Care and Culture

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Care Relations from the Perspectives of Mental Health Caregivers in Ethnic Minority Families

By

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In memory of Kjell A. Rugkåsa

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Oslo/Oxford, May 2015

INTRODUCTION

> *There are a lot of carers out there. There is a lot. Not just with mental illness, but physical illness as well. A lot of carers out there and they [service providers] weren't taking any notice, you know, they just. They listened, but they weren't hearing. But now the voices of the carers are being heard more, because they are speaking more. They are speaking more, because I think carers are getting a bit fed up of not being heard. [...] And I think more should be done for carers. More, because it's a hard job. I know the person we care for is our blood. It's our blood, but we need, we need help as well. We need support too, you know. And it's only now that you find that things are getting done for carers, a bit. Things are getting done and we hope that it can get better. (Liz)*

Liz made these points when discussing how her role as family caregiver had changed over the twenty years or so that she had been looking after her youngest daughter who suffers from schizophrenia. Her story touches on issues of kinship, obligation, the effects of caring on the caregiver, communication with health professionals and support provided by the state. Liz's story is one of the 29 personal accounts of mental health caregiving in ethnic minority families in the UK that form the basis for discussing all these issues in this book.

Giving and receiving care is a ubiquitous part of the human condition. We simply would not survive were it not for the intense care given to us over the first few years of our lives. Many, like Liz's daughter, continue to need high levels of care throughout much of their lives and most of this care is provided through close relationships. As looking after one another is at the core of the human experience, it is remarkable that we have relatively little sociological knowledge about what it is like to be a caregiver for another adult in one's own family.

What we do know is that care is embedded in family life. It is about love, commitment, relatedness and duty, all of which make the caregiving experience deeply *personal*. The orientation towards the other means it is also a fundamentally *social* activity. Perceptions of the need to care and the forms that caregiving take have *cultural* influences. We know little, however, about how the subjective, social and cultural dimensions come together in personal experiences of caregiving.

In the UK, as in many other modern welfare states, the contribution of informal family caregivers is increasingly formalized and the term “carer” is applied to those providing it. This is a relatively new term and is not always easily recognized by family caregivers. Given its role in current policy and because most of the people who participated in this research project used it, it is the term I will us in this book, although I sometimes use “family carer” or “caregiver” for clarity.

In a process of politicization, the carer role (and particularly that of mental health carers) connects the caregiver to public services, legislation and ultimately the state. Caregiving can therefore be seen as a point where macro and micro level processes meet: it simultaneously concerns the organization of welfare states and the everyday lives of the millions of people who give and receive care. Furthermore, the carer *role* may be where cultural notions of kinship, family and connectedness meet the concept of “carer”, as conceived and applied in social policy. The way in which the carer role is conceptualized and performed by those occupying it may therefore be of importance for understanding the dynamics both at the micro and macro levels. Yet there is limited sociological attention directed towards theorizing about caregivers’ perspectives, particularly as regards adults who care for other adults and caregivers from minority backgrounds. This perhaps reflects a general lack of recognition or understanding of caregiving in society. As the participants in this study pointed out, without personal experience it is difficult to imagine what it is like to care for a family member who is severely disabled. My purpose in this book is to move towards such an understanding by listening to the stories of caregivers in contemporary Britain. Specifically, I explore how caregivers who define themselves as belonging to an ethnic minority group perceive their role in three sets of relations which form part of their individual care situations: their relationship to the care recipient,[1] to professionals with clinical responsibility for people with mental health problems, and to the welfare state. I look at cultural, social and personal dimensions that shape people’s perceptions and experiences of these relations. Often, the care situation and the carer role mean that other social roles remain unfulfilled. The conflict between expectations of and experiences of how one’s life (including

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[1] Because my focus is on care “givers”, I use the term “care recipient” when I talk about the person who is unwell. This is not, of course, to imply that receiving care is the most important role for that person. When I discuss their interactions in other contexts I use either the term “service user”, or the relevant kinship term. When referring to people who are hospitalized I occasionally use the term “patient”.

the carer role) unfolds emerge as a central theme in the stories I analyse here. This dissonance provides a lens through which we can view cultural and social dimensions to care relations, as embedded in personal life and expressed in personal narratives.

