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SYSTEMATIC REVIEW

# The qualitative accounts of black informal carers of people with psychosis and their experiences accessing mental health services: a systematic review

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## Abstract

**Background** Individuals from Black racially minoritised backgrounds are disproportionately diagnosed with psychotic disorders at higher rates. This presents unique caregiving challenges to informal (unpaid) carers. Black informal carers are more likely to face socio-economic challenges, including exposure to racism and discrimination, that impact their caregiving experiences and access to support. This systematic review aims to explore two primary questions:

**Methods** A systematic review was undertaken following the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines. The databases CINAHL, PsycINFO, EMABSE and MEDLINE via OVID were searched for articles reporting qualitative accounts of Black racially minoritised informal carers supporting a relative with psychosis from inception to 4th December 2024. The Critical Appraisal Skills Programme tool was used to assess the quality of included studies.

**Results** 669 records were identified from the database searches and 11 studies were included in this systematic review. Seven key themes were identified from qualitative carer accounts that reflected issues related to stigma, shame and secrecy; mistrust and fear; faith communities; police relations; knowledge gaps; system navigation, and the cultural misfit of services.

**Conclusions** Black racially minoritised informal carers in psychosis report several challenges in their roles, operating at individual, community, and societal levels. Improving our awareness of these issues and intervening to address their impacts are important as part of necessary steps required to provide effective support for Black informal carers and families affected by psychosis.

**Registration** PROSPERO registration number: CRD42023438867.

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**Text box 1. Contributions to the literature**

- First systematic review to report the qualitative accounts and experiences accessing mental health services of Black racially minoritised informal carers of people with psychosis.
- Calls attention to the unique caregiving challenges faced by Black racially minoritised communities affected by socio-economic difficulties.
- Highlights a critical need for the development of racially and culturally informed support for informal carers from Black racially minoritised backgrounds in psychosis, informing public health policy and practise.

## Background

Psychotic disorders are diagnosed at significantly higher rates in people from Black racially minoritised backgrounds compared to White majority populations [1–4]. In the United Kingdom (UK), for example, adults from Black Caribbean and Black African communities are diagnosed with psychosis at 6–9 times the rate of White majority peers [1]. Higher diagnostic rates are also observed in individuals from Black racially minoritised backgrounds living in European countries compared to peers living in their country of origin or ancestral heritage [5].

Several causal explanatory factors, including social disadvantage and exposure to discrimination and racism, have been associated with elevated psychosis diagnoses in Black racially minoritised groups [6, 7]. Evidence also attests that Black racially minoritised groups are disproportionately exposed to mental health care pathways that are circuitous [8], negative, and often only accessed via contact with law enforcement agencies [9–11]. Moreover, the care they receive can often be coercive [8]. Significantly higher rates of compulsory psychiatric admissions [12–14] and deaths while in psychiatric inpatient care are also recorded for Black racially minoritised groups [2, 15, 16]. In addition, poorer clinical, social, and quality of life outcomes are recorded for Black racially minoritised groups when compared to White majority peers [6, 17, 18].

Many people who are living with a psychotic disorder receive informal (unpaid) care and support from their families or significant others (e.g. friend). Families and significant others (from here on collectively referred to as informal carers) play a vital role in facilitating the support and recovery of care recipients in psychosis [19–21]. Informal carers will often be the first to identify early indicators of decline in the care recipient's health [22] and influence the timely access to relevant care and services [23]. In parallel, more than seven decades of research findings confirms that caregiving roles can also have a deleterious impact on carer health and are linked to elevated rates of common mental health conditions, sleep disturbances and psychotic-like experiences when compared to non-caregiving peers [24–26].

The differential pattern of psychosis diagnoses recorded in Black racially minoritised groups arguably demands for a detailed understanding of the lived experiences of informal carers from Black racially minoritised backgrounds. We know, however, that informal carers from Black racially minoritised backgrounds, irrespective of care recipient condition, are more likely to provide greater caregiving hours in comparison to their White majority peers [27], and encounter social challenges including racism and discrimination, and financial difficulties that individually, and in combination, negatively impact their caregiving [28, 29]. There is a need, therefore, for a more nuanced account of the impacts of psychosis in Black racially minoritised communities.

A systematic review was conducted to provide a broader perspective, comprehensive synthesis, and improve our understanding of the experiences of Black informal carers, who are often underrepresented in studies [29]. This would represent an important and necessary step in understanding the impact of psychosis in Black racially minoritised communities. Consequently, this review seeks to identify and synthesise qualitative accounts, illustrating the caregiving experiences of informal carers from Black racially minoritised backgrounds who are supporting a relative living with psychosis. Specifically, the review aims to explore two primary questions:

(1) What are the first-person qualitative accounts of Black informal carers supporting a relative with psychosis?
(2) What are the reported barriers and facilitators for Black informal carers in accessing mental health services and establishing helpful relationships with professionals?

## Method

### Reporting guidelines and protocol registration

The systematic review was conducted in accordance with the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines [30], with a registered protocol on PROSPERO (registration number: CRD42023438867).

### Search strategy

To identify relevant articles, searches were conducted across four databases comprising CINAHL, PsycINFO, EMABSE and MEDLINE via OVID from database inception to 9th October 2023. An updated database search was conducted on 4th December 2024 using publication date limits with no additional articles identified. Search strings were formed following the PICOS (population, intervention, comparison, outcome, and study design) strategy [31]. The search strategy, including Medical

Subject Headings (MeSH) terms, were applied around four key concepts: (i) Caregiving, (ii) Black racial minority (iii) psychosis, and (iv) 'Life course perspective' [see supplementary material– Additional File 1]. Truncations were used to account for different spellings and word endings, in addition to Boolean operators "AND, OR" to combine and connect concepts, where relevant. To identify additional relevant papers, backward citation tracking was conducted whereby a manual search of the reference list for relevant papers were completed. Forward citation tracking was also conducted through identifying studies that have cited the eligible papers, allowing for more recent research studies.

