healthwatch
Lambeth

Time for Our Ethnic Voices

Experiences of Unpaid Carers of Black Men With a Serious Mental Illness

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About Healthwatch Lambeth

We are the independent champion for people who use health and social care in Lambeth. We have the power to make sure NHS leaders and other decision makers listen to local feedback and improve standards of care.

Acknowledgments

We are grateful to Carol Aka and Matthew McKenzie, who co-produced the interview guide for carers, and to the Carers' Hub Lambeth and Joint Southwark and Lambeth Mental Health Carers Forum for their effort in supporting the recruitment of carers. A special thanks to all the carers who took their time to share their experience with Healthwatch Lambeth.

Introduction

Healthwatch Lambeth engaged with Black carers to understand their experiences of providing care to family members with a Severe Mental Illness. This report draws on carers' personal stories to highlight the challenges they face in their supporting role and their experience of mental health services. It accompanies and complements '**A Fulfilling Life, What Matters to Me**,' our report exploring the experiences of Black male service users with a Severe Mental Illness (SMI) in Lambeth.

Background

There are over 18,000 unpaid adult carers in the borough of Lambeth, many from Black communities, who provide essential care for family members with SMI.[1]

Formal recognition of carers in mental health services has been the focus of several policy and practice initiatives. For example, the 'Triangle of Care' aims to strengthen partnerships between carers, professionals, and patients, ensuring better support.[2] Additionally, recent changes to the Mental Health Act also seek to improve care and make services fairer.[3]

However, despite these efforts, some carers feel marginalised and excluded from care planning.[4-6] Barriers to involvement include a lack of recognition and appreciation of their role, and cultural barriers relating to power imbalances within the system.[7]

Evidence also suggests that many carers from Black, Asian and minority ethnic communities face unique challenges in their interactions with mental health services, including language and cultural and racial barriers, and fear that proactive involvement would lead to negative care responses.[8]

More broadly, organisations such as the Carers Hub in Lambeth offer support through advice, peer support groups and information tailored for adult carers, including those with mental health conditions.[9-10]

Research gaps include a lack of specific data on Black carers, their long-term wellbeing, and their experiences of involvement with mental healthcare for the person they care for. More research is needed with this group to develop culturally tailored support services.

Project Aim

The aim was to explore Black carers' experiences of caring for a male family member with SMI, their interactions with mental health services and the extent to which they felt services met the needs of their loved ones and themselves.

Methodology

The project used an exploratory qualitative approach involving one-to-one semi-structured interviews with carers and offering up other opportunities for carers to share their chosen experiences, for example, poetry. Poetry in qualitative research is a creative way to capture the subtle details of human experience. It helps share emotions and ideas clearly and engagingly.[11]

Interview topics and settings

We co-produced the topic guide for carers with two experienced carers. They shared aspects of their caring experience. This included their:

- Role as a carer
- Involvement in care planning for the care of the person they support
- Experiences of working with healthcare professionals (interactions and relationships)
- Other factors or challenges that affect their experience as carers

Five interviews with carers took place in person, and one took place via Zoom. Sensitive interview techniques were used to build trust and create a rapport.

Carers gave written and verbal consent to participate in the interviews and received a gift voucher for their time.

Data analysis

Interviews were transcribed and manually checked for accuracy. Inductive thematic analysis was used to examine the data and identify and agree on key themes.

Profile of carers

Three of the six carers we interviewed identified as Black Caribbean, and three were of Black African heritage. The oldest carer was over 80 years old. Five carers identified as female, and one identified as male. All carers were close family members, either a sibling or a parent of the person they cared for. None of the carers interviewed were related to the men we spoke to as part of our project looking at the experiences of Black male service users with a Serious Mental Illness.

Findings

Caring for a loved one with mental health challenges can be an emotional and demanding journey. Unpaid carers provide vital support, yet their experiences often go unrecognised and unsupported. The themes below and the analysis of the poem presented at the end of this section shed light on their experiences and how support for them can be improved.

Identity and recognition as a carer

Unpaid carers viewed their responsibilities as an integral and natural part of their family life rather than a distinct role. They only recognised themselves as "carers" when formally identified by others.