Mental illness[1] is a leading cause of disability worldwide (WHO, 2001). Severe mental illness, such as psychotic illnesses or prolonged severe depression, has implications for autonomy and self-determination. When a person loses mental capacity during psychotic episodes there will often be prolonged periods when (legal) responsibilities and care decisions are shared or negotiated by families and mental health professionals. Mental health caregiving therefore brings to the fore some specific issues surrounding informal caregiving such as the participation, recognition and power of carers. Conflicts between mental health service users and their families occur (McCann, 2002; Vaddadi, Gilleard & Fryer, 2002; Cooney & Howard, 2004; Phillips, 2007). Conflicting views among families and professionals are also common. I explore these relations from a particular viewpoint – that of carers. The views and experiences reported below may therefore not correspond with those of care recipients or professionals who are also part of these care relations.

At a theoretical level I will argue for an orientation towards the study of personal experiences of caregiving which can account for the complexities involved by exploring their embeddedness in personal, social and cultural contexts. Methodologically, I use in-depth interviews that provide rich data which facilitate description and theorising of such experiences, as I explain towards the end of this Introduction. Analytically, I draw on a range of theoretical perspectives which I outline in Chapter 1. These fall into three interrelated sets of ideas. First, I perceive care as part of family practice and reflected in interdependencies and connectedness. The performance of the caregiving role, as narrated in the interviews, can be viewed as expressing the *relatedness* of personal and social identities. Relatedness, which implies that personhood, identity and morality are developed in the context of social relationships, is a central concept here. I also draw on Carol Smart's (2007) concept of *personal life*. I adapt Kathleen Lynch's (2007; Lynch, Baker &

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[1] The terminology involved in the study of mental health is fraught with difficulty (Livingston & Cooper, 2004; Lester & Glasby, 2006). As I discuss in Chapter 4, some scholars and activists deny the existence of mental illness, seeing the related diagnostics and treatment as forms of social control. Those who took part in this study described mental disorders as illnesses (albeit ones that are difficult to define and with uncertain aetiologies). I therefore use this term, though interchangeably with "mental health problems" which was another term frequently used by the research participants.

Lyons, 2009) descriptions of different types of *care relations* to develop my ideas around carers' relationships in different contexts. This helps to focus on the connections between dynamics at micro and macro levels in processes such as the commodification of care.

Second, I argue that we need a concept of *culture* which can account for how representations of care, families and obligations vary between, but also within, socially defined groups of people. I will apply a concept of culture from practice oriented cognitive sociology and social anthropology which perceives it as shared mental representations, emerging experientially in the context of personal life (Strauss & Quinn, 1997; Lizardo & Strand, 2010).

The third set of ideas I bring to the analysis surrounds issues of mutuality and reciprocity in people's expectations of and experiences of their relationships (Honneth, 1992; Anderson & Honneth, 2005). As an analytical tool to explore carers' representations of their different relations, I draw on Alan Fiske's idea of different *relational models* of reciprocity in social relationships (Fiske, 1991, 2002, 2004). These models help us tease out some of the taken-for-granted aspects of people's experiences which might not always be articulable (Whitehead, 1993; Strauss, 2005).

Before providing an outline of the empirical basis for this book and the content in the chapters that follow, I briefly present some aspects of the research and policy context surrounding informal care and the scope of this analysis. More detailed outlines are presented, where relevant, in the later chapters.

Informal Care: The Policy and Research Context

Informal care in the UK

A number of demographic changes shape the demand for and supply of informal family care in the UK and across many other countries around the world. Longer life expectancy, lower birth rates and the inclusion of both women and men in the workforce means care needs are increasing while fewer people are available to try to meet them (Harper, 2003; Harper & Levin, 2005). In parallel, deinstitutionalization of public services has become central to public policy over the last few decades (Fakhoury & Priebe, 2002; Hamlin & Oakes, 2008). The number of beds in psychiatric hospitals in the UK, for example, has been reduced from around 150,000 in the 1950s to 30,000 today (Molodynski, Rugkåsa & Burns, 2010). This has led to an increase in the number of people with severe mental illness being cared for in the community, and much of this care is provided by family or friends.

