. One of the women, Mrs. Tang, seems to be already in a bad mood when she enters the room. Frowning, she points her finger at the photographer and tells him not to take her photograph. The nurses arrange themselves in a circle around the table, handing the elderly man an illustrated picture book to flip through and giving the other woman a colouring page and crayons. Nurse Yu and the other nurses speak in

CHAPTER 2

animated voices, chatting playfully around the patients, even though the conversation is one-directional, as the two patients are already immersed in their activities.

Mrs. Tang sits to the side, slightly removed from all the commotion, frowning. Her posture is rigidly upright, arms crossed. She seems to be getting more upset with every clicking sound of the photographer's camera. When he steps back for a wider shot, she covers her face with her arms. The nurses and the *hugong* laugh.

"It's ok, Mrs. Tang. Don't worry, it's just a photo," Nurse Yu gently reassures her.

This seems to make Mrs. Tang more upset. She stands up from her chair and points two fingers at the photographer. He seems taken aback, laughing a little nervously.

"Don't take photos of me!" she shouts at him. Her voice makes up in sternness what it might lose in volume or shrillness. He obliges, telling her he will only take photos of the other two, who are still drawing and playing with the toys, undisturbed. After a few minutes, the photographer seems satisfied and excuses himself out of the room. The nurses and *hugong* help the two other patients up from their chairs and accompany them back to their rooms, while Mrs. Tang remains firmly seated, arms crossed, refusing to move. Nurse Yu offers to walk her back to her room.

"Let's go home, Mrs. Tang," Nurse Yu says in an upbeat voice.

"I don't have a home," Mrs. Tang replies sharply. "Do you know where my home is?"

"Yes, I do."

"Then take me to Beijing."

"Ok, let's take a car back to Beijing."

"How long will it take, then?" Mrs. Tang asks suspiciously, as though she already knows the answer herself and is testing Nurse Yu.

"Just one day," Nurse Yu responds in a playful tone, when in reality it only takes two-and-a-half hours. "We'll get there quickly, let's go!"

Mrs. Tang frowns. "It takes longer than a day to get to Beijing. I can't trust you." She looks straight ahead of her, brow furrowed. The nurses are cleaning up the table and chuckling. One of the nurses gently tries to take her hand, but Mrs. Tang jerks her arm upward and almost hits the nurse in the face, then stands up from her seat. "I can't trust any of you," she says to the nurses. "That photographer—you need to ask him to file a report for my approval. You know, I'm an important person at Qinghua." Nurse Yu later tells me that Mrs. Tang used to be a professor at the prestigious Qinghua University, and this is a fact, along with the year 1937 and the Cultural Revolution, that Mrs. Tang often mentions.

"Yes, ok, but how about we go home first?" says Nurse Yu in response, putting the toys away in the closet and turning off the music. In the abrupt silence, Mrs. Tang looks around and notices that no one is at her side.

"Where did you all go?" she asks. "Oh, what happened to helping me go back home? You're all fake." The nurses laugh and Nurse Yu quickly comes over and tries to take Mrs. Tang's hand again. Mrs. Tang jerks away. Looking up at Yu, she says, "Your job is over. Beijing doesn't need you!"

Nurse Yu laughs. I wonder if this kind of aggressive language is hurtful, but she seems to not take the words personally. One of the male *hugong* returns to the room.

"Hey, there's a car outside waiting for you, Mrs. Tang. It's going to take you to Beijing. Can I take you?" he asks politely, offering her his hand. It is clear to me that there is no car waiting outside, and that this is a creative tactic he is using to help placate Mrs. Tang and coax her back to her room. Surprisingly, Mrs. Tang responds positively to his suggestion and, with some reluctance, allows him to escort her out of the room.

The Recreation Room is quiet now and emptied. The sudden change in scene is evocative of something almost theatrical, a kind of drama at play.¹² The set-up with the photographer from the health magazine and the arrangement of games, plastic toys, colouring books, as well as the loud music, all together performed a certain form of play—perhaps an idealization of play, to be put on display for the photographer and later in the glossy pages of a magazine, with a caption that might say "Elderly patients enjoy playing games at the Beijing Geriatric Hospital." It is not so much that there is something false or insincere in the way that play has been presented in this setting; rather, it demonstrates how play can be enacted as an activity "characterized by its own distinct performances and stylizations" (Sutton-Smith 1997:219), particularly in a clinical setting of care.

Contrary to its use in children's care, play therapy for adults is an as-of-yet uncommon technique of care, though there is growing interest in its development (see Killick 2013; Schaefer 2002). One of the most noticeable distinctions made in thinking about the concept of play is the vastly different roles it appears to take on for children and for adults. Whereas play is seen as an essential part of child development (Winnicott 2005), it is primarily thought of as a leisurely distraction and diversion for adults in the

¹² There is an extensive body of literature on the anthropology of performance (for an overview, see Korom 2013; Turner 1988) and specifically in therapeutic contexts (see Mattingly 1998; Summerson Carr 2010) that is beyond the scope of this thesis.

form of games and hobbies. To quote the author of a practical guide for developing playfulness with people with dementia: "In the adult world, play has to contend with every kind of obstacle in its path—the perception of childishness by others, and by the self; the idea that it is contradictory to the work ethic; the impression that it is time-wasting; that it is unproductive in material terms" (Killick 2013:15). To restate the argument that scholars have made before, here in the therapeutic context, such an understanding of play ignores the intensity and seriousness with which it can completely absorb the player. "How can it be that such ecstatic adult play experiences, which preoccupy so much emotional time, are only diversions?" (Sutton-Smith 1997:7).

It would seem that this question is posed not only critically but also, to some extent, rhetorically; it leads one to take the stance that play is something fundamental in the experience of being alive, and it is precisely this position that advocates for adult play therapy have taken in both research and clinical practice. In a 1997 study on the psychology of playfulness in adult personality traits, Charles Schaefer and Robyn Greenberg measure play by developing "A Playfulness Scale for Adults" to be used by play therapists, consisting of five factors: fun-loving, sense of humour, enjoys silliness, informal, and whimsical (Schaefer and Greenberg 1997:25). The "healing potential of play" (Ward-Wimmer 2002) for people with dementia has been focused primarily on the therapeutic effects of sensory stimulation, through modalities such as group therapy, drama therapy (see Gorst 2007), art and music therapy (see Abraham 2005; Waller 2002), gardening, reading and storytelling, and sandplay (see Suri 2012), as well as with stimulus objects, including toys, games, cards, cloths, and dolls (see Ehrenfeld 2002), to name only a few. "An individualized, play-therapeutic manner of communicating and

interacting can create a more harmonious, enjoyable relationship with less aggression, hostility, and resistance" (Mayers 2002:273).

Every day at the Beijing Geriatric Hospital, the hour between two and three o'clock in the Recreation Room is dedicated to play therapy, or perhaps, more aptly, therapeutic play. Although my visit happened to fall on an atypical day at the hospital, I nevertheless witnessed—perhaps the idealized version of—not only the various activities that patients can participate in, but also the spirit of play that Nurse Yu and the staff take part in. Because play therapy is so often compared to children's play, one of the objections that elderly patients and their families might raise is that such a mode of therapy is infantilizing (see Mayers and Block 1990). In describing the scene above, I have taken care not to make any implicit or explicit value judgments on the kind of play that took place. I am more interested in the notion that play is not a discrete activity that belongs to one life stage and not another, but rather a fundamental and necessary part of being alive. I wonder, would it be a problem to suggest that playing with toys and colouring books could be, simply, human play?