> "I have cared for [my brother] for many years, and I didn't know I was a carer! I didn't know that I was classified as a carer until I was invited to a carers' forensic group at Lambeth Hospital. Nobody has assessed me as a carer. If I go back over the years, it was obvious that I had been his carer, but I didn't see myself as a carer because I'm his sister!"

Official recognition prompted a realisation and a change in self-identity.

> "I wasn't aware I was a carer at first, because it's a family member, so you continue to do care as you usually do. I found out I was a carer when I attended the carers group, which the community mental health team had offered me and my family."

Involvement in care planning

The degree to which carers were involved in the planning of their family member's care varied considerably. Some carers reported feeling sidelined and not given the opportunity to understand and discuss care and treatment that would help recovery. This left them feeling anxious or worried.

> "I was never involved [in my son's] care plan. He goes to [Lambeth] hospital to take his tablets, and I go with him to collect his medication and when he has his blood test. I would like to know if my son will ever get better. Are the tablets for life? I'm worried about him. The doctor at Lambeth Hospital should tell me what's wrong with my son and if he will ever get better."

Carers sometimes felt their involvement was unwelcome.

> “I was never involved in shaping my brother’s care plan. I felt at times it seemed as if there was resentment that I was involved, almost as if I were a nuisance…but this is just my feeling. I was given invites to CPA meetings,
>
> I felt as if I were an irritant…My brother feels apprehensive about me attending meetings because he knows I worry so much.”

Others described a more collaborative approach. One carer talked about attending care planning meetings (CPA) to discuss their family member’s care needs, which made them feel included in shaping the care of their loved one.

> “At the care planning meetings, we were able to add any comments, along with what he had to say. As a family, we were an integral part of the planning, e.g. the next steps to be taken, and what needed to be put in place at discharge. Were able to ask questions about his treatment, medication, and therapy. We were satisfied with the process.”

These mixed experiences suggest that while some services encourage participation, overall communication still needs improvement.

Culturally sensitive personalised care

Some carers described care plans that effectively recognised specific requirements, such as needing an interpreter for a French speaker or matching the gender of the professional with that of the service user. This can contribute to positive experiences of care and aid recovery.

> “From the initial assessment, professionals realised that the person we cared for is French speaker, so sometimes they needed an interpreter. They also had African Caribbean health professionals and carers to look after him at home. We recognised that they went above and beyond in making sure that his needs were met in terms of cultural preferences.”

Conversely, when these needs are overlooked, the impact can be negative, contributing to feelings of stigmatisation.

> “No cultural needs were discussed with my brother. Over the years, from the outside, he was viewed as a threat… Black men experience a different type of stigma in relation to mental health issues.”

Communication with health professionals

In supporting their loved ones, carers communicate with a range of professionals such as Care Coordinators, GPs, community mental health teams, pharmacists, and workers within supported living accommodation. Effective communication with service providers is essential to the well-being of both the person receiving care and the carer.

Carers interviewed described mixed experiences. Some carers benefited from proactive engagement with health professionals in relation to booking appointments and having their queries addressed.

"I can talk to staff [in supported accommodation]. I would make an appointment with them to make sure things are put in plan for my son about progress with his care, and I make them know how I feel."

"If I were not clear about something, I would ring SLAM and they'll say...we will make an appointment for you and [my son] to come in together so we can sit down and discuss why [my son] is playing up like that, what's going on with him."

On the other hand, there were significant frustrations when information was not shared in a timely or transparent manner.

"When he [person cared for] had appointments at the hospital for his treatment, the professionals would not always tell us that he had one... I would like a text to notify me that my brother has a blood test due, so if I'm free, I may want to accompany him."

"Not everyone is computer literate or savvy to access services or assist someone who needs help. All this slows things down or creates a delay in getting the service we need for the person we are caring for."

Racial bias and discrimination

Carers shared examples of how they perceived that either their family member or themselves as a carer had experienced discrimination. One carer felt that an assumption had been made about her inability to safeguard her family member because of her own emotional difficulties.

"In terms of discrimination, I have been seen as a troublemaker, also because of the issues I have myself. It was not said to my face, but it was kind of...how dare you think you can safeguard [your family member] when you have your own issues? You yourself are not right in your own head."

Carers also felt that the disproportionate use of Community Treatment Orders for Black men and a focus on medication rather than talking therapies in the treatment of those they cared for were racially driven.

