International Psychogeriatrics (2011), 23:7, 1070–1077 © International Psychogeriatric Association 2011
doi:10.1017/S1041610211000214

Why do ethnic elders present later to UK dementia services? A qualitative study

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ABSTRACT

Background: Western policy initiatives prioritize early diagnosis of dementia, but minority ethnic (ME) people currently present later to dementia specialist care than their indigenous counterparts. In order to allow the development of rational interventions, we completed this first study to explore the link between attitudes to help-seeking for dementia and the help-seeking pathway in the ME and indigenous population.

Methods: We purposively recruited a maximum variation sample comprising 18 family carers of people with dementia from the major UK ethnic groups. We used semi-structured interviews to determine the barriers to and facilitators of help-seeking, and the pathways to diagnosis. Two researchers independently coded interviews and recruitment continued until theoretical saturation was reached.

Results: ME carers, in contrast to the indigenous population, tended to delay help-seeking until they could no longer cope or until others commented on the problems. They often thought that families should look after their own elders and a diagnosis alone was purposeless. This appeared to relate to beliefs about the etiology of cognitive impairment, negative beliefs about psychiatry and their sense of familial responsibility.

Conclusions: ME carer beliefs were an important barrier to early diagnosis. Further work should explore whether an intervention can modify these attitudes, so that families understand that a diagnosis may allow planning and avoidance of crises; rather than signifying a failure in duty, disloyalty, or relinquishing of the caring role. Further research should focus on developing interventions to tackle barriers to help-seeking in ethnic minorities so that healthcare access can be equitable for all.

Key words: ethnicity, care pathway, dementia, access to services, barriers

Introduction

Dementia is a major cause of disability (World Health Organization, 2003), and its prevalence is expected to double over the next 20 years (Ferri *et al.*, 2005). The cost of dementia to the economy is greater than that for heart disease and cancer combined (Luengo-Fernandez *et al.*, 2010), despite most of the care being provided by family and friends (Knapp and Prince, 2007). Policy initiatives in many Western countries prioritize early diagnosis of dementia in order to enable access to treatment, information and support for people with dementia and their families, and thus avoid crises and delay institutionalization (Department of Health, 2009; Weimer and Sager, 2009).

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People from minority ethnic (ME) groups comprise 15% of the English population and 39% of the London population (Office of National Statistics, 2007). Although they access primary care at a similar rate to the indigenous population, they are less likely to access specialist services (Livingston *et al.*, 2002). The UK National Audit Office has proposed the development of special services for ethnic minority groups who may find it harder to access care (National Audit Office, 2007). Despite the high prevalence of dementia in African-Caribbean people in Britain (Adelman *et al.*, 2009), ME people with dementia in Western countries tend to present to secondary care when their illness is more severe than the indigenous population (Cooper *et al.*, 2010). In the latter systematic review, ME people with dementia were more cognitively impaired, and Hispanic people reported a longer duration of memory loss than non-ME people, at the time of referral to diagnostic dementia services in the USA and Australia. We

https://doi.org/10.1017/S1041610211000214 Published online by Cambridge University Press

designed the current study because we need to understand why this occurs in order to facilitate their earlier presentation. Barriers to help-seeking for dementia reported in studies of ME groups include: negative experiences such as discrimination or feeling their symptoms were dismissed, language barriers, lack of clarity about where or how to access help, lack of knowledge about dementia, and beliefs that nothing could be done to help (Mukadam *et al.*, 2009).

In the current study, we explored for the first time the effect of culture and ethnicity on beliefs and attitudes of carers to help-seeking for dementia symptoms and the impact of these beliefs on the pathway to diagnostic and therapeutic services.

Methods

The study was approved by the East London and The City REC Alpha ethics committee and Camden and Islington NHS Trust research and development department. Carers were initially approached by a clinician whom they knew. Consenting carers were interviewed at home or in a healthcare setting, depending on preference. Self-identified carers of patients with a diagnosis of dementia were recruited from an ethnically diverse London inner city mental health trust that included areas of deprivation and affluence. We used purposive sampling to recruit carers from a range of ethnic groups, including Black Caribbean, South Asian and White UK groups, as these are the most common UK ethnic groups (Office for National Statistics, 2007). We sought to recruit male and female carers with diverse sociodemographic characteristics (age, level of education, relationship to patient, co-resident with patient or not); and those caring for people at different stages of dementia.