### Eligibility criteria

Studies eligible for the review were: (i) first-person qualitative accounts from (ii) informal (unpaid) adult carers who were from (iii) Black racially minoritised backgrounds and (iv) supporting a care recipient with psychosis. Studies with varied racially minoritised samples were eligible for inclusion if separate data on Black minoritised carer participants were reported. All papers were required to be English language and peer reviewed journal publications.

Papers were excluded if studies included solely non-Black racially minoritised informal carers; carers under the age of 18; informal carers of any non-psychosis conditions, including organic disorders; formal (paid) carers; studies reporting solely quantitative data; systematic reviews, book chapters, conference proceedings, dissertations, and grey literature sources.

### Study selection

All studies retrieved from database searches were imported into the EndNote21 software [32], removing duplicates found. Titles and abstracts were imported into Covidence software [33] and all titles and abstracts were screened by two reviewers independently (AK & JL). The full text of remaining articles were assessed against the inclusion criteria by both reviewers, with disagreements resolved through discussion and achieving consensus in consultation from a third reviewer (JO).

### Risk of bias (quality) assessment

The Critical Appraisal Skills Programme tool– CASP [34] was used to assess the quality of studies included in this review. The CASP tool is a ten-item checklist serving as a structured framework for critically appraising individual studies. The checklist assesses the quality and methodological standard of studies with key considerations of the appropriateness of research aims, clarity of the data collection method, and the rigour of analysis. The quality appraisal of each article was independently assessed by all three reviewers (AK, JL, and KA). Any discrepancies were resolved through discussion and consensus, in consultation with a fourth reviewer (JO).

### Data extraction and synthesis

Data from the included studies were extracted using a data extraction form detailing study aims, methodology, participant demographics and key findings. Two reviewers independently extracted the data (AK & JL).

Data syntheses were conducted following Thomas and Hardens' (2008) [35] thematic synthesis approach, incorporating three main steps. Firstly, key concepts and codes were identified from line-by-line coding of primary studies. These codes were subsequently organised into groups to construct descriptive themes. Finally, through interpretating data and identifying relationships within and across studies, analytical themes were developed. Thematic synthesis was selected as the most appropriate approach to secondary data synthesis, given its ability to integrate qualitative findings across multiple studies while sustaining the richness of participants' experiences. This approach identifies recurring themes across studies alongside the nuanced insights of participants [35].

## Results

### Search results

A total of 669 reports were retrieved from database searches of which 232 duplicate articles were removed. The remaining 437 articles underwent title and abstract screening. From this screening process, 44 articles underwent full text review with 33 papers excluded mostly due to incorrect study design ($n = 17$) or care recipients with non-psychosis conditions ($n = 13$).

A total of 11 studies met the eligibility criteria. The article selection process is outlined in Fig. 1.

### Study characteristics

The study characteristics of included articles are shown in Table 1. The majority of studies were conducted in England, United Kingdom (UK) ($N = 7$) [36–42] with the remainder from the United States of America (USA) [43–46].

### Participants and caregiving relationships

The participant sample comprised a total of 141 informal carers from Black racially minoritised backgrounds with reported gender or sex mostly listed as female/woman ($n = 104$, 74%). Participant age ranged from 22 years old [40] to 75 years old [41]. The relationship between informal carers and care recipients were reported in 7 studies [36, 38, 42–46], and the majority were listed as being the mothers of care recipients ($n = 41$).