What is also striking about therapeutic play in this particular setting of care is the communication between Mrs. Tang and the staff. Winnicott claims that describing adult play is a more difficult task than its counterpart for children because play with adults is often based in verbal communication. "I suggest that we must expect to find playing just as evident in the analyses of adults as it is in the case of our work with children," he writes. "It manifests itself, for instance, in the choice of words, in the inflections of the voice, and indeed in the sense of humour" (Winnicott 2005:54). All three of these manifestations are evident in Nurse Yu's verbal engagement with Mrs. Tang, though

Mrs. Tang herself continually asserts her refusal to play. Suspicious of the photographer from the moment she entered the room, Mrs. Tang rejects the invitation to play—one that she did not consent to, reminding us of the assumptions we have about the selfhood and capacities of people with dementia. Despite Nurse Yu's playful suggestions for driving Mrs. Tang back to her home in Beijing, the older woman's unrelenting refusal shows how "an individualized, play-therapeutic manner of communicating and interacting" does not necessarily result in "a more harmonious, enjoyable relationship with less aggression, hostility, and resistance" (Mayers 2002:273). In listening and speaking playfully with the senile voice, it seems as though one must be creative, flexible, adaptable, and ready "to improvise in the face of an ever-changing world" (Malaby 2008:2)—such are the qualities of what Li would call a "smart caregiver."

"When I first came here, I'll admit that I had a lot of anxiety and psychological pressure, because I wasn't sure what to do," Nurse Yu tells me as we continue to tour the unit after the activities session. She explains that, in her experience, caring for dementia patients is more challenging than for other patients because of safety concerns for both patients and staff. Some patients can be physically aggressive toward caregivers, while it is the responsibility of the staff to ensure a physically safe environment for their patients by reducing risks for falling, injury, and wandering outside.

For Nurse Yu, playfulness and humour, as practices of communicative care, have evolved from the initial trepidation, anxiety, and uncertainty she experienced. After nine years of working at this hospital, Nurse Yu, who is in her thirties, has developed the necessary skills to be fluent in communicating—and knowing how to communicate with the dementia patients under her care in this 34-bed unit. She is acutely aware of

"what is appropriate or logical to do in some site or situation, and what is not" (Mol 2008:8). Her verbal responses to Mrs. Tang's accusations, protests, and outbursts in the Recreation Room were playful and experientially well-versed without coming across as either scripted or disingenuous.

I have the chance to appreciate Nurse Yu's sense of humour when she tells me about the pair of roommates in one of the rooms we pass by: the two elderly men had met at the hospital one day and enjoyed so much talking with each other that they would talk late into the night, and eventually, the staff moved them so they could live in the same room.

"It's funny sometimes because one asks a question and the other answers with something totally unrelated. 'Have you eaten already?' 'I went for a walk today.' It's like, *lü tou bu dui ma zui*. But they keep each other company and they're happy," she says, laughing. The saying, which means, "The donkey's head does not fit the horse's mouth," is used to describe comic moments of mismatch. The phrase, itself comical, is not commonly used, and there is a sense of delight for both Nurse Yu and me when she makes the comparison between the humourous saying and the conversations between the two men. In other words, their apparent semantic mismatches do not preclude a mutual enjoyment of each other's company and friendship. In the way that she tells this anecdote and uses this phrase, I get the sense from her that she recognizes in it a quality of play and finds joy in the utterances of these senile voices, on their own terms and in their own resonances. Here, for Nurse Yu, play is not merely an activity but also a sensibility to being able to listen to senility differently.

At the same time, this is not to say that play is present in all aspects of Nurse Yu's job as a formal caregiver for dementia patients-after all, only one hour per day is formally designated to recreational play. Her work as a head nurse involves not only directly providing care for patients but also overseeing the duties of the other staff in the unit. She has to ensure that patients take their medications and are safe within the physical space of the unit, and she often takes creative measures to make sure conditions are safe. For example, vests are devised to help patients sit upright in their wheelchairs and on benches in the hallways so that they do not fall and injure themselves. Mittens are made for a patient who has a tendency to pull out his IV and nasogastric tubes. Some of the most difficult patients to care for, she tells me, are those who are physically aggressive and combative against staff, particularly during the injection of a medication. "It becomes dangerous when I have a needle in my hand and a patient is hitting me with their arms. I have to protect myself and also give them their medication," she says. For patients with volatile tempers, the goal of communication is to help calm their moods. She emphasizes that communication, which can be playful, is important in building a sense of trust and establishing a feeling of security and reassurance for her patients.

It could be argued that the caregiving context in which Nurse Yu works places certain constraints on the kind of care that she can provide. Kleinman argues, "[I]nstitutional settings... limit the experience of professionals, impairing them from bringing the fullness of their presence into interactions with patients and families. Yet there are health professionals who do, showing it can be done" (Kleinman 2010:19). He claims that, compared with familial caregivers, professionals often "simply do not have enough at stake in their relations with patients" (Kleinman 2010:19). In extending Kleinman's argument, I shift the focus away from a moral evaluation of whether or not "enough" is at stake for a formal caregiver like Nurse Yu, toward an understanding that there are different stakes at play in her care than for Xiaoyi and Yeye, reflective of the ways that logics and styles of care, and of play, are contingent on particular contexts and relationships.

My conversation with Nurse Yu, as well as my observations of the Recreation Room activities, raises a critical question in thinking about play in a care setting: is play not a means to a practical end here, an end that might take the form of something like "smart caregiving"? There is, however, more than play therapy—more than the attempt to provide sensory stimulation—in Nurse Yu's caregiving at the Beijing Geriatric Hospital's Dementia Unit. Play *can be*, but is not necessarily, therapeutic, and it is this disposition toward therapeutic play that makes possible an understanding of the potential of play not just for creative and improvisatory activity, but also for how communication might take place as part of dementia care. In doing so, therapeutic play, as a particular modality and style of play, essentially shifts the analytical frame for what has conventionally been associated with senility, moving away from the devastation of loss to the possibility of something new and evolving.

In this chapter's final vignette, I return to the encounter with Liu, her daughter Xin, and Dr. Wang in the outpatient clinic at the No. 6 Hospital, replaying their conversation with a focus on Dr. Wang's role as a geriatric psychiatrist, in an analysis that takes into account how psychotherapeutic care might be imagined as play.

Act 3: Psychotherapy as Play, and Taking an Imaginative Leap

"Psychoanalysis—as a form of conversation—is worth having only if it makes our lives more interesting, or funnier, or sadder, or more tormented, or whatever it is about ourselves that we value and want to promote; and especially if it helps us find new things about ourselves that we didn't know we could value. New virtues are surprisingly rare."—Adam Phillips, *On Kissing, Tickling, and Being Bored*

"My description amounts to a plea to every therapist to allow for the patient's capacity to play, that is, to be creative in the analytic work. The patient's creativity can be only too easily stolen by a therapist who knows too much."—Donald Winnicott, *Playing and Reality*

"There's much less medicine for my high blood pressure in the container now," Liu

tells Dr. Wang, certain that someone is stealing clothes from her home and changing her medications.

"But it's not less!" her daughter Xin protests, eyebrows raised, eyes wide. "They're always packaged. I've made sure that they're always packaged neatly for you in your container. How could they disappear?" Liu looks at her briefly, then turns to look at Dr. Wang.

"Do you think explaining this to her is helpful?" Dr. Wang asks Xin in her neutral voice. Xin laughs, a little nervously. "I just want to ask you, have you found that your explanations help her?" An uncomfortable silence looms overhead, as Xin says nothing in response. Turning her attention to Liu, Dr. Wang says, "I understand how you feel. When you see that something of yours is no longer where you put it, of course you'd be worried, right?"

Liu answers by saying, "Even just a few days ago, I checked and saw that it was the same sweater. But then the floral pattern wasn't the same. This kind of thing really makes me angry. Imagine things in your home getting stolen and replaced." There is anger, indignation, and frustration in her voice.