The UK government describes a carer as "someone who looks after and supports a friend, relative or neighbour who could not manage without their help. This could be due to age, physical or mental illness or disability" (Directgov, 2011). In the 2011 census, 6.5 million people (58% of them women) in the UK identified themselves as providing informal care and nearly 600,000 of them come from ethnic minorities (Carers UK, 2014).[1] The total number of carers is predicted to increase to nine million by 2037. The vast majority of caregivers (93%) look after a close relative, and around half care for someone living in the same household as themselves (Carers UK, 2014). The proportion of carers in ethnic minority communities corresponds to that of the general population (Nazroo & Sproston, 2002; NBCCWN, 2008). There are, however, differences between ethnic groups, the most striking being that women of Bangladeshi or Pakistani backgrounds are nearly three times more likely to be a carer than those in other population groups (Young, Grundy & Jitlal, 2006; Carers UK, 2014). Carers in ethnic minority communities are also more likely than others to care for someone with mental illness (Yeandle, Bennett, Buckner, Fry, and Price, 2007; Greenwood, Habibi, Smith & Manthorpe, 2015). Around 13% of those providing informal care in the UK do so due to mental health problems and a further 10% look after someone with Dementia (Carers UK, 2014). Informal care is therefore an issue that affects large parts of the population including those who provide it, those who receive it and those with someone in the family or household who give or receive it.

Public policies and the public purse increasingly rely on informal care (Twigg, 1998; Dalley, 1996; Milne, Hatzidimitriadou, Chryssanthopoulou & Owen 2001). At the same time as designing individualized services, policy makers rely on family obligations to care for one another (Sevenhuijsen, 2000; Lloyd, 2000; Adamson & Donovan, 2005). Indeed, care policy across Western Europe has for more than 30 years portrayed the best quality care as that provided in the community by family members (Milne & Larkin, 2015). Recognizing that caregiving affects people's lives, a range of policy initiatives have been designed to support carers (see Chapter 5). As with social policy more generally, this state sponsored support is increasingly commodified, privatized and directed towards the individual (Lewis & Bennett, 2003; Newman, Glendinning & Hughes, 2008).

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[1] These figures exclude care for able bodied young children.

Informal care and sociology

Informal care forms part of complex social processes which have been studied from different perspectives. Consider these two statements:

> Caring is embedded in relationships of obligation such as marriage, parenthood, kinship, in which people feel responsible for spouses, children or parents and obliged to give care. These are not voluntary relationships, and these feelings of obligation have consequences for their lives – often […] severe consequences. (Twigg & Atkin, 1994, p. 10)

> Care is not only personal; it is an issue of public and political concern whose social dynamics operate at local, national and transnational levels. (Williams, 2001, p. 487)

The role of informal carers, as these two quotes illustrate, can be studied from the perspective of individual experiences as well as that of social policy and the welfare state. The paucity of studies bridging these two approaches leaves a gap in the literature (Twigg & Atkin, 1994; Knijn & Kremer, 1997; Ahmed & Jones 2008). The "structural" approach to studying informal care has been criticized for failing to account adequately for subjective experiences and variation among carers. Studies of personal experiences of caregiving do explore such meaning, but rarely take analysis beyond the micro-level. There are some notable exceptions such as a number of analyses by feminist scholars that illuminate connections between the organization of care and the position of women (e.g., Wærness, 1984; Ungerson, 1990; Graham, 1983, 1993; Opie, 1994). Moreover, Nolan and colleagues discuss links between micro and macro dynamics in the context of care for older people (Nolan, Keady, Grant & Lundh, 2003; Keady & Nolan, 2003), and Lynch and her colleagues explore these links in their concept of affective inequality (Lynch, Baker & Lyons, 2009). Others have investigated links between care and welfare in contemporary Britain (Williams, 2004), including broad ranging analyses of childcare (Duncan & Edwards, 1999; Duncan, Edwards, Reynolds & Aldred, 2003; 2004).

Micro-level analyses within and beyond sociology have for some time examined the effects of caring on carers' lives. This has developed into a research focus on the "burden" of caregiving. There is now a significant body of research demonstrating how caring can lead to psychological and emotional distress and physical illness. Disruption to family life, family conflict, deterioration of social and sexual relationships, curtailment of social activities and feelings of guilt and isolation are also reported. Economic impact, such as loss of income or opportunities for paid work, has been found to result in financial hardship for many carers (Perlick, Miklowitz, Chessick et al., 2007; Arber & Ginn, 1992, 1993; Glaser & Grundy, 2002; Hirst, 2004; Carers UK, 2014). Stigma and fear associated with mental health problem seem to exist cross-culturally (Wakefield, 2002; Hussain & Cochrane, 2004; Connor, Grenfield, Lester et al., 2014; Rossen, Stenager & Buus, 2014). This makes mental illness something many families choose to conceal (Keating & Robertson, 2004; MacKenzie, 2006) which in turn adds to the complexities of the caregiving role, as I consider in Chapter 2.