The interview

We collected participants' demographic information. We then conducted semi-structured, qualitative interviews, using a topic guide, based on our previous literature review. Interviews lasted about 30–45 minutes and took place in English, using interpreters where appropriate. Topics encompassed: how and why the family sought help for memory problems; the carer's attitudes towards dementia and accessing services; and barriers and facilitators to accessing dementia services. Recruitment continued until theoretical saturation was reached.

Analysis

Interviews were audio-taped and transcribed. Participants were sent transcripts and invited to comment on their accuracy and add any further comments. We used ATLAS-ti Version 5.6 software. Authors (CC, GL and NM) met to identify themes and refine the interview and coding. NM and BB used an iterative process to independently code transcribed data in order to identify ideas, concepts and themes (Strauss and Corbin, 1990). BB was blind to the identity and ethnicity of the participants. Coding began after the first five interviews so that any emergent themes could be incorporated into subsequent interviews and inform the selection of participants.

Results

Sample characteristics

Of the 32 carers approached for the study, 18 (56%) agreed to take part. They comprised four White UK carers, five South Asian, five Black (African or Caribbean), one White Irish, one White Other, one Asian Other and one Chinese. Their ages ranged from 27 to 85 years (mean 57). More carers were female but each group contained at least one male. Most of the patients had the same ethnicity as the carer being interviewed. English was the first language for ten of the carers but only three carers (all South Asian) needed an interpreter for the interview. Two of the carers who came from an ME group were born in the UK (one Black Caribbean and one Bangladeshi carer). Those carers who were of ME status had been resident in the UK for between 10 and 54 years (mean 36). The carers' sociodemographic characteristics are shown in Table 1.

Themes

We identified six major themes from carers' accounts of their help-seeking pathways. These were: noticing symptoms, reasons for not seeking help after noticing symptoms, factors precipitating help-seeking, pathway to dementia specialist services, delay in obtaining a diagnosis; and attitudes to diagnosis and psychiatric involvement.

Noticing symptoms

Nearly all the carers reported that the first symptom they noticed was forgetfulness:

> *"I suppose repetitions was the first thing that we noticed, . . . you'd say . . . something to him and then he'd come very soon after ask you again the same thing."* (46-year-old, Black UK, daughter, tertiary education)

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Table 1. Sociodemographic characteristics of the participating carers (n = 18)

Gender	5 men, 13 women
Relationship to patient	9 spouses, 6 children, 2 daughters–in-law, 1 son-in-law
First language	10 English, 4 Bengali, 1 Tigrinya, 1 Persian, 1 Tagalo, 1 Gujarati
Time with patient	11 live together, 4 >15 hours a week, 3 < 15 hours a week
Educational level	10 tertiary, 7 secondary, 1 primary

"He will talk about a book but then suddenly switch off to another topic . . . and then if he was reminded that you were talking about the book, he will say no." (76-year-old, Asian Indian, female spouse, secondary education)

Reasons for not seeking help after noticing symptoms

Delaying until symptoms were unmanageable

Carers did not always immediately seek help for the symptoms they had noticed. People from ethnic minorities tended to report waiting until there were neuropsychiatric symptoms or problems with basic activities of daily living:

"When she wears her trousers she puts both legs into one trouser and she thinks she is too fat or it is too tight. . .um. . .so a lot of things that she used to do normally she was not able to do and we asked her to cook and she couldn't do it. Two times she left the gas fire on . . ." (53-year-old, Black African, son-in-law, tertiary education)

"He . . . used to wake up in the middle of the night and say that someone's trying to get in, . . . to kill him through the window." (32-year-old, Asian Bangladeshi, daughter, tertiary education)

Delays due to attribution of symptoms to other causes

Ten of the carers (both White UK and ME carers) thought the symptoms were part of normal aging:

"Like your bones getting weaker it's all part of the same thing." (79-year-old, White UK, male spouse, tertiary education).

Explanations for symptoms that were mentioned only by ME groups included: the symptoms being part of other physical illnesses, adjusting to life changes and feigning the problems.