"I know what you mean." Dr. Wang tells Liu, maintaining eve contact. "If that had happened to me, where something that I had put in a certain place was no longer there. I would be really angry too. But no matter how angry we get, it doesn't help resolve the problem. The best way to resolve the problem is for the thing that makes you not *manyi* to become something that makes you *manyi* again. Right? No matter what it is-your medications, your clothes at home—I want to help you make it something that makes you *manyi* again. When you take your medicine, we'll make sure that it's the right amount. Maybe sometimes you'll look at the pills and think, 'how come the colour is different now?' There might be many reasons for this. Maybe the medicine really has changed. Or maybe, the angle from where you're standing and looking at the medicine has changed, so the colour has changed too. It could be that the pharmaceutical company has changed the design of the pill, so then it would also look different. Or it might be that the medicine that you saw before really is different now. There could be many reasons. But our priority is to make sure that the quantity of medicine is just right for your treatment. How about that? Is that ok?" In response, Liu nods quietly.

Using repetition and paraphrasing throughout her interaction with Liu, Dr. Wang demonstrates her intention to attend to Liu's utterances without explicitly supporting either their factuality or their fiction. Circling around the reaffirmation of Liu's conviction that someone is stealing from her, Dr. Wang redirects Liu's attention to the importance of being satisfied and content (*manyi*) with her situation. The crux of the encounter is that of the stolen clothes: for Liu, they are a fact, a reality; for Xin, they represent the fiction and fantasy of her mother's senile mind; and for Dr. Wang, they are classified as delusions that warrant psychotherapeutic care. Dr. Wang's meticulous

CHAPTER 2

phrasing allows her to carefully bypass this central issue in question, shifting the focus from the *why not manyi* to the *not manyi*. In order to resolve this problem, Dr. Wang's question for Liu becomes: what can we do about making you *manyi* again?

In revisiting this scene from the previous chapter, my question now becomes: how can we imagine the psychotherapeutic encounter as play? At a first glance, it would seem like taking somewhat of an intellectual leap to interpret Liu and Dr. Wang's conversation as an instance of play—communicating with a dementia patient about her paranoid delusions hardly seems like a playful matter, in the sense of laughter, games, and fun. However, drawing upon concepts of play developed by Bateson and by Winnicott, I want to suggest that it is indeed possible to rethink psychotherapy as a kind of play, which can be simultaneously fun, joyous, intense, and serious.

For Bateson, play is profoundly similar to psychotherapy. "Both occur within a delimited psychological frame, a spatial and temporal founding of a set of interactive messages... As we see it, the process of psychotherapy is a framed interaction between two persons, in which the rules are implicit but subject to change" (Bateson 2006:326). Like play, psychotherapy is an evolving communicative process occurring within a particular psychological frame that delineates what might be deemed appropriate and inappropriate. The goal of psychotherapy is "to change the patient's metacommunicative habits. Before therapy, the patient thinks and operates in terms of a certain set of rules for the making and understanding of messages. After successful therapy, he operates in terms of a different set of such rules" (Bateson 2006:326). According to Bateson, there is a transformative purpose to the practice of psychotherapy. Although he explicitly makes

the connection between psychotherapy and play, he does not go so far as to actually call it play in itself.

On the other hand, for Winnicott, psychotherapy *is* play; it is not just *like* play or acts *as* play. He writes, "*Psychotherapy takes place in the overlap of two areas of playing, that of the patient and that of the therapist. Psychotherapy has to do with two people playing together*" (Winnicott 2005:51; italics original). Play is a "form of communication in psychotherapy" and conversely, psychotherapy "has been developed as a highly specialized form of playing in the service of communication with oneself and others" (Winnicott 2005:26). The play of psychotherapy is characterized by the arrival of both players in a creative, shared intermediate area in which nonsense does not need to be organized and transformed by either the patient or the therapist to make coherent sense. Psychotherapeutic play, according to Winnicott, should not be an attempt to look for "order in chaos" (Winnicott 2005:75).

Dr. Wang's psychotherapeutic voice is engaged in a communicative practice with Liu's senile voice that takes place in "a framed interaction" (Bateson 2006:326) of play, Here, the therapist does not seek to correct her patient's thoughts and speech, yet she aims to help her patient think and operate "in terms of a different set of set rules" (Bateson 2006:326). Perhaps the conversational techniques that Dr. Wang uses are not so unique, as psychotherapy is generally not a practice of correcting the patient to adhere to an objective truth. However, what left a deep impression on me was the dynamic of the triadic caregiving relationship and the difference between Dr. Wang's and Xin's communicative approaches to engaging with Liu's utterances. Whereas the psychiatrist is consistent with the practice of psychotherapeutic care by listening to Liu's voice on her own terms, the family caregiver is, at the same time, consistent with the discomfort one can feel in listening to the apparent nonsense of a senile voice, as well as the subsequent impulse one might have to correct its speech. Rather than attempting to explain this phenomenon by claiming that Dr. Wang and Xin simply have different stakes in their roles as Liu's caregivers, I want to bring attention to the possibility of care that takes place when communication does not entail a search for coherence and for sense. Such is the logic of play that I have tried to gesture toward; it does not require an individual's speech to correspond to a semantic referent, to what is deemed logical or illogical. Rather, play invites its participants to arrive together as they are in an intermediate, interactive, and relational space. Therapeutic play, whether in the Recreation Room at the Beijing Geriatric Hospital with Nurse Yu or in Dr. Wang's psychiatric clinic at the No. 6 Hospital, does not necessarily need to advance the notion of transformation as a core tenet of its practice, but it certainly does have the potential to be transformed and transformative according to its own logic.

Coda: Caring About Playing with Senility

The four vignettes presented in this chapter are organized around the idea of play and its trajectory and evolution in the practice of caregiving for a person with dementia. Together, they are meant also to highlight the significance of caregiving contexts, which include those of interpersonal relationships and of institutional settings. As part of a community health outreach program, Li's caregiver training session lends emphasis to the role of communication in "smart caregiving," introducing the idea of a logic of care, that is, a particular rationale and style to practicing care. The evening spent at home with Xiaoyi, Shen, and Yeye takes up the idea of a logic of play as it is played out experimentally in response to their father's senile voice, decoupling play from its conventional associations with fun, games, and laughter. For Xiaoyi, play can simultaneously be a tear-inducing joke about bottomless feet, as well as a serious effort to monitor the emotional atmosphere and to *shun zhe ta lai*. The therapeutic modalities of play involved in Nurse Yu's work at the Beijing Geriatric Hospital and in Dr. Wang's work as a geriatric psychiatrist further explore the multiple dimensions of play, as both disposition and activity, in two distinct therapeutic milieus. Nurse Yu's playfulness and humour are made clear and deliberate as elements of communication in the Recreation Room, while the apparent seriousness of Liu's appointment with Dr. Wang offers a rethinking of the play of psychotherapy.

The presentation of these four scenes together points to a shared strand—perhaps, a shared intermediate area—of play as a mode of communication in caregiving. There is an overall play logic being explored, experimented with, and experienced by these different individuals that figures into their diverse relationships as a crucial interactive element. Play demands creativity, flexibility, as well as a serious attentiveness to human communication in its myriad forms—as rational language, as incomprehensible speech, as embodied movement, as facial expression, and as gesture. At the same time, in engaging with the concept of play as care, one has to be careful to avoid reproducing an exclusionary principle, similar to that which underlies the problem with the concept of personhood. Along this line of thought, one might be compelled to ask: are only those fortunate enough not only to have caregivers, but moreover to have caregivers who recognize the need for play in care, capable of taking part in play?