Much of the sociological debate about informal care, family life and intimate relationships has been based on research among White, middle class majority population groups (Harper & Levin, 2005). What is known about the experiences of the growing part of the population with more diverse ethnic and cultural backgrounds is therefore often framed by the experiences of the majority. Minority experiences are often inadvertently portrayed as deviations from the "norm" of the White middle class (see Chapters 1 and 3). To the extent that ethnicity or culture has been the focus of research on informal care, this has generally been in small-scale studies of a particular community in a local area (Harper & Levin, 2005; Phillips, 2007). In many of these studies explanations are sought, and sometimes found, *in* culture or ethnicity. An ethnic minority carer may therefore implicitly be considered to be more "ethnic" than "carer" which for the person involved, of course, is absurd. The lack of research into subjective experiences of ethnic minority carers on their own terms is problematic for several reasons. First, to understand any social phenomenon we must establish its relevance and manifestation across all population groups (Hirst, 2004). Second, the development of services or interventions becomes problematic if the research on which it is based is biased (Yancey, Ortega, & Mumanyika, 2006). Third, it is a matter of social justice: the exclusion of ethnic minority perspectives from research might perpetuate existing power imbalances and inequities (Neufeld, Harrison, Hughes, Spitzer, & Stewart, 2001; Williams, 2005; Rugkåsa & Canvin, 2011). My aim is that this book will contribute towards including ethnic minority voices in the pool of knowledge about informal caregiving.

Research on informal carers in general and ethnic minority carers in particular often focuses on the caregivers' relationships to care recipients (e.g., MacKenzie, 2006), health professionals (e.g., Wilkinson & McAndrew, 2008) or the welfare state (e.g., Merrell et al., 2006). More specifically, these studies tend to focus on either the so-called care dyad, on how carers are marginalized in services, or on how their role is perceived (or ignored) in policy. These approaches have undoubtedly brought the study of personal experience of informal care a big step forward. A focus on description has meant that less attention has been directed towards theorizing about the experiences of carers (Phillips, 2007; Ahmed & Jones, 2008). In particular, what such segregated approaches cannot tell us is what impact relations in these three contexts may have on one another. For example, how does the relationship between a carer and a care recipient affect that carer's relationship with the health professionals or services involved? How do these relationships affect that caregiver's bonds to family or friends? What do carers think about the ways in which the welfare state "reaches" into the care dyad or public policy seeks to shape the carer role? How does the carer manage or prioritize the different needs and demands of complex sets of relations? How do power dimensions in the different relations interact? By presenting a model of how the three types of care relations are interlinked (Chapter 6), this is a second area where I believe this book adds to the literature on informal carers.

The role of ethnicity in studying caregiving experiences

Issues of ethnicity and gender have often been ignored both in social policy and the analysis of such policy (Williams, 1989). There is limited understanding of how "care in the community" affects carers with ethnic minority backgrounds (Katbamna, Ahmad, Bhakta & Baker, 2004; Greenwood, Habibi & Manthorpe, 2015). Policy often either ignores them or it is premised on unrealistic assumptions of extended families supposedly available and prepared to provide care (Gunaratnam, 1993; Netto, 1998; Katbamna, et al., 2004). Research from ethnic minority communities has shown, however, that as in the rest of the population, little assistance is available outside the immediate family (Butt & Moriarty, 2004; Kokanovic, Petersen, & Klimidis, 2006; Sin, 2006). Compared to other carers, those from ethnic minorities have been found to be:

- worse off financially (Yeandle et al., 2007);
- more reliant on services provided by the third sector (Harper & Levin, 2005);
- less aware of local services and also less likely to use them even if they are aware (Merrell, Kinsella & Murphy, 2006; Yeandle et al., 2007; Greenwood, Habibi & Manthorpe, 2015);

- more likely than other carers to spend over 20 hours each week providing care (Joseph Rowntree Foundation, 2006), which is associated with increased likelihood of mental or physical ill health (Hirst 2004).