"Because of his illnesses, his diabetes and . . . an open bypass heart surgery . . . so they thought maybe his illnesses causes him [memory problems]." (27-year-old, Asian-Bangladeshi, daughter-in-law, secondary education)

"When somebody's retired and they've also have on top of that, illness you . . . have to work out what's just normal adjustment . . ." (46-year-old, Black UK, daughter, tertiary education)

"I thought he was just messing about at that time." (57-year-old, Other Chinese, female spouse, vocational qualification)

Delays due to the person with dementia

Denials by the person with dementia that there was a problem or refusal to accept help were reasons for delayed help-seeking across all ethnic groups (two White, one Black, two Asian, one Other):

"It was quite tricky to even get him to even consider that there could be something . . . to actually go and see somebody" (46-year-old, Black UK, daughter, tertiary education).

"He went as soon as . . . this good friend of his had noticed and said he ought to go so there was two of us . . . you know, confirming the fact that he needs to . . .'cause . . .men they don't really listen to their wives [laughs]"(57-year-old, Chinese, female spouse, vocational qualification)

Carers were sometimes reluctant to seek help due to fears about upsetting or betraying the patient:

"He didn't want to say anything because he was too frightened in case he lost her trust, you know, you have that lovely thing when you're married don't you?" (57-year-old, White Irish, daughter, secondary education)

Delays due to different cultural expectations

The extent to which symptoms interfered with the patient's expected activities was also important in deciding when to seek help. One Asian carer explained that because there was a cultural expectation that the patient would cede household duties to her daughter-in-law, the loss of such skills was not perceived as a problem:

"She used to cook before . . . but you know how it is once daughter-in-law comes, mother-in-law they stop cooking anyway" (38-year-old, Asian Bangladeshi, son, secondary education)

Delays because patient was already seeing a doctor

Three carers (two White, one South Asian), whose relatives were being reviewed for other medical problems, did not seek help because they expected the doctors to manage all the patient's problems including their cognitive impairment:

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"No the doctor they keep seeing him they don't tell me anything . . . I rely on the GP" (75-year-old, Asian Other, spouse, secondary education).

Delays due to family

Two carers (one Black, one White Irish) mentioned discussing the patient's symptoms with their family first before seeking help. The latter also consulted the family priest. They felt they had to respect the family hierarchy:

"They are independent, living adults, you can't get involved in that you have to listen . . . I'm always going to be their child although I am not a child you know what I mean?" (46-year-old, Black UK, daughter, tertiary education)

Two Black carers described their families not accepting that help was needed. They felt a familial responsibility to look after the person with dementia and that outside help may be intrusive:

"It's her mum and she says we have to tolerate her. Maybe she is ill, maybe she may have a reason and something like that." (53-year-old, Black African, son-in-law, tertiary education)

"You don't want to bring in outside agencies unless you have to . . . because it's intrusive . . . and when you can't deal with it we'll go to outside agencies who will help us deal with it. That's where we're coming from." (46-year-old, Black UK, daughter, tertiary education)

Two Black carers mentioned family concerns about referral to a psychiatrist; one was concerned about the stigma of mental illness and both had previous negative experiences of psychiatry which made them reluctant to seek help, saying:

"You know mental illness always has a stigma attached to it; it's not like just saying that person's just broken their leg . . . I think there's that the residue of having to deal with institutions and outside agencies from a very, for something that's for a mental illness." (46-year-old, Black UK, daughter, tertiary education)

Delays connected to services

Some carers mentioned delays because of lack of trust or of information in the healthcare system. One White Irish carer mentioned that the patient had a lack of faith in their general practitioner (GP), making them reluctant to see them. This carer also said the GP told her that the symptoms were normal aging. An Asian carer was unsure how to access help for the patient's disruptive behavior as they had never been in that situation before. Healthcare-related delays also occurred after initial help-seeking and this is explored later.

Factors precipitating help-seeking

Cognitive impairment

Cognitive impairment itself was the most common reason for seeking help. This occurred across all ethnic groups although three White carers did not need to seek help for the dementia symptoms as the physicians consulted for other problems identified the dementia in their care recipients and referred them to psychiatric services.

Physical health

The second most common reason for seeking help across all ethnic groups was physical health problems which led to dementia being recognized (one White, two Black and two Asian carers).