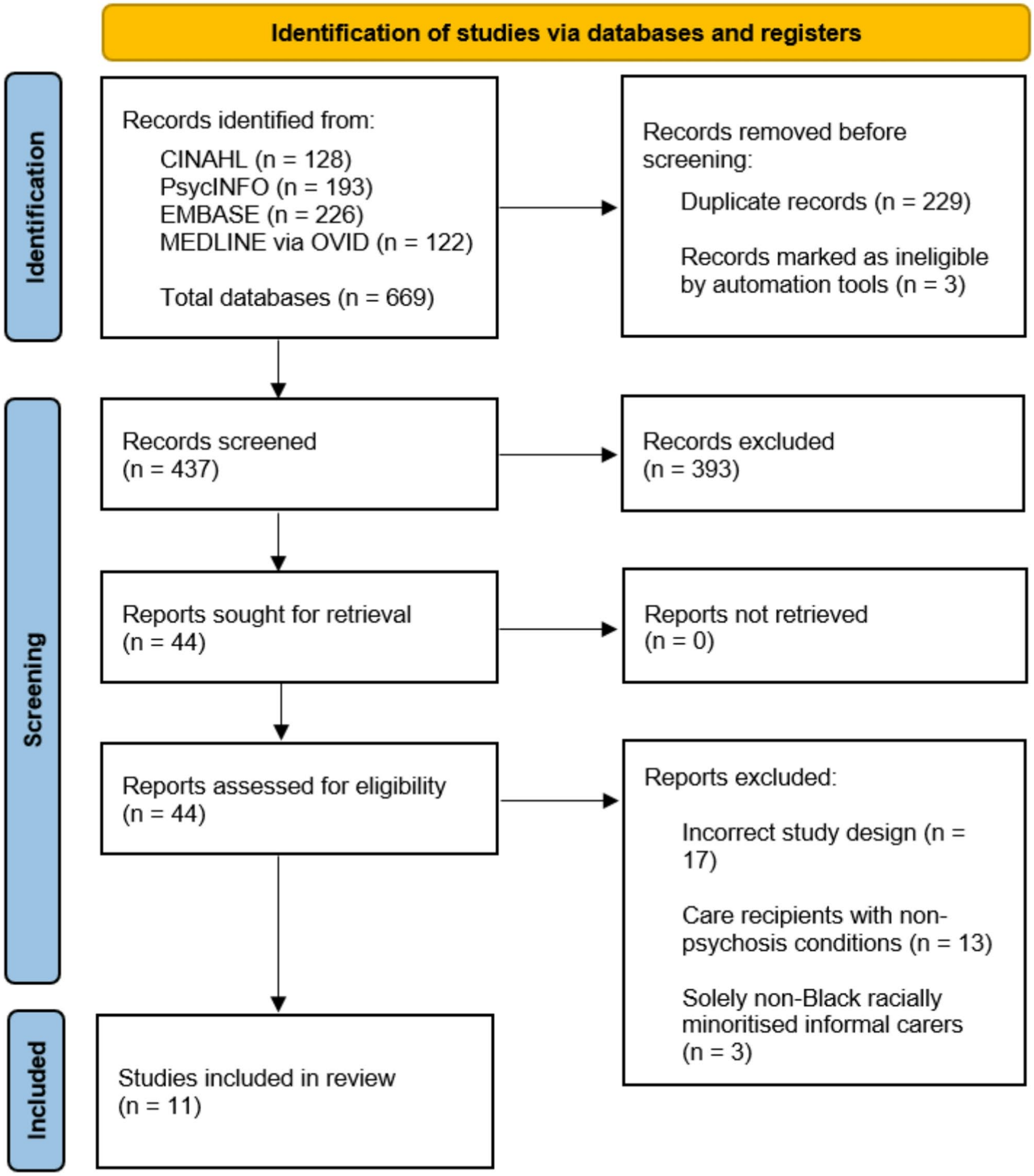

**Fig. 1** PRISMA flow diagram of the identification and selection of studies on the qualitative accounts of black informal carers of people with psychosis

### Study quality appraisal

Of the eleven studies included, three studies were assessed as demonstrating high methodological rigour [39, 41, 42], having employed strengths in the appropriateness of their qualitative methodology. Six studies were assessed as demonstrating moderate methodological rigour [37, 38, 40, 44–46]. Though strengths in their research design were noted, such as rigorous data analysis, they fell short on discussions of ethical considerations. Two studies achieved low quality rating [36, 43] due to insufficient detail on the research design and

**Table 1** Key characteristics of included studies of a systematic review of the qualitative accounts of black informal carers of people with psychosis

| | Authors (Year) | Region | Research Objectives | Methodology | Analysis method | Carers participants (*N*) | Participant Demographics (age (age mean), gender, ethnicity) | Key Findings |
|---|---|---|---|---|---|---|---|---|
| 1 | Morley et al., (1991) | UK - London | To explore the experiences and attitudes of Afro-Caribbean relatives supporting an individual with psychosis. Comparing between those admitted to hospital informally and compulsory. | Quantitative questionnaires and individual interviews | N/R | *N* = 25 | 37–75 years old<br>Female = 15<br>Black Caribbean = 15 | Carers did not have positive opinions of psychiatric hospitals, comparing them to 'prisons'. Carers expressed the lack of support from services, often feeling unheard or redirected to police services. |
| 2 | Hines-Martin (1998) | USA - Southern | To explore the experiences and perceptions of African American caregivers regarding their experiences, coping mechanisms, support, and caregiving concerns. | Individual semi-structured interviews, participant observations, historical records and artifacts | Reiterative data analysis | *N* = 16 | 30–60 years old<br>Female = 16<br>African American = 16 | 3 themes were identified and focused on:<br>1) Community perceptions and stigma<br>2) Resources used by informal carers<br>3) The use and evaluation of mental health services |
| 3 | Keating & Robertson (2004) | UK wide | To explore the content and consequences of 'fear' in African and African Caribbean service users and carers. | Focus groups | Thematic approach (Miles & Huberman, 1984) | *N* = 19 | 30–74 years old<br>Female = 12<br>Black Caribbean = 15<br>Black African = 4 | Carers' experiences and sources of fear focused on:<br>- Stigma of mental health problems<br>- Negative experiences of care to due to racism and discrimination<br>- The disregard of carers' concerns from professionals |
| 4 | Franz et al., (2010) | USA - Southern Eastern | To explore the role of stigma in the duration of untreated psychosis as perceived by family carers. | Individual semi-structured interviews | Inductive approach through content analysis | *N* = 12 | Mean age 47.8 years old +/- 7.6 years<br>Female = 5<br>African American = 12 | 4 key themes identified:<br>- Society beliefs about mental illness<br>- Carer beliefs about mental illness<br>- Stigma around mental illness<br>- Delays in seeking treatment |
| 5 | Singh et al., (2013) | UK - Birmingham | To explore how service users and their carers understand psychosis and initiate help-seeking. | Semi-structured interviews | Thematic approach | *N* = 12 | Female = 10<br>Black Caribbean = 5 | Findings included:<br>1) Importance of family in help-seeking<br>2) Religion and culture help-seeking decisions<br>3) Delays in seeking medical treatment<br>4) Reluctance to involve police |
| 6 | Rabiee et al., (2014) | UK wide | To explore the experiences of accessing services among Black African and African Caribbean service users and carers. | Focus groups and semi-structured interviews | Thematic approach (Krueger and Casey, 2000; Rabiee, 2004) | *N* = 24 | Female = 14<br>Black Caribbean = 15<br>Black African = 9 | Key themes included:<br>- Social stress<br>- Support networks<br>- Experiences of using mental health services |
| 7 | Ally et al., (2015) | UK - London | To explore the experiences of East African Muslim carers of schizophrenia patients. | Semi-structured interviews | Thematic analysis (Braun and Clarke, 2006) | *N* = 4 | 22–40 years old<br>Female = 4<br>East African = 4 | 4 themes were identified:<br>1) Issues around diagnosis<br>2) Consequences of treatment<br>3) Lack of choice<br>4) A more culturally sensitive mental health provision |