It is precisely this kind of dualism that the concept of play refuses to participate in. and thereby, disrupts. In taking play seriously as a fundamental part of being human, it is not about who can and who cannot play; the question becomes one of how. I am not attempting to claim that play should be universally applied to all caregiving practices; the interactive space that exists in a relationship of care is necessarily contingent on individual dispositions, characters, and interpersonal histories and dynamics. In caregiving for a person with dementia, a condition that can be manifested in different ways, play will not always succeed, nor will it be appropriate in every context. However, it can be surprising, transformative, and therapeutic. It is part of our human potential, and an ethnographic exploration of play in this sense allows for new possibilities to emerge in the daily, ongoing practice of care, as well as in our imagination and understanding of what it means to be senile and to embody difference. As it evolves through communication, play gives rise to a different kind of care—one that embraces those qualities of difference that we hear and recognize in senility, one that equips us with the capability to take care to really listen to and engage with the senile voice.

Conclusion

"So the point of my keeping a notebook has never been, nor is it now, to have an accurate factual record of what I have been doing or thinking. That would be a different impulse entirely, an instinct for reality which I sometimes envy but do not possess... In fact I have abandoned altogether that kind of pointless entry; instead I tell what some would call lies. 'That's simply not true,' the members of my family frequently tell me when they come up against my memory of a shared event. 'The party was *not* for you, the spider was *not* a black widow, *it wasn't that way at all*.' Very likely they are right, for not only have I always had trouble distinguishing between what happened and what merely might have happened, but I remain unconvinced that the distinction, for my purposes, matters... *How it felt to me:* that is getting closer to the truth about a notebook."—Joan Didion, *Slouching Towards Bethlehem*

Revisiting the Difficulty with Dementia

This thesis is about taking care to listen differently to a voice of difference. Asking, "How do we recognize the distinctiveness of senility?", it offers a critical exercise in putting into question how categories of memory, (re)cognition, and language have come to define for us what it means to be a coherent self, and inversely, to be "out of one's mind." It is, however, primarily an ethnography of the experiences of people whose lives have been affected by dementia, of those who feel at a loss for words as they and their loved ones seemingly occupy, more and more, radically different worlds. The vignettes I have chosen to write about are glimpses into the back-and-forth flow of voices invoking one another. They have been deliberately selected from many more hours of interviews, conversations, and observations, and pages of fieldnotes, whose concerns lie not with communication, but with the convoluted diagnostic process, the daily challenges of caregiving, and the obstacles in finding appropriate treatment and care. Not found in this thesis are stories of noticeable behavioural changes that led to a diagnosis, of the paranoia experienced by people with *chidaizheng*, of people wandering out of their homes and getting lost in the metropolitan tangle of Beijing—scaring their family members to death

("*ba wo xia si le*")—of the trouble with taking several medications and not being able to afford them when insurance was not covered, of problems with sleep, digestion, and incontinence, of constant worries and fears and anxieties. What I realize this thesis might not show is, simply put, the difficulty with dementia.

The research that foregrounds this thesis takes place at a special time in China as the nation faces increasingly pressing concerns about elderly care, particularly for those who have dementia. One of the family caregivers I interviewed, whose wife suffered from what he referred to as *"jiyi zhang'ai*" ("memory impairment") rather than as *chidaizheng*, lamented the shortage of nursing homes and long-term care facilities in Beijing, and the generally inadequate quality of care provided at existing such facilities. *"I* can take care of her at home for now, but what will happen when I get older and I'm no longer able to?" he asked. *"I* only wish that there were some place we could both go when that happens—somewhere that will give us good care." I, too, wish for these problems of care to be taken seriously and addressed, and it is my hope that this ethnography acts to move forward a larger discussion about age, dementia, and care so that we may attentively listen and respond to the concerns, needs, desires, wishes, and hopes of those who take part in everyday relationships of care.

With this thesis as a participant in this broader discourse on dementia care, I want it to show something different, something new, something that might have gone otherwise unnoticed. Such is the challenge in writing about senility, in that one aspect is inevitably, it seems, privileged over another. In this case, it is voice and its communicative potential that take center stage in the anthropological play of dementia. The idea of ironic listening, which I draw from Lawrence Cohen, renders possible an abandonment of the impulse to

106

listen for words that must match their expected correspondences. Listening ironically allows for vocal utterances to be heard in their own registers and resonances, as simultaneously sense and nonsense. Yet, it is not about making up a new "senile language"—the point is that coherence itself is abandoned as a necessary element of the self, and of selves interacting with one another.

This thesis began with Sun, an 86-year-old woman, saying, "No one speaks to me anymore." As it took up this invitation to listen, it engaged the concept of play as an analytical lens to explore how exactly something other than loss and deterioration can figure into the everyday lives of those who live with dementia. Huizinga calls the nature of play "labile," writing, "At any moment 'ordinary life' may reassert its rights either by an impact from without, which interrupts the game... or else from within, by a collapse of the play spirit, a sobering, a disenchantment" (Huizinga 1949:21). Play, as an event and as a sensibility, is indeed labile in the flexibility of its contours. I want to suggest, however, that it need not be a rare, extra-ordinary moment that ruptures at the first provocation, but that it can be interwoven into the fabric of everyday, "ordinary" life. In doing so, play reconfigures the binary distinction between capacity and incapacity in thinking about dementia, and illustrates how seemingly disparate affective states—joy, sadness, seriousness, intensity, and laughter—can co-exist in a relationship of care.

Taking Care with Ethnography

"The prose writer does not purge words of intentions and tones that are alien to him, he does not destroy the seeds of social heteroglossia embedded in words, he does not eliminate those language characterizations and speech mannerisms (potential narrator-personalities) glimmering behind the words and forms, each at a different distance from the ultimate semantic nucleus of his work, that is, the center of his own personal intentions."—Mikhail Bakhtin, *The Dialogic Imagination*

Writing ethnographically about senility and about play without reproducing their conventional descriptive tropes has been a difficult task. Writing theoretically about these same concepts has also been an inconclusive undertaking. Because neither fits into clearly demarcated categories of thought or of lived experience, the attempt to capture the essence of what it means to be senile, and what it means to play, becomes a challenge of language. Writing carefully requires attention to the same phenomena that one takes note of during fieldwork—details of speech, inflections of voice, facial expressions and gestures, bodily movements—and finds ways to describe them in words. Perhaps ethnography itself is also a practice of care, attending to what matters to the people it engages. It communicates something that may have gone unheard. Thus, this thesis is also a conversation comprised of the words of the people I spoke with in China, of the scholars who have worked on the concepts that I grapple with, as well as my own. As such, it is an invitation to take part in what I hope is critical discourse about dementia and care.

It is also an invitation to think imaginatively about difference and unfamiliarity. Watching an older person guess her own age or the name of a mundane object during an MMSE was at times discomforting for me; I felt I was bearing witness to the cognitive degeneration of a self, to the weight of profound loss. Similarly, listening to the so-called mismatches in speech was at first awkward, because it was a use of language that I had never heard before. However, the experience of being with people with dementia and their caregivers demonstrated for me that, as with life, there is much more to senility than loss. There can be anger, frustration, tears, and sorrow, but there can also be play, laughter, love, creativity, imagination, and joyful surprise.

The day before I left Beijing in September, Dr. Wang and her research team hosted a celebratory Activities Day for patients and their families that coincided with World Alzheimer's Day. Food and drinks were provided, a children's volunteer group performed music and dances, and students and staff worked together with older people to make photo albums from the old family photos they had brought in. I was able to see many of the people I interviewed during my summer in Beijing, some who remembered me, and others who did not. Regardless, we were happy to see each other, chatting about their family photos and making scrapbooks together. It is because of these other, and very tangible, dimensions of dementia that I have chosen to write about care through the lens of play as communication.