"And then she fell over and we had to get medical help. The doctor said she's got a memory problem." (79-year-old, White UK, male spouse, tertiary education)

"He had a mini stroke and . . . I took him to neurologists . . . and I think the neurologist picked it [dementia] up." (71-year-old, Black Caribbean, female spouse, tertiary education)

The two Asian carers who sought help for medical problems, did so in response to acute events:

"He fell down at home and he was taken to hospital when he was falling often and so when they put the pacemaker after that, . . . the doctor . . . started noticing that his memory was going little by little." (76-year-old, Asian Indian, female spouse, secondary education)

"Then recently when she had the urine infection .. .they said her memory will go down and she's going to have problems." (38-year-old, Asian Bangladeshi, son, secondary education).

Neuropsychiatric symptoms

Initial help-seeking for neuropsychiatric symptoms only occurred in ME groups. They had noticed other cognitive symptoms previously:

"One day he got quite aggressive . . . he was doing things that he'd never done before like was getting quite violent, he was throwing things . . . I said to the doctor 'Look, you know, my mum can't cope, I can't cope and I'm afraid to leave my mum alone in the house'. . .." (32-year-old, Asian-Bangladeshi, daughter, tertiary education)

"She started to become paranoid . . .and she was talking to people in the TV and she thought they were communicating with her and . . . and I took her to the GP." (53-year-old, Black-African, son-in-law, tertiary education)

Safety

In ME groups, help was also often sought either because symptoms were worsening, resulting in concerns about safety, or because other people had started noticing or being affected by the symptoms:

"He was walking around with sums of money and had lots of different papers . . . so he was making himself

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vulnerable . . . we realized that there was something that just needed to be addressed" (46-year-old, Black UK, daughter, tertiary education).

"Once she got lost and we found her and the second time she got lost again . . . so there must be something wrong." (29-year-old, Asian-Bangladeshi, daughter-in-law, secondary education)

Other people noticing problems

"I suppose that outside confirmation, that outside there were people phoning you up and going 'your dad's in this office and he's been here three times' you kind of go 'Right, that's something that needs to be addressed now'." (46-year-old, Black-UK, daughter, tertiary education)

"Then some a-an old friend of his noticed he was doing that. So err I thought it was about time that we went to see the doctor, our GP." (57-year-old, Chinese, female spouse, vocational qualification)

Practical problems

One carer sought help only because her husband was unable to manage their finances.

"It didn't occur to my mind [to seek help for the cognitive impairment]. . . . Only . . . recently when I started having problem financially and I went to the bank and the bank advised me that you have no access to his money unless you set it Power of Attorney . . . So I went to see the solicitor . . . . and the solicitor said . . . I will write to his GP." (75-year-old, Asian Other (Filipino), female spouse, secondary education)

Pathway to dementia specialist services

The commonest pathway to diagnosis was via the GP, as the initial contact, who referred the patient to a psychiatrist who made the diagnosis. Four Black, two Asian and one carer from another minority ethnic group experienced this pathway to a diagnosis of dementia. For example:

"He [GP] says well I think that erm there is the beginning of memory loss . . . shortly after that we had this referral to see doctor [Psychiatrist.]" (79-year-old, Black Caribbean, male spouse, tertiary education)

"The GP they referred her to. . .the hospital and some clinics as well." (29-year-old, Asian Bangladeshi, daughter-in-law, secondary education)

One White UK carer also sought help from their GP, but the GP did not refer to specialist services and the carer only received a diagnosis when a crisis occurred.

The next commonest pathway was where carers sought help due to a crisis (a physical illness or behavioral/social problem) and diagnosis was obtained either from a medical professional treating the physical illness or from a psychiatrist. This type of pathway occurred only among ME people (one Black, three Asian and one carer from another ME group).

"*In the night it was really bad . . . so I called up the person who did the assessment and I said look, you know, we really need to do something, this can't carry on . . . she called the ambulance and basically we had to get him via the A&E route.*" (32-year-old, Asian Bangladeshi, daughter, tertiary education)

Delays in obtaining a diagnosis

Delays in the diagnostic pathway sometimes occurred due to the attitudes of the healthcare professionals and their inability to pick up cognitive impairment. Some carers felt they were not being listened to and had to chase up appointments themselves. One Black carer reported that a health professional said they would refer the patient to a psychiatrist but did not do so. None of these factors seemed to occur more frequently in particular ethnic groups.