"The person I care for received a Community Treatment Order (CTO), so I feel the person was discriminated against. The proportion of other Black men who have it as a condition of hospital discharge... Why does CTO not apply to White people? Why can't Black service users just be discharged to their family or CMHT? There is a disparity between Black and White service users."

"I know (from my experience) that Black men are less likely to be offered talking therapy and are more likely to be medicated. They should be side by side. It's more just... take the medication."

Another carer shared with us her perception that some Black male professionals may have a discriminatory attitude towards other Black male service users because of differences in their cultural background.

"We are Black people, but there has been discrimination not because of our race but because of differences in culture. If there is a staff member who is Black, sometimes they may have a discriminatory attitude towards a Black service user if they have a different background. This is my experience. Over the years, I have met many really good staff who cared for my family member, but very rarely met staff who identified as Caribbean, e.g. from Jamaica or St Lucia"

The value of carers' meetings

All carers highlighted their appreciation for carers' meetings. They were seen as providing a safe, supportive space to obtain information, validate and share their experience, support each other emotionally, discuss challenges and build a rapport with mental health professionals.

"It's good to have a separate meeting from the person I look after. As carers, we have a different perspective from the service users. It is important to acknowledge the experience of carers and work closely with professionals, building rapport. We should all work together to improve the care for all service users."

These meetings provided practical care information and offered much-needed emotional support and an avenue for carers to finally have their voices acknowledged.

> “The [forensic] carers’ meeting at Orchard House (Lambeth Hospital) gives a safe space to discuss some general things about the relative’s care. It’s about how we, as carers, feel and the challenges we may experience as carers, how we help ourselves emotionally when we care for someone with complex mental health issues. It’s also a space where you go unwind and have a cup of hot chocolate. I found it helpful…I voiced something that I hadn’t voiced in 20 years.”

Time for our ethnic voices

One carer shared his feelings through a poem highlighting the pain of Black carers who suffer in silence and are often invisible, bearing burdens quietly without opportunities for expression. It describes how carers' voices are often ignored, leaving them feeling undervalued. It highlights how carers feel blamed for the problems of those they care for and perceive a lack of accountability by the system. It exposes the harsh effects of discrimination and racism and how this confounds their struggles. The narrative asks for change, calling for carers’ voices to be recognised, listened to and valued. It also calls for better representation and real change, so everyone who cares for others is treated fairly.

Time for Our Ethnic Voices

For too long we have been silent
Coping with it
Getting on with it
Never letting others know.

For too long we have suffered
Not being identified
Watching our loved ones grow unwell
Feeling blamed for failing to care

For too long not getting any feedback
Constantly waiting
Feeling disappointed
Just no recognition at all

For too long this bias is present
We have to fight it
Push it all aside
Makes no difference at all

For too long there's no representation
Just Discrimination
From all the Racism
This all leads to accusation

For too long there has been no change
No lessons learned
No accountability
Never their fault, they just blame me

Until there was a chance
To feedback our views
Now is the time
For our ethnic voices to finally be heard

Matthew Mckenzie, Joint Southwark & Lambeth MH Carers Forum

Conclusions and Implications for Service Development

This report highlights the need for better support for unpaid carers in mental health services. Many carers do not recognise themselves as such until formally acknowledged, often feeling invisible and undervalued. Early recognition and active engagement are crucial.

Carers' involvement in care planning for relatives with Serious Mental Illness is inconsistent. Some feel excluded from decisions, while others report collaboration. Their voices must be heard, ensuring meaningful contributions.

Communication with professionals significantly impacts carers. Many struggle to access timely, clear information on hospital appointments, treatment updates, and the roles of professionals. Improving communication and addressing digital access barriers is essential.

Cultural considerations are often overlooked. Providing interpreters and addressing stigma can enhance inclusive and effective care. Perceived racial bias highlights the need for training and full implementation of the Patient and Carer Race Equality Framework (PCREF) to ensure equitable care.

Carers' support groups offer vital emotional and practical support. More promotion of accessible services is needed, particularly for diverse communities. Feedback from carers aligns with existing research underscoring the challenges Black carers face and the importance of the 'Triangle of Care' model.

The insight in this report was provided by a small number of carers, and therefore, we cannot assume that the feedback is reflective of all carers. Further study is required into their specific needs.

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