These issues are related to the lack of recognition of cultural differences, racism and poverty which remain part of daily life for many people from ethnic minorities, shaping their experience and identities (Skellington, 1996; Blakemore & Boneham, 1994; Williams 2004; Craig, 2008; Carers UK, 2011). Ethnic minority populations suffer disproportionate health disadvantages (Nazroo, 1997; Acheson, 1998; Johnson, Owen, Blackburn & Nazroo, 2000; Bhopal, 2001) and health services often fail to meet their needs (Boneham et al., 1996; Greenwood, Hussain, Burns, & Raphael, 2000). Connections between ethnicity and mental health are hotly debated and politicized in the UK and perceptions of discrimination and racism form part of these debates (see Chapter 4). A whole range of issues therefore form the backdrop for the experiences of ethnic minority mental health caregivers. Given the complex nature of their roles, it is vital that we study the experiences of these caregivers *on their own terms*. This is a central concern in this book. I therefore do not compare or contrast the study participants' caregiving experiences with those from the majority population apart from reflecting on interviewees' perspectives on such differences.

Ethnicity, along with culture, is sometimes described as possessing causal powers. In current social theory, ethnicity is understood as cultural differences made relevant in interaction (Eriksen, 1993; 1995). It is a classificatory tool for recognizing and identifying oneself and others. The importance or relevance attached to ethnic identities (and to some extent the content of such identities) thus vary with contexts (Eidheim, 1969). Ethnicity (like race or nation) is therefore a *relational* concept, not an ontological reality (Brubaker, Loveman & Stamarov, 2004). As a sociological concept ethnicity relates to identifiable properties of social groups perceived to share a significant heritage and to grouping processes of categorization and classification (Brubaker, Loveman & Stamarov, 2004, p. 45. See also Barth, 1969; Fenton, 2003). To the extent that ethnicity is relevant to understanding caregiving experiences, I consider it part of the context of caregiving; a context in which other social categories such as gender, class, age and so forth are also at play (Fenton, 2003). People's experiences are acquired in the context of their various social positions (Cerulo, 2000), which naturally form part of their stories. In order to explore the experiences of the study participants on their own terms I do not presume that they primarily stem from their ethnic background. Whether or not they do is an empirical issue and would require a different methodology from the one I apply here.

Rather, my aim is to explore how carers from a range of ethnic and cultural backgrounds perceive the carer role, bearing in mind that multiple identities have informed their views and experiences. Such an approach has potential to

> open up the possibility for understanding world-views and identities in the modern world by extending analysis to a broad range of culturally created but nonetheless socially real thought communities such as religions, occupations, neighbourhood types, institutional settings, and sub-cultural groups as they intersect and compete with the more disciplinary salient demographic categories of race, class and gender. (Brekhus, 2007, p. 460)

I discuss culture in detail in Chapter 1, but I do not problematize the concept of ethnicity further. Following the classification commonly applied in public policy I apply "ethnic minority" as a descriptive term in relation to people or groups who are not "White British" even if some of them are White and many consider themselves British. When relevant, I use more precise (and more meaningful) descriptions of people's backgrounds (McKenzie & Crowcroft, 1996; Bradby, 2003).

Collecting Personal Experiences

As I mentioned above, this book aims to contribute to the sociology of caregiving by giving voice to ethnic minority carers and by improving our understanding of informal care on the basis of the personal experiences of those providing it. The best way to achieve this seemed to be to interview people and listen to what they had to say about it. Individual in-depth qualitative interviews, more than any other research method, "grants to the subject narrative privileges that he or she would not normally enjoy" (Hill, 2005, p. 183). An epistemological assumption behind using interviews as a data generating method is that the interviewees will use their cultural models in their talk. I explain what I mean by cultural models in Chapter 1, but in essence they are experientially acquired shared mental representations. These are often so taken-for-granted that they are rarely explicitly stated (Whitehead, 1993) and if asked to describe them, we may struggle to respond. The interview as method is therefore partly an attempt to bring models into play as "people's talk on a subject is the best available window into its cultural meaning for them" (Quinn, 2005a, p. 45). So by asking the interviewees to talk about their experiences of being carers, the data generated helped elicit the models they held of that role and of their care relations (Quinn, 2005b). In this way, personal discourse (talk) provides information about cultural as well as personal meaning and give insight into implicit meaning as well as explicit content.