Epilogue: Grandma Barbara, and My Memory

I remember visiting Grandma Barbara, my paternal grandmother, in her assisted living home on the west coast of Canada, where she had moved to live in the same city as our family. Sitting with her on the sofa in her beautifully decorated room, with its golden lamps and oil paintings of lush forests, and lovely stationery neatly stacked on her desk, where she would sit to write letters to friends, Grandma Barbara would ask me about how I was doing in school. In high school then, I would tell her about my classes, my friends, and any piano recitals I had coming up, which I would invite her to. She would then ask, "Did you know I went to comptometer school after I finished high school?" I would nod vaguely as she told me the story, quietly wondering if maybe this time she would remember that she had already told me this story countless times before. I would look at my dad, sitting in a chair nearby, and wonder if he felt as awkward as I did about the repetitiveness of her stories. A few minutes later, she would ask me about how I was

doing in school, and I would again tell her about my classes, my friends, and any piano recitals I had coming up, which I would invite her to.

Grandma Barbara passed away four years ago, when I was away at university, at the age of 91. Had I the chance to speak with her now, I would revel in the chance to ask her questions about comptometer school, about America in the forties and fifties, about her life in the past and the present, about what she enjoyed reading, about what brought her happiness in old age, about what she wished and hoped for. Above all, I would make sure to listen as she repeated her words, questions, and stories, not with strangeness, but with that remarkable spirit of play that brings us joy in being together.

Glossary

"Dementia" Nomenclature	
chidaizheng (痴呆症)	an illness of idiotic m
jiyi zhang'ai (记忆障碍)	memory impairment
nao tuihua zheng (脑退化症)	cerebral degeneration
renzhi zhang'ai (认知障碍)	cognitive impairment
renzhi zhang'ai zheng (认知障碍症)	cognitive impairment

INTRODUCTION

Er shi qi xiao (二十四孝) gou tong (沟通) jiao liu (交流) jisheng yidai (寄生一代) ken lao (啃老) "Wo de fuqin muqin" (我的父亲母亲) zuo ren (做人)

SONGTANG HOSPITAL

fo jiao (佛教)Buddhis"fo jiao shi zui wei da de""Buddhis(佛教是最伟大的)"Buddhis('tai hao le!" (太好了)"Excelleying guo (因果)karma"zhe zhi shi wo de kan fa""This is(这只是我的看法)yeye (爷爷)grandfatzong jiao (宗教)religion

an illness of idiotic madness; dementia memory impairment cerebral degeneration disorder cognitive impairment cognitive impairment disorder

The 24 Paragons of Filial Piety to communicate to have an exchange; to communicate parasite generation to gnaw one's elder "My Father and Mother" to do as a person does

Buddhism "Buddhism is the most powerful" "Excellently!" karma "This is only my opinion" grandfather

DR. WANG, LIU, AND XIN	
manyi (满意)	to be content; to be satisfied
meijingang (美金刚)	memantine
XIAOYI, SHEN, AND YEYE	
baomu (保姆)	a female hired home health aide
bing ren (病人)	a sick person; a patient
chang fang kuai'er (长方块儿)	a rectangle
fudan (负担)	a burden
guo chan (国产)	domestic products
jiao ban'er (脚板儿)	soles of the feet
laonian ren (老年人)	an elderly person
shun zhe ta lai (顺着他来)	to just go along with him
"wo men shi ni chan de!" (我们是你产的)	"We're your products!"
xinli bu'an (心里不安)	without peace of heart
CAREGIVER TRAINING SESSION	
"congming de zhaoliaozhe"(聪明的照料者)	"Smart Caregivers"
BEIJING GERIATRIC HOSPITAL	
beijing laonianren yiyuan	Beijing Geriatric Hospital
(北京老年人医院)	
chidai ke (痴呆科)	Dementia Unit
hugong (护工)	a hospital-hired health aide
jingshen xinli ke (精神心理科)	Psychiatry and Psychology Department
"lü tou bu dui ma zui"	"The donkey's head does not fit the horse's
(驴头不对马嘴)	mouth"
Conclusion	
"ba wo xia si le" (把我吓死了)	"It scared me to death"

References

Abraham, Ruth

2005 When Words Have Lost Their Meaning: Alzheimer's Patients Communicate through Art. Westport: Praeger.

Adams, Trevor, and Paul Gardiner

2005 Communication and interaction within dementia care triads: Developing a theory for relationshipcentred care. Dementia 4(2):185-205.

Alzheimer's Australia

2007 Anaesthesia for Older People and People with Dementia. accessed June 12, 2014, http://www.fightdementia.org.au/common/files/NAT/20121211_NAT_UpdateSheet_DementiaQA20_A naethesia.pdf

Alzheimer's Disease International

2012 World Alzheimer Report 2012: Overcoming the stigma of dementia. London: Alzheimer's Disease International 2012.

American Psychiatric Association

2013 Diagnostic and Statistical Manual of Mental Disorders (5th edition). Arlington: American Psychiatric Publishing.

Angrosino, Michael, and Judith Rosenberg

2013 Observations on Observation: Continuities and Challenges. *In* Collecting and Interpreting Qualitative Materials (4th edition). Norman K. Denzin and Yvonna S. Lincoln, eds. Pp. 151-175. Thousand Oaks: SAGE Publications.

Arendt, Hannah

1958 The Human Condition. Chicago: University of Chicago Press.

Aulino, Felicity

2012 Senses and Sensibilities: The Practice of Care in Everyday Life in Northern Thailand. Ph.D. dissertation, Department of Anthropology, Harvard University.

Austin, John Langshaw

1962 Sense and Sensibilia. G. J. Warnock, ed. Oxford: Clarendon Press.

Bakhtin, Mikhail Mikhailovich

1981 The Dialogic Imagination: Four Essays. Michael Holquist, ed. Caryl Emerson and Michael Holquist, trans. Austin: University of Texas Press.

Bateson, Gregory

2006[1955] A Theory of Play and Fantasy. *In* The Game Design Reader: A Rules of Play Anthology. Katie Salen and Eric Zimmerman, eds. Pp. 314-328. Cambridge: The MIT Press.

Bauman, Richard, and Charles L. Briggs

1990 Poetics and Performance as Critical Perspectives on Language and Social Life. Annual Review of Anthropology 19:59-88.

Biehl João, with Byron Good, and Arthur Kleinman, eds.

2007 Subjectivity: Ethnographic Investigations. Berkeley: University of California Press.

Biehl João

2013 Vita: Life in a Zone of Social Abandonment. Berkeley: University of California Press.

Borges, Jorge Luis

1994 Ficciones. Anthony Kerrigan, trans. New York: Grove Press.

Borneman, John

1997 Caring and To Be Cared for: Displacing Marriage, Kinship, Gender, and Sexuality. International Social Science Journal 49(154):573-584.

Bornstein, Eric, and Peter Redfield

2011 Forces of Compassion: Humanitarianism Between Ethics and Politics. School for Advanced Research Advanced Seminar Series. Santa Fe: School for Advanced Research Press.

Bourdieu, Pierre

1977 Outline of a Theory of Practice. Richard Nice, trans. Cambridge: Cambridge University Press.

Caillois, Roger

1961 Man, Play, and Games. Meyer Barash, trans. New York: The Free Press.

Calvino, Italo

1988 Under the Jaguar Sun. William Weaver, trans. New York: Harcourt Brace Jovanovich.

Canguilhem, Georges

1991 The Normal and the Pathological. Carolyn R. Fawcett, trans. Brooklyn: Zone Books.

Carr, E. Summerson

2010 Scripting Addiction: The Politics of Therapeutic Talk and American Sobriety. Princeton: Princeton University Press.

Castillo, Elizabeth Herskovits

2011 Doing Dementia Better: Anthropology Insights. Clinics in Geriatric Medicine 27(2):273-289.

Cavarero, Adriana

- 2005 For More than One Voice: Toward a Philosophy of Vocal Expression. Paul Kottman, trans. Stanford: Stanford University Press.
- Chan, Kit Yee, with Wei Wang, Jing Jing Wu, Evropi Theodoratou, Josip Car, Lefkos Middleton, Tom C. Russ, Ian J. Deary, Harry Campbell, Wei Wang, and Igor Rudan

2013 Epidemiology of Alzheimer's disease and other forms of dementia in China, 1990-2010: a systematic review and analysis. The Lancet 381:2016-2023.