**Table 1** (continued)

| | Authors (Year) | Region | Research Objectives | Methodology | Analysis method | Carers participants (*N*) | Participant Demographics (age (age mean), gender, ethnicity) | Key Findings |
|---|---|---|---|---|---|---|---|---|
| 8 | Islam et al., (2015) | UK - Birmingham | To understand the challenges in mental health service provision for Black and minority ethnic carers in relation to the cultural appropriateness, accessibility, and experiences of the Early Intervention for Psychosis Services. | Focus groups | Thematic approach (Ritchie & Spencer, 2002) and framework analysis (Krueger and Casey, 2009) | *N* = 11 | 36–75 years old<br>Female = 8<br>Black Caribbean = 5<br>Black African = 2 | 5 themes were identified and focused on:<br>1) Help-seeking<br>2) Culture and beliefs<br>3) Social stigma and shame<br>4) Experiences of mental health services<br>5) Improving access of services |
| 9 | Joy et al.,(2017) | USA - Pennsylvania | To better understand African-American caregivers' approaches on medication adherence and other supports of the care recipient and themselves. | Individual semi-structured interviews | Thematic analysis (Braun and Clarke, 2006) | *N* = 10 | 28–50 years old<br>Females = 7<br>African American = 10 | Key themes included:<br>- Stigma and shame<br>- Support for caregivers<br>- Religious beliefs |
| 10 | Onwumere et al., (2018) | UK wide | To examine the perspectives of carers exposed to violence from their relative with psychosis. | Individual semi-structured interviews | Interpretative Phenomenological Analysis (Smith, Flowers, & Larkin, 2010) | *N* = 8 | 37–72 years old<br>Female = 7<br>Black and minority background = 7 | Main findings included:<br>- Experiencing sudden onsets of violence<br>- Changing relationships with care recipient<br>- Ideas of support |
| 11 | Oluwoye et al., (2023) | USA - Pacific Northwest | To explore the pathways into coordinated specialty care among caregivers and care recipients of first episode psychosis. | Individual semi-structured interviews | Qualitative descriptive approach (Sandelowski, 2010, Sandelowski, 2000) | *N* = 8 | 31–57 years old<br>Female = 6<br>African American = 8 | Key themes included:<br>- Social functioning<br>- Help seeking and support<br>- Interaction with law enforcement<br>- Delays in seeking treatment<br>- Navigating services |

Key: N/R = Non reported

**Table 2** Quality appraisal of included studies using the critical appraisal skills programme qualitative checklist

| Quality criteria | Morley et al. (1991) | Hines-Martin (1998) | Keating and Robertson (2004) | Franz et al. (2010) | Singh et al. (2013) | Rabiee et al. (2014) | Ally et al. (2015) | Islam et al. (2015) | Joy et al. (2017) | Onwumere et al. (2018) | Oluwoye et al. (2023) |
|---|---|---|---|---|---|---|---|---|---|---|---|
| Was there a clear statement of the aims of the research? | Y | Y | Y | Y | Y | Y | Y | Y | Y | Y | Y |
| Is a qualitative methodology appropriate? | C | Y | Y | Y | Y | Y | Y | Y | Y | Y | Y |
| Was the research design appropriate to address the aims of the research? | C | Y | Y | Y | C | Y | Y | Y | Y | C | C |
| Was the recruitment strategy appropriate to the aims of the research? | Y | C | Y | Y | Y | Y | N | Y | C | Y | Y |
| Was the data collected in a way that addressed the research issue? | C | Y | Y | Y | Y | Y | Y | Y | Y | Y | Y |
| Has the relationship between researcher and participants been adequately considered? | N | N | N | N | N | C | N | C | N | Y | N |
| Have ethical issues been taken into consideration? | N | C | C | N | C | C | C | C | C | Y | Y |
| Was the data analysis sufficiently rigorous? | N | N | Y | Y | Y | Y | Y | Y | Y | Y | Y |
| Is there a clear statement of findings? | C | C | C | C | C | Y | Y | Y | Y | Y | C |
| How valuable is the research? | C | Y | Y | Y | Y | Y | C | Y | Y | Y | Y |
| **Total Ranking** | **L** | **L** | **M** | **M** | **M** | **H** | **M** | **H** | **M** | **H** | **M** |