I wanted to include a wide range of voices and experiences in the analysis (Patton, 1990; Sandelowski, 1995). To achieve this I established contact with local community groups and organizations that targeted different ethnic groups and freelance recruiters with connections across many communities who approached carers on my behalf. I also disseminated information about the study widely to carer and mental health organizations and to organizations working for ethnic minority communities more generally. Details of the recruitment process and reflections on recruiting for a mental health study among ethnic minorities have been published elsewhere (Rugkåsa & Canvin, 2011).

In total, I interviewed 32 people between February and October 2007 although three of them later withdrew from the study. The 29 remaining participants were from a wide range of ethnic backgrounds. They lived across England, and two in Northern Ireland. The sample included significantly more women (23) than men (6). Participants varied in age from 28 to 74 and had been caring between two and forty years. All cared for adult consanguine or affinal kin: parents, adult children, siblings, partners or spouses and in one case an aunt. Two people cared for more than one family member. The majority of participants (24) were born outside the UK but most of them had lived in the UK for much of their lives. The remaining five were born and raised in the UK. Care recipients' mental illnesses included schizophrenia, depression, bipolar disorder, obsessive compulsive disorder, personality disorder, post-traumatic stress disorder, dementia and Alzheimer's disease and some had more than one diagnosis. Even if most were married (including some mixed marriages), the constitution of their families differed in most cases from the prototype "nuclear" family. Some lived with a parent or a grown-up child (in most cases this was the care recipient, but some lived in extended households), some were lone parents or lived alone, and a few lived in "reconstituted" families. A detailed outline of the sample, including their family context and the language spoken in the interview, is provided in Figure 1.

As a White, Norwegian female academic relatively recently arrived in England and with limited direct experience of mental illness and of caregiving, my life experiences were very different from those of the interviewees. My position as an "outsider" meant it was relatively easy for me to ask people to elaborate and reflect on issues or events of

Figure 1. Overview of the research participants

Name	Sex	Age	Self-defined ethnicity	UK born	Location	Care recipient (ethnicity if different from carer; diagnosis)
Jaspreet	F	51	British-Indian	No	Midlands	Mother (Indian; schizophrenia)
Ben	M	72	British-Indian	No	London	Son (schizophrenia)
Mukbul	M	40s	Bangladeshi	No	London	Wife (depression)
Alicia	F	72	Spanish	No	London	Husband (Afro-Caribbean; Alzheimer's)
Vivian	F	51	Black African	No	London	Son (schizophrenia)
Shanaz	F	63	Bangladeshi	No	London	Husband (dementia)
Vijaynti	F	55	Bangladeshi	No	London	Husband (depression)
Nisha	F	65	Indian	No	London	Aunt (Alzheimer's)
Christine	F	42	Afro-Caribbean	Yes	North	Sister (mental disability, schizophrenia)
Milena	F	35	Croatian	Yes	South	Husband (Irish; bi-polar)
Asha	F	46	British-Indian	No	Midlands	Mother (Indian; manic depression)
Jayshree	F	50	Indian	No	London	Son (schizophrenia)
Weigang	M	72	Chinese	No	Northern Ireland	Two sons (Irish-Chinese; schizophrenia)
Rita	F	41	Nigerian	No	Northern Ireland	Brother
Tony	M	63	Sri Lankan	No	London	Mother (dementia)

Living with care recipient?	Family/household constitution	(Previous) occupation type	Language spoken in interview
No	Living with son, husband abroad	Professional	English
No	Living with wife. Other adult children elsewhere	Skilled	English
Yes	Living with wife and three children	Manual	English
Yes	Living with husband. Adult children living elsewhere.	Skilled	English
No	Living with second husband and their two children	Professional	English
Yes	Living with husband and extended family	Never worked	Bengali
Yes	Living with husband	Never worked	Bengali
Yes	Living with her aunt (both widowed). Adult children living abroad	Professional	English
No	Living with her children (divorced)	Professional	English
Yes	Living with husband and his three children from a previous marriage	Professional	English
No	Living with husband, their two sons (young adults) and husband's parents	Professional	English
No	Living alone (divorced)	Professional	English
No	Living alone (divorced)	Skilled	English
No	Living with husband and baby daughter	Professional	English
Yes	Living with mother	Professional	English