One White Irish and one Chinese carer reported multiple GP appointments because the cognitive impairment was not picked up initially. The White Irish carer said that dementia was also not picked up by the psychiatrist who assessed her mother initially.

"He went the first time and err he didn't get much erm advice he didn't get any treatment . . . a year later his word search was getting worse so I asked him to go back to the doctor . . . and then he was sent to a specialist and er had a brain scan and everything and was diagnosed." (57-year-old, Other Chinese, female spouse, vocational qualification)

"He got [Psychiatrist] to come out and actually see my mother you know second time around and he said you know he said she scored 30 to 36. . . I said yeah is that good or bad. Well, he said you know what he said, to be honest it's pretty average." (57-year-old, White Irish, daughter, secondary education)

"I just found at first I felt like I was being. . . pushed, 'get out of that door . . . coming here with all these accusations and making out that she's got mental health when she hasn't . . . I was so bamboozled . . . It seems like all the time we were banging out head and banging the door trying to get in'." (57-year-old, White Irish, daughter, secondary education).

"I did have to phone up and go, 'is this happening. . .what's happening?'" (46-year-old, Black UK, daughter, tertiary education).

Significant physical health problems in patients sometimes seemed to result in cognitive impairment being missed and some carers felt that more could have been done to diagnose the problem earlier.

"I just think the hospital should be better equipped to deal with that kind of situation. I know he's my dad,

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ultimately he's our responsibility but he's in hospital because he's not well, I just assumed they would deal with it. Or try and investigate further into if you see what I mean." (32-year-old, Asian Bangladeshi, daughter, tertiary education)

Excluding carers from appointments and correspondence also led to some delay as patients did not have the ability to remember details of consultations.

"I actually don't know [details of the consultation between GP and patient] because he couldn't tell me or he didn't remember or he didn't understand." (57-year-old, Chinese, female spouse, vocational qualification)

Attitude to the diagnostic pathway and services

Most White carers felt that getting a diagnosis was of benefit but this was not the case for all ethnic minority carers.

"It's nice to know what's going on …. that there are medicines that might stop her condition getting worse." (79-year-old, White UK, male spouse, tertiary education)

"It's nothing [getting the diagnosis], you know, it's like I knew that from before" (38-year-old, Asian Bangladeshi, son, secondary education).

Many carers across ethnic groups found psychiatric involvement to be helpful, because of accessing medication, advice and support.

"It was a big turning point after we met the psychiatrist. Not only, you know, she is getting antipsychotic medication but also all the help we are getting, the advice and how … we are going to manage for the future." (53-year-old, Black African, son-in-law, tertiary education)

"Generally she's improved hell of a lot … due to the medicine she's taking." (48-year-old, Iranian, son, tertiary education)

The importance of a sympathetic GP and continuity of care from a professional were also emphasized.

"I knew that … I could talk to her [GP] about it and that she if there was something she could … put me in the right direction." (67-year-old, White UK, female spouse, vocational qualification)

"After [psychiatrist] visited us everything is going well because now we are continuously in contact with her [community mental health team member]… and this really helps because we can discuss anything." (53-year-old, Black African, son, tertiary education)

Discussion

This is the first study to explore how carers from different ethnic groups decide when to access health services for people living with dementia, to explore their experiences afterwards, and to compare this in the indigenous and ME population.

All carers seemed to identify relatively early symptoms of dementia, and some white UK and ME carers sought help at this stage. Several ME families commented that elders were not expected to carry out household activities after a certain stage in life, and thus were less concerned than the indigenous carers by the cessation of these activities. In some ME families a sense of familial responsibility also deterred them from seeking help earlier from outside agencies, which were perceived as potentially intrusive. For many in the ME (but not in the indigenous) population, help-seeking occurred later, in response to specific events, such as people outside the family commenting that there was a problem, or a crisis with which the family alone could not cope. Many of the ME carers described having to accommodate their family member's changing cognition and behavior, until this was no longer possible. These findings are comparable with previous studies which also found that people from ethnic minorities in the USA were more likely to access dementia services in response to crises (Hinton *et al.*, 2004); and that in many families of ME people in inner and outer London, coping with a family member on your own is the default position (Lawrence *et al.*, 2008).