Charcot, Jean Martin

1866 Leçons sur les maladies des vieillards et les maladies chroniques. Paris: A. Delahaye.

Cheng, Yang, with Mark W. Rosenberg, Wuyi Wang, Linsheng Yang, and Hairong Li 2011 Aging, health and place in residential care facilities in Beijing, China. Social Science & Medicine 72(3):365-372.

China Central Television

2012 我的父亲母亲 [My Father and Mother]. Beijing: China Central Television.

Chinese Society of Psychiatry

2001 中国精神疾病分类方案与诊断标准 [Chinese Classification of Mental Disorders], 3rd edition. Beijing: Chinese Society of Psychiatry.

Clark, Margaret

1967 The Anthropology of Aging, a New Area for Studies of Culture and Personality. The Gerontologist 7(1):55-64.

Cohen, Lawrence

- 1994 Old Age: Cultural and Critical Perspectives. Annual Review of Anthropology 23:137-158.
- 1998 No Aging in India: Alzheimer's, the Bad Family, and Other Modern Things. Berkeley: University of California Press.
- 2003 Senility and Irony's Age. Social Analysis 47(2):122-134
- 2006 Introduction: Thinking about Dementia. *In* Thinking About Dementia: Culture, Loss, and the Anthropology of Senility. Annette Leibing and Lawrence Cohen, eds. Pp. 1-22. New Brunswick: Rutgers University Press.
- 2008 Politics of Care: Commentary on Janelle S. Taylor, "On Recognition, Caring, and Dementia." Medical Anthropology Quarterly 22(4):336-339.

Davies, James

2010 Introduction: Emotions in the Field. *In* Emotions in the Field: The Psychology and Anthropology of Fieldwork Experience. James Davies and Dimitrina Spencer, eds. Pp. 1-31. Stanford: Stanford University Press

Desjarlais, Robert

2011 Counterplay: An Anthropologist at the Chessboard. Berkeley: University of California Press.

Didion, Joan

1968 Slouching Towards Bethlehem. New York: Farrar, Straus and Giroux.

Ehrenfeld, Mally

2002 Using Therapeutic Dolls with Psychogeriatric Patients. *In* Play Therapy with Adults. Charles E. Schaefer, ed. Pp. 291-300. New York: John Wiley & Sons.

Emerson, Robert M., with Rachel I. Fretz, and Linda L. Shaw

2013 Participant Observation and Fieldnotes. *In* Handbook of Ethnography. Paul Atkinson, Amanda Coffey, Sara Delamont, John Lofland, and Lyn Lofland, eds. Pp. 352-368. Thousand Oaks: SAGE Publications.

Farquhar, Judith, and Qicheng Zhang

2012 Ten Thousand Things: Nurturing Life in Contemporary Beijing. Brooklyn: Zone Books.

Fassin, Didier

2012 Humanitarian Reason: A Moral History of the Present. Rachel Gomme, trans. Berkeley: University of California Press.

Fassin, Didier, and Mariella Pandolfi, eds.

2010 Contemporary States of Emergency: The Politics of Military and Humanitarian Intervention. New York: Zone Books.

Fei, Wu

2010 Suicide and Justice: A Chinese Perspective. Routledge Contemporary China Series. Oxford: Routledge.

Feldman, Ilana, and Miriam Ticktin, eds.

2010 In the Name of Humanity: The Government of Threat and Care. Durham: Duke University Press.

Feng, Lei, with Helen Chiu, Mian-Yoon Chong, Xin Yu, and Ee-Heok Kua

2011 Dementia in Chinese populations: Current data and future research. Asia-Pacific Psychiatry 3:109-114.

Ferguson, James

1994 The Anti-politics Machine: Development, Depoliticization and Bureaucratic Power in Lesotho. Minneapolis: University of Minnesota Press.

Forbat, Liz

2003 Relationship Difficulties in Dementia Care: A discursive analysis of two women's accounts. Dementia 2(1):67-84.

Freud, Sigmund

1919 The 'Uncanny'. *In* The Standard Edition of the Complete Psychological Works of Sigmund Freud, Volume XVII (1917-1919): An Infantile Neurosis and Other Works. J. Strachey, ed. Pp. 217-256. London: Hogarth Press.

Gao, Xiao, with Todd Jackson, Hong Chen, Yanmei Liu, Ruiqing Wang, Mingyi Qian, and Xiting Huang 2010 There is a long way to go: A nationwide survey of professional training for mental health practitioners in China. Health Policy 95:74-81.

Garcia, Angela

2010 The Pastoral Clinic: Addiction and Dispossession along the Rio Grande. Berkeley: University of California Press.

Geertz, Clifford

1977 The Interpretation of Cultures. New York: Basic Books.

2005[1971] Deep play: notes on the Balinese cockfight. Daedalus Fall:58-86.

George, Daniel R., and Peter J. Whitehouse

2014 The War (on Terror) on Alzheimer's. Dementia 13(1):120-130.

Good, Byron

1994 Medicine, Rationality and Experience: An Anthropological Perspective. Lewis Henry Morgan Lectures. Cambridge: Cambridge University Press.

Good, Mary-Jo DelVecchio

2007 The Medical Imaginary and the Biotechnical Embrace: Subjective Experiences of Clinical Scientists and Patients. *In* Subjectivity: Ethnographic Investigations. João Biehl, Byron Good, Arthur Kleinman, eds. Pp. 362-380. Berkeley: University of California Press.

Good, Mary-Jo DelVecchio, with Sandra Teresa Hyde, Sarah Pinto, and Byron J. Good, eds.
 2008 Postcolonial Disorders. Ethnographic Studies in Subjectivity. Berkeley: University of California Press.

Gordon, Avery F.

1997 distractions. *In* Ghostly matters: Haunting and the Sociological Imagination. Minneapolis: University of Minnesota Press.

Gorst, Anita

2007 Awakening from the Dream of Thought: Research Into Dramatherapy and Dementia. Dramatherapy 29(2):10-16.

Graeber, David

2014 What's the Point If We Can't Have Fun? The Baffler 24: Spring 2014. http://thebaffler.com/past/whats the point if we cant have fun

Guest, Greg, with Emily E. Namey, and Marilyn L. Mitchell, eds.

2013 Collecting Qualitative Data: A Field Manual for Applied Research. Thousand Oaks: SAGE Publications.

Guo, Jinhua, and Arthur Kleinman

2011 Stigma: HIV/AIDS, Mental Illness, and China's Nonpersons. *In* Deep China: The Moral Life of the Person. Berkeley: University of California Press.

Guo, Mingxian, with Li Gao, Guihong Zhang, Yunming Li, Shasha Xu, Zhao Wang, Qiumin Qu, and Feng Guo

2012 Prevalence of dementia and mild cognitive impairment in the elderly living in nursing and veteran care homes in X'an, China. Journal of the Neurological Sciences 312:39-44.

Han, Clara

2012 Life in Debt: Times of Care and Violence in Neoliberal Chile. Berkeley: University of California Press.

Heidegger, Martin

1962 Being and Time. John Macquarrie and Edward Robinson, trans. New York: Harper and Row.

Hoffmann, Deborah

1994 Complaints of a Dutiful Daughter. 44 min. Women Make Movies. New York.

Hughes, Julian C.

2011 Thinking Through Dementia. International Perspectives in Philosophy and Psychiatry. Oxford: Oxford University Press.