**Key**: Y = Yes, C = Can't tell, N = No

H = High, M = Moderate, L = Low

**Table 3** Summary of key themes identified from thematic synthesis of included studies detailing the qualitative accounts of black informal carers of people with psychosis and their experiences accessing mental health services

|  | Themes | Brief description | Number of studies | Papers contributing |
|---|---|---|---|---|
| 1 | Stigma, shame and secrecy | Negative consequences of caring for an individual with severe mental health problems | *N* = 5 | Hines-Martin, (1998); Keating and Robertson, (2004); Franz et al., (2010); Singh et al., (2013); Joy et al., (2017) |
| 2 | Mistrust and fear | Mistrust and fear of mental health services creates barriers in accessing these services. | *N* = 5 | Morley et al., (1991); Keating and Robinson, (2004); Ally et al., (2015); Islam et al., (2015); Oluwoye et al., (2023) |
| 3 | Faith, spirituality and religion | Faith can hold significant importance, offering a source for support and resilience | *N* = 6 | Hines-Martin, (1998); Singh et al., (2013); Ally et al., (2015); Islam et al., (2015); Joy et al., (2017); Oluwoye et al., (2023) |
| 4 | Police relations | Negative experiences and encounters with the police | *N* = 6 | Morley et al., (1991); Hines-Martin, (1998); Singh et al., (2013); Ally et al., (2015); Onwumere et al., (2018); Oluwoye et al., (2023) |
| 5 | Awareness and knowledge gaps | Limited awareness and literacy of mental health problems | *N* = 6 | Hines-Martin, (1998); Keating and Robinson, (2004); Rabiee et al., (2014); Ally et al., (2015); Islam et al., (2015); Joy et al., (2017) |
| 6 | System navigation challenges | Challenges and barriers in successfully navigating health systems | *N* = 7 | Morley et al., (1991); Hines-Martin, (1998); Keating and Robertson, (2004); Singh et al., (2013); Rabiee et al., (2014); Ally et al., (2015); Islam et al., (2015) |
| 7 | Cultural misfit of services | Support that offers culturally relevant services | *N* = 7 | Morley et al., (1991); Keating and Robertson., (2004); Singh et al., (2013); Rabiee et al., (2014); Ally et al., (2015); Islam et al., (2015); Oluwoye et al., (2023) |

chosen analysis of data. Full assessment of the quality of included studies are outlined in Table 2.

### Qualitative synthesis

Seven key themes were identified from the thematic synthesis. The identified themes and their descriptions are reported in Table 3; Fig. 2.

### Stigma, shame and secrecy

This theme reflected the felt stigma, shame, and, at times, fear Black informal carers experienced as the relatives of someone with severe mental health problems. Carers described how stigma hindered their caregiving experiences and presented additional challenges that often led them to experience shame and keep the mental health diagnosis a secret from others. Negative attitudes expressed towards those with mental health problems were argued to have their origins in wider society but were deeply rooted within Black racialised communities. This theme was reported across five studies [37, 38, 43–45].

> *"[Blacks] tend to hide it and put it in the closet. They don't even talk about their family members being*