Beliefs that physical illnesses, feigning or life changes were causing dementia symptoms only occurred in ME participants, possibly suggesting a different understanding of mental health issues, particularly as some carers in these groups had negative views of psychiatry. Across ethnic groups and educational attainment, carers believed that dementia symptoms were due to normal aging and that they themselves might experience symptoms like this from time to time.

Delays in obtaining a diagnosis on the part of healthcare professionals occurred across ethnic groups so would not, from this small study, appear to explain relatively greater delays in diagnosis among ME older people. Denial of the symptoms or the patient's reluctance to seek help did not occur exclusively in ethnic minorities. However, the stigma of mental illness and negative experience of psychiatric services were only mentioned as barriers to help-seeking among ME carers.

Although many ME carers found accessing other services, medication or getting help from a care coordinator helpful, knowing the diagnosis (and thus being able to make appropriate plans) did not

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change anything and was not perceived as useful. This barrier to early help-seeking may be because a diagnosis did not change their familial obligations and duties.

Strengths and limitations

The qualitative methodology gives a detailed picture of how different ethnic groups feel about dementia and what paths they take to access mental health services. This approach is appropriate to exploring complex personal narratives and experiences of accessing services, but does not enable us to quantify how important the barriers to and facilitators of accessing care were to those interviewed. Although the study was small, care was taken to ensure this was a maximum variation sample within an inner city area. We interviewed carers from each major ethnic group and included a further selection from other ethnic groups for comparison. Carers were purposively sampled to include carers who were looking after people with varying severity of dementia and who had a variety of relationships with the patient. Each group contained a mix of genders and carers with a range of educational attainment. However, as this was not a quantitative study we did not formally control for these and other important confounders including socioeconomic status, so it is possible that differences between groups are attributable to socioeconomic and educational as well as ethnic differences.

Coding of interviews was carried out independently by two researchers and later agreed by consensus with other researchers so the codes generated had reliability and validity. One of the researchers carrying out the coding was blind to the ethnicity of the participants to avoid bias. Recruitment continued until theoretical saturation was reached, which suggests that the full range of experience in this cohort is likely to have been covered. It was not possible to send out transcripts in any language other than English, as the interviews were translated and then transcribed. Thus those who could not speak English were less able to comment on the interviews, although in practice no carers made substantial changes at this point.

This study was carried out in inner city boroughs of London which may limit its generalizability to other settings. We did, however, find that our results were comparable with studies conducted in inner and outer London (Lawrence *et al.*, 2008) and the USA (Hinton *et al.*, 2004). Some carers refused to participate, particularly within the ethnic minority groups. The experiences and attitudes recorded in this study may therefore not include those of all carers within ethnic minorities. The sample is drawn from carers who are already in touch with services but, as ME families appear to access dementia care later than the indigenous population, we feel that we have included a full range of views. We did not seek the views of dementia patients themselves, as they were likely to have lacked the detailed memory of the help-seeking pathway.

Conclusion

This is the first study to explore how carers from different ethnic groups decide when to access health services for people living with dementia, and their experiences afterwards. The ME carers tended to think that families should look after their own elders and that a diagnosis would have no purpose until they reached a stage when they could not cope. This attitude was grounded in their sense of familial responsibility and negative perceptions of psychiatric services, and was an important barrier to early diagnosis. Future quantitative research in a representative sample would enable us to quantify the barriers to and facilitators of healthcare access identified in this study. Further work should explore whether attitudes can be modified through intervention to an acceptance that diagnosis allows planning and possible avoidance of crisis and therefore is in the interest of family members, rather than being a failure in duty, disloyalty, or a relinquishing of the caring role.

Conflict of interest

None.

Description of authors' roles

NM, CC and GL designed the study and drafted the paper. NM recruited and interviewed participants, coded and analyzed the data. GL and CC reviewed and modified the coding structure and the paper. BB independently coded transcripts for codes and themes.

Acknowledgments

We are grateful to all the carers who agreed to be interviewed and to clinicians in Camden and Islington NHS Foundation Trust who supported the study.

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