Figure 1. Overview of the research participants (continued)

Yuka	F	38	Japanese	No	South	Husband (British-North African; PTSD, depression)
Meena	F	55	Indian	No	London	Son (schizophrenia)
Anita	F	38	Black African	No	North	Husband
Emma	F	40	British, religious minority	Yes	North	Husband
Liz	F	60s	Afro Caribbean	No	North	Daughter (schizophrenia)
Paramjit	F	40s	Indian	No	North	Husband (depression)
Ros	F	59	German	No	South	Son (schizophrenia)
Ashok	M	55	South Asian	No	Midlands	Wife (depression)
Mukesh	M	60	South Asian	No	Midlands	Wife (depression)
Li	F	60s	Chinese	No	London	Son (depression)
Jan	F	50	Chinese	No	London	Daughter (OCD, depression)
Lou	F	28	Black British	Yes	London	Father (Afro Caribbean, Paranoid Schizophrenia), Sister (Schizophrenia), Brother (Manic Depression)
Lan	F	60s	Chinese	No	North	Husband (mental illness)
Rosy	F	61	Mixed Heritage	Yes	South	Father (Afro Caribbean, vascular dementia)

Yes	Living with husband	Professional	English
Yes	Living with husband and her son. Adult children living elsewhere.	Skilled	English
Yes	Living with husband and her daughter from a previous relationship	Manual	English
Yes	Living with husband and her two daughters from a previous relationship	Professional	English
Yes	Living with her husband and their daughter (adult). Adult children living elsewhere.	Skilled	English
Yes	Living with husband and their grown-up son, his wife and two children	Never worked	Punjabi
Yes	Divorced, lives with her grown-up son. Adult children living elsewhere	Professional	English
Yes	Lives with his wife. Adult children living elsewhere	Manual	Gujarati
Yes	Lives with his wife. Adult children living elsewhere.	Skilled	Gujarati
No	Lives alone. Other adult children living elsewhere.	Manual	Cantonese
No	Lives alone. Adult children living elsewhere	Skilled	Cantonese
No	Living with her mother	Professional	English
Yes	Living with husband and two children, young adults	Manual	Cantonese
No	Living alone. Adult children living elsewhere	Professional	English

which I was not expected to have prior knowledge. I therefore sought to utilize "the gap in experience between interviewer and interviewee that creates a space for respondents to describe and tease out meanings and assumptions that may otherwise remain unspoken" (Carter 2004, p. 348). Many of the issues we discussed were sensitive and emotional, and tears were shed in most interviews, yet no one wanted to end their interview prematurely or to come back to it at a different time. As will be explained in later chapters, many of the interviewees had experiences of being marginalized or not listened to. Several of them told me that they appreciated the opportunity to talk at length about their situation and some said they wanted to help others by sharing their experiences. Others saw participating in the study as an opportunity to voice their concerns about issues such as the stigma attached to mental illness or the inequalities suffered by carers from ethnic minority communities. While I was pleased that the interviewees found the experience meaningful, the point to make here is that they all were motivated to tell me about their carer experience. So while the final sample was relatively modest in size, the data set entailed an incredible richness due to the interviewees' eagerness and the great variety of backgrounds and experiences that their stories collectively comprise.

I used a mix of qualitative methods to analyse the data (see Rugkåsa, 2010 for details). Overview analyses identified the occurrence of themes within and between cases (Ziebland & McPherson, 2006) and allowed for more detailed analyses of these themes and how they were interrelated (Glaser, 1965; Denzin & Lincoln, 1993). I sought to find implicit meaning relevant to perceptions of the carer role and care relations using cultural analysis of individual discourse (Quinn, 2005b; Strauss, 2005) where the analytical task is to go beyond exploring what people say to look at "what else they have to assume for those statements to make sense" (Strauss, 2005, p. 204).