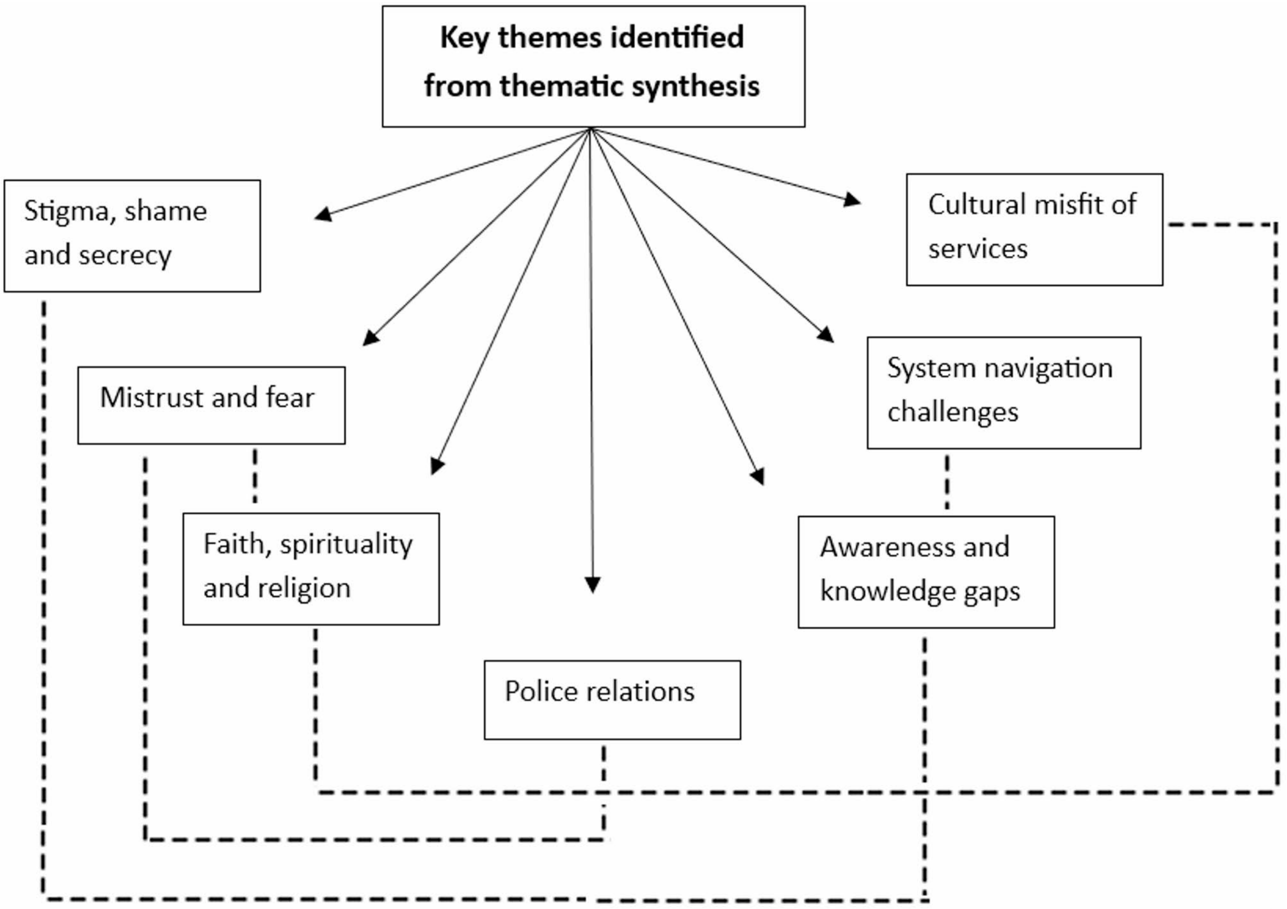

**Fig. 2** Diagram of key themes identified from thematic synthesis of Black informal carers' experiences of supporting an individual with psychosis. Perforated lines highlight relationships between themes

> *mentally ill. They don't say anything. They just say, 'he's sick'. a lot of blacks don't even know the cause of mental illness and when you talk to someone about it, or they'll say 'don't say he's mentally ill' or 'just say he's got an illness' or 'he's got a nervous problem.' They really do not, very few people actually come out and talk about it." [43].*
>
> *"You really don't want anyone to know because no one wants to be looked at in a different way, as abnormal. You know, something's wrong with that person. Sometimes it's just overwhelming, dealing with them differently." [44].*
>
> *"Everybody has that crazy uncle or aunt... but nobody really discusses it. So, by asking around, I found out that two people in his family had something, but no one really told me what that was" [45].*
>
> *Informal carers described reports of having been socially excluded due to negative attitudes, with one informal carer noting "Oooh they don't look at 'em good. They think they're a joke. I've seen people laugh at folks and, ya know, make comments and stuff, but society does not have a clue or understand what's going on" [44]. There was often also alienation towards those with psychosis.*
>
> *"One daughter, the one after him, is a social worker and she understands it and is sympathetic. But, the other daughter, she is eighteen and she is not very happy to have him around when her friends come over" [38].*
>
> *"What we tell people now is A was in the Army, and when he came out he had post-traumatic stress or bipolar. But we don't tell them schizophrenia, because it just seems, when you say that word..." [45].*

Informal carers felt their experiences of stigma were often barriers to accessing their own care and support. There was a reluctance to seek help due to a need to establish and maintain secrecy of having severe mental health problems in their family and close networks.

> *"Sometimes in the Black community, there's such a stigma, that they [informal carers] won't go to someone. they believe that if someone's mentally ill or something, that you just kind of keep that from the*

> *community, because you're ashamed, and you don't tell anyone." [45].*
> *"I don't want to say anything because of the repercussions for my daughter" [37].*

### Mistrust and fear

This theme reflected the challenges faced by Black informal carers in accessing mental health services or relevant care, and in a timely fashion. A mistrust of professionals and the services and organisations they represented were directly linked to reports of poorer service engagement and delayed help seeking. The lack of trust fuelled ongoing fears about the support they, and their care recipient, would receive [36, 37, 40, 41, 46].

> *"I knew my son had problems, but was wondering how he was going to end up?... and feared for my son" [37].*
> *"When he goes to the hospital, they do not actually look at him. they do not take into account what you are saying. They do not give us a proper explanation on how it is going to help him, the advantages and disadvantages; they do not really go into that deeply" [40].*
> *"But she wouldn't listen to me, her staff wouldn't listen to me, it was basically, I feel that because my son was African American he was targeted and we have to do what they say" [46].*

A specific fear of medication-based treatments and their implications for Black communities and possible adverse effects on their bodies were also associated with delays in help seeking and receiving treatment for mental health conditions. One informal carer stated when she saw how obese and bloated her friend's son had become after receiving treatment and medication for their mental health problems, she delayed seeking treatment with her son until it reached a critical point [37].

> *"I did not want him to have medication that would make him a zombie. I'm scared of medication" [36].*

### Faith, spirituality and religion

Against a backdrop of fear and mistrust in mental health services, Black informal carers often sought support and guidance from spiritual, religious and faith-based communities. For many informal carers, faith in 'God' provided hope and prayer served as a form of support.

> *"We just thought maybe it [psychosis] was more of a spiritual one. That was what we thought anyway or that he needed prayers." [46].*
> *"Trust in God because God don't lie. I lean on Him each and every day no matter what situation I go through and He always carries me through." [45].*
> *"[I] continued praying as that was the only way I could cope. My faith became stronger and helped me cope" [38].*

However, while some informal carers sought faith-based support, faith and religious communities, themselves, were perceived as often having limited knowledge and understanding of mental health problems, and how best to support those affected. Limited mental health knowledge within faith and religious communities seemingly created barriers in accessing timely and effective support from professional services.

> *"Our ministers, they aren't as educated on mental illness as they should be. But a lot of them don't know a lot about mental illness either. Maybe if they understood it or knew a little more about it. Like if they had members of their congregations who needed help, they may be able to help or steer them in the right direction, you know." [43].*
> *"The Christian Black church environment is less helpful. They wanted to know not because they wanted to help me but because they were curious." [38].*
> *"No I didn't tell the church, I kept it secret from the church members, I didn't tell them. I don't think they would have understood" [41].*

### Police relations

More than half of the included studies captured Black informal carers' negative encounters with the police service and how these invariably shaped their fear appraisals about mental health services and treatments [36, 38, 40, 42, 43, 46]. This fear underpinned their intentional decision to avoid involving the police in mental health situations even when circumstances would suggest that they should.