Huizinga, Johan

1949 Homo Ludens: A Study of the Play-Element in Culture. London: Routledge & Kegan Paul.

Hyde, Sandra Teresa

2010 Global Flows in Drug Treatment: Heroin Addiction and Therapeutic Community Approaches in China. Asia Pacific Journal of Public Health 22(3):197-202.

Ikels, Charlotte

1983 Aging and Adaptation: Chinese in Hong Kong and the United States. Hamden: Archon Books.

- 1998 The Experience of Dementia in China. Culture, Medicine, and Psychiatry 22:257-283.
- 2002 Constructing and deconstructing the self: Dementia in China. Journal of Cross-Cultural Gerontology 17:233-251.

Ikels, Charlotte, ed.

2004 Filial Piety: Practice and Discourse in Contemporary East Asia. Stanford: Stanford University Press.

Jacobs, Andrew, and Adam Century

2012 As China Ages, Beijing Turns to Morality Tales to Spur Filial Devotion. New York Times, September 6:A11.

Jia, Jianping, with Fen Wang, Cuibai Wei, Aihong Zhou, Xiangfei Jia, Fang Li, Muni Tang, Lan Chu,
Youlong Zhou, Chunkui Zhou, Yong Cui, Qi Wang, Weishan Wang, Peng Yin, Nan Hu, Xiumei Zuo,
Haiqing Song, Wei Qin, Liyong Yu, Dan Li, Longfei Jia, Juexian Song, Ying Han, Yi Xing, Peijie
Yang, Yuemei Li, Yuchen Qiao, Yi Tang, Jihui Lv, and Xiumin Dong
2014 The prevalence of dementia in urban and rural areas of China. Alzheimer's & Dementia 10(1):1-9.

Kaufman, Sharon

1986 The Ageless Self: Sources of Meaning in Late Life. Madison: The University of Wisconsin Press.

Kaufman, Sharon R., with Julie Livingston, Hong Zhang, and Margaret Lock

2013 Transforming concepts of ageing: three case studies from anthropology. *In* Oxford Textbook of Old Age Psychiatry (2nd edition). Tom Dening and Alan Thomas, eds. Oxford: Oxford University Press.

Killick, John

2013 Playfulness and Dementia: A Practice Guide. London: Jessica Kingsley Publishers.

Kitwood, Tom

1997 Dementia Reconsidered: The Person Comes First. New York: McGraw-Hill Education.

Kleinman, Arthur

2009 Caregiving: the Odyssey of Becoming More Human. The Lancet 373:292-293.

2010 Caregiving: The Divided Meaning of Being Human. *In* Rethinking the Human. J. Michelle Molina and Donald K. Swearer, eds. Pp. 17-30. Cambridge: Harvard University Press.

Kohn, Eduardo

2013 How Forests Think: Toward an Anthropology Beyond the Human. Berkeley: University of California Press.

Kontos, Pia C.

2004 Ethnographic reflections on selfhood, embodiment and Alzheimer's disease. Ageing and Society 24(6):829-849.

Korom, Frank J., ed.

2013 The Anthropology of Performance: A Reader. Oxford: Wiley-Blackwell.

Lam, Linda, with K. K. Lau, Vincent Mok, C. Y. Huang, S. W. Li, Y. M. Wu, Elsie Chung, M. F. Leung, Bernard Kong, and Patrick Li

2012 A proposal for an appropriate nomenclature to late-onset cognitive impairment for Hong Kong in the 21st century: dementia (痴呆症) revisited. Hong Kong Medical Journal 18(5):447-449.

Lamb, Sarah

2000 White Saris and Sweet Mangoes: Aging, Gender, and Body in North India. Berkeley: University of California Press.

Lee, Sing.

2011 Depression: Coming of Age in China. *In* Deep China: The Moral Life of the Person. Berkeley: University of California Press.

Leibing, Annette

2014 Heterotopia and Illness: Older women and Hypertension in a Brazilian Favela. Anthropology & Aging Quarterly 34(4):225-237.

Li, Li

2011 No Country for Alzheimer's Patients. China Daily, last modified March 22, 2011, http://www.chinadaily.com.cn/china/2011-03/22/content_12205656_4.htm

Liang, Xiying

2012 Name change hoped to end dementia's stigma. Beijing Today, last modified November 3, 2012, http://beijingtoday.com.cn/2012/11/name-change-hoped-end-dementias-stigma/

Lim, Soh-Leong, with Ben Kock Hong Lim, Rand Michael, Rainbow Cai, and Cheryl K. Schock 2010 The Trajectory of Counseling in China: Past, Present, and Future Trends. Journal of Counseling & Development 88:4-8.

Liu, Jia, with Lu-ning Wang, Ji-ping Tan, Ping Ji, Serge Gauthier, Yu-lan Zhang, Teng-xiao Ma, and Shaoni Liu

2012 Burden, anxiety and depression in caregivers of veterans with dementia in Beijing. Archives of Gerontology and Geriatrics 55:60-563.

Lock, Margaret

1993 Encounters with Aging: Mythologies of Menopause in Japan and North America. Berkeley: University of California Press.

2013 The Alzheimer Conundrum: Entanglements of Dementia and Aging. Princeton: Princeton University Press.

Lock, Margaret, and Deborah Gordon, eds.

1988 Biomedicine Examined. Dordrecht: Kluwer Academic Publishers.

Macdonald, Mary Ellen

2009 Growing Quality in Qualitative Health Research. International Journal of Qualitative Methods 8(2):97-101.

Mackenzie, Catherine

2011 Dysarthria in stroke: A narrative review of its description and the outcome of intervention. International Journal of Speech-Language Pathology 13(2):125-136.

Malaby, Thomas M.

2008 Anthropology and Play: The Contours of Playful Experience. Social Science Research Network.

Mattingly, Cheryl

1998 Healing dramas and clinical plots. Cambridge: Cambridge University Press.

Mauss, Marcel

1985[1938] A category of the human mind: the notion of person; the notion of self. *In* The category of the person: Anthropology, philosophy, history. W. D. Halls, trans. Michael Carrithers, Steven Collins, and Steven Lukes, eds. Cambridge: Cambridge University Press.

Mayers, Kathleen S.

2002 Play Therapy for Individuals with Dementia. *In* Play Therapy with Adults. Charles E. Schaefer, ed. Pp. 271-290. New York: John Wiley & Sons.

Mayers, Kathleen, and Christina Block

1990 Specialized services for demented residents in Washington state nursing homes: Report of a survey. American Journal of Alzheimer's Care and Related Disorders and Research 5(4):17-21.

McLean, Athena

2007 The Person in Dementia: A Study of Nursing Home Care in the US. Peterborough: Broadview Press.

2007 When The Borders of Research and Personal Life Become Blurred: Thorny Issues in Conducting Dementia Research. *In* The Shadow Side of Fieldwork: Exploring the Blurred Borders between Ethnography and Life. Athena McLean and Annette Leibing, eds. Pp. 262-287. Oxford: Blackwell Publishing

Merleau-Ponty, Maurice

2005 Phenomenology of Perception. Colin Smith, trans. London: Routledge.

Mol, Annemarie

2008 The Logic of Care: Health and the Problem of Patient Choice. Annemarie Mol and Peek Language Services, trans. Oxford: Routledge.