The inclusion of eight non-English interviews where transcripts were translated into English meant I was unable to go back to audio recordings to check how statements were expressed or words emphasized as I did with the other interviews and instead I relied more on the content of what was explicitly said. The advantage of including these interviews was, of course, that the analysis could benefit from perspectives that I would otherwise not have had access to. The inclusion of seldom heard voices is one of the strengths of the research interview as a method:

> Interviews may elicit discourse and reveal the cultural understanding underlying that discourse that would not otherwise be voiced by any people

> under any other circumstances, in any type of discourse. That is to say, some cultural knowledge that we as researchers want to retrieve would remain forever untold if not for the interview as a stimulus to its revelation. (Quinn, 2005b, p. 9)

A limitation to most qualitative research is that the voices of the research participants are filtered through the lens of the researcher, which can make it difficult to validate whether interpretations reflect what was originally said. In an attempt to compensate for this, or at least to be transparent about how I have interpreted people's stories, I quote at length from the transcripts in the empirical chapters. Allowing the "presence of real people" (Smart, 2007, p. 185) in the presentation of research can bring issues to life as well as help validate interpretations. Of course, a vast amount of the data informing my interpretations cannot for practical reasons be included in the text. Throughout I have selected quotations that, while being situated in a personal context, are pertinent to others in the sample. Where issues are representative only for one or two people I make this clear. All names have been changed here and in some cases I have altered demographic details in order to protect anonymity.

Organization of the Book

The quote from Liz's story with which I opened touches on many of the questions that I discuss on these pages: how are family and kinship ties linked into carers' motivations to care? What does caring for someone with a mental illness involve and what impact does it have on the caregiver? How does the lack of voice that some people experience affect their ability to carry out their caregiving duties? In what ways should carers be supported in their role? How are their needs defined? Why is there a gap between how carers view their contribution and how their role is recognized in policy and practice? By addressing these questions, my aims for this book is to add the voices of carers from ethnic minorities to the literature and to bring the sociology of caregiving forward by presenting a model of care relations which use these experiences. In Chapter 1 I present the theoretical perspectives that I build upon throughout the book. I first discuss the *relatedness* inherent in family practice and I outline what I mean by the carer role being part of people's personal, social and cultural contexts. Second, I consider a concept of *culture* which incorporates its connections to personal life. Third, I explain how I see a role for using *reciprocity* as a perspective in the analysis of personal experiences of care. I suggest that differentiating between types of reciprocal mechanisms may help to develop further the analysis of carers' role in different contexts, particularly as regards issues of mutuality and recognition.

The next four chapters are largely empirical and focus on the three contexts for care relations that caregivers are engaged in. Chapters 2 and 3 focus on the caregivers' relations to care recipients, while Chapter 4 discusses their relations to health professionals and Chapter 5 is about their relation to the state. More specifically, the topic of Chapter 2 is caregivers' concepts of their role as situated in their social world. I explore carers' models of their role by analysing narratives on what their caregiving entails. The concept of generalized reciprocity (Sahlins, 1972) will be central to a discussion of the participants' model of a "good carer".

In Chapter 3, I problematize the concept of the burden of caregiving and critique the way in which it has been applied in the literature and particularly in studies of ethnic minority carers. I explore the effect of care situations on carers' lives with focus on their perception of caregiving burden. Applying models for reciprocity to the analysis of burden provides a new perspective on this topic which may enhance our understanding of the issues underlying subjective burden, such as changes to the carer's social landscape.

After focusing on relationships within families in Chapters 2 and 3, in Chapter 4 I turn to the second context for care relations and investigate carers' models for and experiences of interactions with mental health professionals. These professionals have clinical responsibility for the care recipient and also play a central part in the implementation of public policy surrounding carer involvement in service planning and delivery. Different models of how to align the role of "good carer" in their interactions with professionals are presented, each with a different degree of power and autonomy. I show how carers describe such autonomy (albeit within restrictions) in their performance of their social roles and how relatedness is a key factor for role variation.

With increasing politicization of the carer's role, mental health caregiving creates new positions vis-à-vis the welfare state. In Chapter 5, I explore positive and problematic consequences of the ways in which state sponsored support is delivered to carers. I problematize issues around commodification of care and conditionality for support and I discuss carers' experiences of these processes.

Finally, in Chapter 6, I draw out the main issues from the previous chapters and discuss how they provide new insight into how the carer role, as perceived and performed by mental health carers, is linked to processes at micro, meso and macro level. I propose a new model for understanding