> *"I prefer not to involve police because I don't think it was that level of aggression, that I have to really do it, I, I still don't really think its aggression but there are perhaps some elements of aggression in it." [42].*

In situations where there was police involvement, informal carers described care recipients being treated as if *"they were criminals"* [36] and the care from the police as having been aggressive and racially discriminatory through the criminalisation of care recipients.

> *"I don't understand why he should be taken to the police station and kept overnight. He had done noth-*

> *ing. He needed the doctor not the police. They kept him there all night and he showed us bruises on his back from the police manhandling. He told me that the police had hit him. They should not treat him like that [mother starts crying]." [38].*
>
> *"[He's] a young man who has never been in trouble with the police! He went to a parochial school, he is an upstanding citizen, he's a college student!. and we have to do what they say" [46].*
>
> *Informal carers' active avoidance of police assistance with care recipients was further reinforced by how health services operated, as one informal carer noted "The GP did not try and persuade him to go into hospital, but the police did."[36]. Police avoidance was also contributed by involuntary detentions and care comprising coercive and restrictive practices.*
>
> *"They would use force such as the police, and community treatment order (CTO) in order to make sure that she doesn't stop using the medication" [40].*

### Awareness and knowledge gaps

Six studies emphasised how a limited awareness and literacy of mental health problems meant Black informal carers exhibited poorer understanding of psychosis and its related issues and were therefore at a disadvantage in their caregiving roles [37, 39–41, 43, 45].

> *"We (Blacks) don't go to the different events that will give us information that might help. and that hinders. When you go to a lot of the different seminars, there's a small portion of Blacks." [43].*
>
> *Religious-spiritual explanations for severe mental health problems were not uncommon amongst Black racially minoritised carers but were often at odds with more biomedically framed explanations. Informal carers, not infrequently, attributed a change in their care recipients' behaviour to external factors including spiritual beliefs such as 'black magic' or traumatic life events [39].*
>
> *". this [symptoms of psychosis] went on for a period of time where it was getting worse for him.   I started to think, as a Black person there was something wrong, I thought there's a ghost in the place" [41].*

The knowledge gaps also affected help-seeking activities, with informal carers reporting limited knowledge about what information to ask for, awareness of available helpful resources, and how best to navigate healthcare systems. There were challenges in identifying the sources of and pathways to support, securing support, and knowing what care, support and service provision were available to care recipients.

> *"Whites, they get a better network of resources. Whites, they have a better network of information maybe because they go out and we don't go out. There is a very small proportion of Blacks and then everybody else, that has a lot to do with it. We stay within our place with mental illness." [43].*
>
> *The benefits, however, were clear, when carers were able to access information and fill in some gaps in their knowledge and understanding. Having information empowered and enabled informal carers to advocate for themselves and care recipients more effectively. The provision of information, in turn, helped to alleviate the stress associated with caregiving.*
>
> *"It was very helpful, he gave me a little more insight about the schizophrenia, helped me understand a little better. 'Cause for real I didn't know what actually was going on. Without the help of him then I might still have been in the dark a little more than I am, but it was very helpful talking to him." [45].*
>
> *"The doctor did say if I was finding it too hard, they could send someone to sit in with me. They offered." [39].*

### System navigation challenges

Black informal carers reported difficulties in their navigation of mental health services, including encountering barriers to accessing appropriate support and services [36–41, 43]. Some informal carers expressed their criticisms about general practitioners/physicians not acting quickly enough and failing to respond to their concerns, *"unless something drastic happened"* [36].

> *"Why is it such a battle to get them to recognize what the parent is saying you know I was so angry, that's my child, I know my child" [41].*
>
> *"No scanning or checking has been done to find the cause of the illness." [40].*
>
> *While some informal carers expressed difficulty in accessing initial services and treatments, others faced further challenges when interacting with health care professionals. Informal carers reported negative experiences with mental health services including being on the receiving end of negative attitudes from professionals, feeling misunderstood, disrespected, and having their needs and lived experience and expertise overlooked [39]. Navigating healthcare systems often left carers feeling confused and frustrated.*
>
> *"[N]othing was done, even when my husband was vomiting, vomiting up the tablets because he didn't want tablets. And I remember once I had to take a taxi to go to hospital– it was a Sunday– because the consultant didn't believe that he would vomit*

> *out the tablets. So we went there, I give the tablets and show my husband vomit them out almost on his feet. And still that point didn't go through. So, what I have found all along the years is this, I am afraid to challenge them [professionals]... It is always a struggle to be taken seriously." [37].*
>
> *"The family has to take on the responsibility of doing these things totally in the absence of having some insight into the situation. Every time I've gotten any information about my husband it's because I went to seek it out." [43].*
>
> *Despite informal carers playing a vital role in providing support, they felt excluded from decisions about the care recipient, where services often "leave the families out" [43]. This, consequently, left them disempowered when dealing with mental health services, describing instances where "You can ask them questions, but you cannot tell them what to do" [40].*
>
> *"I did not feel that I was a part of the sectioning process. Even when he was in hospital, I felt that things were not communicated to me. I made a formal complaint about it and did not receive a very good response from a manager from my own community." [38].*

### Cultural misfit of services

In seven papers, Black informal carers reported there was a lack of respect for, and integration of, their cultural or spiritual beliefs within mental health services which in turn led to cultural misalignment in service provision [36–41, 46]. Informal carers reported a need for culturally informed treatments and services. There was dissatisfaction with services that were not perceived as being culturally sensitive or open to explanatory frameworks and treatment approaches that extended beyond traditional biomedical models of mental ill health. Black informal carers highlighted how their unique needs could be addressed through the provision of culturally informed support approaches with capabilities of acknowledging and integrating their cultural beliefs and values.