Murakami, Haruki

2003 Norwegian Wood. Jay Rubin, trans. New York: Vintage International.

2005 Kafka on the Shore. Peter Gabriel, trans. New York: Vintage International.

Myerhoff, Barbara

1979 Number Our Days. New York: E. P. Dutton.

Nascher, Ignatz Leo

1914 Geriatrics: The Diseases of Old Age and Their Treatment. Philadelphia: P. Blakiston's.

National Bureau of Statistics of China

2012 China's Total Population and Structural Changes in 2011, accessed June 11, 2014 http://www.stats.gov.cn/english/pressrelease/201201/t20120120 72112

Nguyen, Vinh-Kim

2010 The Republic of Therapy: Triage and Sovereignty in West Africa's Time of AIDS. Durham: Duke University Press.

Noë, Alva

2014 Could Playfulness Be Embedded In The Universe? National Public Radio Blog, April 13. http://www.npr.org/blogs/13.7/2014/04/13/302189232/could-playfulness-be-embedded-in-the-universe

Ortner, Sherry B.

1995 Resistance and the Problem of Ethnographic Refusal. Comparative Studies in Society and History 37(1):173-193.

Oxford Dictionary of English.

2010 dementia. Oxford Dictionary of English (3rd edition). Oxford: Oxford University Press.

Phillips, Adam

1993 On Kissing, Tickling, and Being Bored: Psychoanalytic Essays on the Unexamined Life. Cambridge: Harvard University Press. Phillips, Michael R., with Hanhui Chen, Kate Diesfeld, Bin Xie, Hui G. Cheng, Graham Mellsop, and Xiehe Liu

2013 China's New Mental Health Law: Reframing Involuntary Treatment. American Journal of Psychiatry 170(6):588-591.

Post, Stephen G.

2000 The Moral Challenge of Alzheimer Disease: Ethical Issues from Diagnosis to Dying (2nd edition). Baltimore: Johns Hopkins University Press.

Prince, Martin J.

2013 Dementia in China: east-west collaboration bears fruit. The Lancet 381:1967-1968.

Ramsay, Guy

2013 Mental Illness, Dementia and Family in China. Oxford: Routledge.

Redfield, Kay Jamison

1995 An Unquiet Mind: A Memoir of Moods and Madness. New York: Vintage Books.

Ricoeur, Paul

1995 Oneself as Another. Chicago: University of Chicago Press.

Rhodes, Lorna Amarasingham

1996 Studying Biomedicine as a Cultural System. *In* Medical Anthropology: Contemporary Theory and Method. Carolyn F. Sargent and Thomas M. Johnson, eds. Westport: Praeger.

Rodda, Joanne, and Zuzana Walker

2011 Mental State Examination in the Elderly. *In* Principles and Practice of Geriatric Psychiatry (3rd edition). Mohammed T. Abou-Saleh, Cornelius L. E. Katona, and Anand Kumar, eds. Pp. 113-116. Oxford: Wiley-Blackwell.

Rubinstein, Robert L.

1995 Toward an Anthropology of Old Age. American Anthropologist 97(4):785-787.

Schaefer, Charles E., ed.

2002 Play Therapy with Adults. New York: John Wiley & Sons.

Schaefer, Charles, and Robyn Greenberg

1997 Measurement of Playfulness : A Neglected Therapist Variable. International Journal of Play Therapy 6(2):21-31.

Scheper-Hughes, Nancy, and Margaret Lock

1987 The Mindful Body: A Prolegomenon to Future Work in Medical Anthropology. Medical Anthropology Quarterly New Series 1(1):6-41.

Stewart, Susan

1978 Nonsense: Aspects of intertexuality in folklore literature. Baltimore: Johns Hopkins University Press.

Stevenson, Margaret Elizabeth

2014 Life Beside Itself: Imagining Care in the Canadian Arctic. Berkeley: University of California Press.

Stoller, Paul

1997 Sensuous Scholarship. Philadelphia: University of Pennsylvania Press.

Suri, Rochelle

2012 Sandplay: An Adjunctive Therapy to Working with Dementia. International Journal of Play Therapy 21(3):117-130.

Sutton-Smith, Brian

1997 The Ambiguity of Play. Cambridge: Harvard University Press.

Tang, Boxiong, with Eran Harary, Ricky Kurzman, Joaquín F. Mould-Quevedo, Sharon Pan, Jiyue Yang, and Juan Qiao

2013 Clinical Characterization and the Caregiver Burden of Dementia in China. Value in Health Regional Issues 2(1):118-126.

Taussig, Michael

2010 The Corn-Wolf: Writing Apotropaic Texts. Critical Inquiry 37(1):26-33.

Taylor, Charles

2002 Modern Social Imaginaries. Public Culture 14(1):91-124.

Taylor, Janelle

2008 On Recognition, Caring, and Dementia. Medical Anthropology Quarterly 22(4):313-315.

Ticktin, Miriam

2011 Casualties of Care: Immigration and the Politics of Humanitarianism in France. Berkeley: University of California Press.

Turner, Victor

1988 The Anthropology of Performance. New York: Performing Arts Journal Publications.

Waller, Diane, ed.

2002 Arts Therapies and Progressive Illness: Nameless Dread. New York: Brunner-Routledge.

Walmsley, Bruce D., and Lynne McCormack

- 2013 The dance of communication: Retaining family membership despite severe non-speech dementia. Dementia:1-16.
- Wang, Huali, with Lia Fernandes, Susan Oster, Masatoshi Takeda, Henry Brodaty, and Jacobo E. Mintzer 2013 The state of psychogeriatrics in different regions of the world: challenges and opportunities. International Psychogeriatrics 25(10):1563-1569.

Wang, Huali, with Tianfei Gao, Anders Wimo, and Xin Yu

2010 Caregiver Time and Cost of Home Care for Alzheimer's Disease: A Clinic-based Observational Study in Beijing, China. Ageing International 35(2):153-165

Wang, Xiaodong

2013 New filial law sparks debate. China Daily, last modified July 2, 2013, http://www.chinadaily.com.cn/cndy/2013-07/02/content 16702575.htm

Ward-Wimmer, Dottie

- 2002 Introduction: The Healing Potential of Adults at Play. *In* Play Therapy with Adults. Charles E. Schaefer, ed. Pp. 1-14. New York: John Wiley & Sons.
- Wen, HongBo, with ZhenXin Zhang, JueBin Huang, LeiLei Duan, and QingHua Wang
 2011 Mortality of Dementia and Its Major Subtypes in Urban and Rural Communities of Beijing. Biomedical and Environmental Science 24(5):483-490.

Wentzell, Emily A.

2013 Maturing Masculinities: Aging, Chronic Illness, and Viagra in Mexico. Durham: Duke University Press.

Winnicott, Donald

2005[1971] Playing and Reality. London: Routledge.

Wittgenstein, Ludwig

1953 Philosophical Investigations. G. E. M. Anscombe, trans. Oxford: Basil Blackwell.

Wong, Edward

2014 A Chinese Virtue is Now the Law. New York Times, July 3:A4.

World Health Organization

1992 International Statistical Classification of Diseases and Related Health Problems. Geneva: WHO Press.

2012 Dementia: A Public Health Priority. Geneva: WHO Press.

Xiang, Yu-Tao, with Gabor S. Ungvari, Edwin H. M. Lee, and Helen F. K. Chiu 2012 China's National Mental Health Law: a 26-year-work in progress. The Lancet 379:780-781.

Yan, Yunxiang

2011 The Changing Moral Landscape. *In* Deep China: The Moral Life of the Person. Pp. 36-77. Berkeley: University of California Press.

Zhang, Yaodong, with Yong Xu, Hongwei Nie, Ting Lei, Yan Wu, Ling Zhang, and Minji Zhang 2012 Prevalence of dementia and major dementia subtypes in the Chinese populations: A meta-analysis of dementia prevalence surveys, 1980-2010. Journal of Clinical Neuroscience 19:1333-1337.

Zou, Yi-Zhuang, with Jie-Feng Cui, Biao Han, Ai-Li Ma, Man-Ying Li, and Hong-Zheng Fan 2008 Chinese psychiatrists views on global features of CCMD-III, ICD-10 and DSM-1V. Asian Journal of Psychiatry 1(2):56-59.