> *"I don't really think she got us. She did not get him. He would be better off with a black psychiatrist. His care co-ordinator is of the same ethnicity, but that is no use to us as he has no power. She [psychiatrist] makes all the decisions." [38].*
>
> *"I don't feel like he was receptive to assume that she had a heightened spiritual awareness brought on by psychosis. I don't think he took that into consideration even after I explained that." [46].*
>
> *"Seeking to understand people, their personal circumstances, their culture, and their beliefs– not simply dishing out medication." [39].*
>
> *"At least if they could give us a chance to see what we can do and collaborate with us with the same intention to get the patient better [.] They don't take any actions concerning religious or traditional treatments". [40]*
>
> *Informal carers reported barriers and inequities in accessing perceived helpful treatments particularly in relation to talking (psychological) therapies. Many reported medications as being the default treatment option for care recipients in the absence of exploring other approaches [36]. The need for professionals to work with Black informal carers to find alternative treatments rather than offer and provide an almost exclusive emphasis on medication was shared [40].*
>
> *"He put her in [redacted] place, I didn't know I was putting her in the system. She never had no counselling at all. To this day, she's still in the system and getting worse." [39].*
>
> *"I felt like if I said no to the drugs and you [clinical staff] want to administer them anyways, you are disrespecting my culture." [46].*

## Discussion

This systematic review examined the qualitative accounts of informal carers from Black racially minoritised backgrounds supporting someone with psychosis, to explore their lived caregiving experiences, and the reported barriers and facilitators in accessing mental health services and care. A review of four databases yielded eleven studies of which the majority were undertaken with participants from the United Kingdom and published since 2010. By centring the perspectives of Black informal carers, this review sought to offer insights into the racialised contexts that can shape their caregiving experiences, and interactions with service providers.

The narrative synthesis of carer accounts identified seven key themes from Black informal carers' lived experiences. Mental health stigma served as a key feature in one of the themes. While it is found across many different communities [47, 48] it can have a more nuanced presentation and impact in racially minoritised groups, with evidence suggesting higher levels of felt stigma [49–51]. Stigma observed within Black racially minoritised communities can be influenced by misinformation about mental illness which, in turn, further perpetrates stigmatising beliefs [52, 53]. Jon-Ubabuco et al. (2019) [54] found informal carers from Black racially minoritised backgrounds in America reported pervasive stigma and fear of social repercussions, stating that mental health stigma was a significant problem in their communities. The review findings showed mental health stigma within family and wider networks contributed to the development and maintenance of secrecy about mental ill health and delayed help-seeking. Evidence also attests to lack of communication between Black racial communities with health care providers and reluctance to disclose 'shameful' information [55, 56]. Recognising the factors that are linked to mental health stigma within Black racially minoritised communities may help to reduce potential modifiable barriers to help seeking.

Gaps in carer knowledge and awareness of mental health conditions, including poorer recognition, understanding, and management of psychosis as a condition and its presentation within a relative, was also key theme. This theme was consistent with recent literature highlighting how an understanding of mental health conditions impacted on individual readiness to engage in help seeking activities [57, 58]. Pederson et al. (2023) [58] reported a positive correlation between mental health knowledge and help-seeking behaviours, observing that knowledge gaps are likely to underpin the treatment gaps seen in Black communities. Mental health illiteracy can serve as a direct barrier to seeking timely treatments and interventions and is exacerbated by poorer accessibility to mental health services and limited understanding of treatment options [59]. Further, Hurley et al. (2020) [60] also observed how poor mental health literacy alongside negative attitudes towards mental health care were associated with lower levels of service engagement. Therefore, the development of targeted and culturally informed knowledge enhancing interventions might help to optimise timely engagement with and access to mental health treatment.

Reported negative encounters with the police service were consistent with wider literature, and potentially reflecting the historical context of racialised policing [61–63]. Through increased rates of compulsory detention, evidence confirms that police involvement is higher amongst Black racially minoritised service users in their pathways to mental health care, compared to their White peers. Moreover, Barnett et al. (2019) [12] highlighted a lack of change in the racial disparity in detention rates over the years. The policed care pathway arguably contributes to Black informal carers' feelings of fear and concern for the safety of their care-recipient and avoidance of police involvement irrespective of their need [64, 65]. These concerns are reflected in wider literature as informal carers of care recipients in compulsory detention report the need for trustworthy relationships with police and service providers to alleviate fears [66, 67].

System navigation challenges were reported by Black informal carers and served as a significant barrier in accessing appropriate support for themselves as well as care recipients. There is consistent evidence that individuals from Black racially minoritised backgrounds are more likely to receive coercive care with mental health services, often typified by reports of racism and discrimination [68–71] that exacerbate challenges in service navigation [72]. Hamed et al. (2022) [73] conducted a scoping review identifying 213 articles examining patient and user experiences, and effects of racism within healthcare. Their qualitative studies confirmed that healthcare staff used racial slurs as well as reprimands and scolding. Racism can lead to higher levels of mistrust, unmet care needs, and delays in seeking support. Due to the difficulties in navigating formal mental health services, Black informal carers often rely heavily on community networks and informal support systems to bridge gaps in care and information.

## Clinical implications

This review of the qualitative accounts of Black informal carers identified several key areas that can be used to inform improvements in the access to, offer, delivery and experience of mental health care for those affected by psychosis. With the understanding that mental health literacy has an impact on caregiving, mental health services should consider the development and dissemination of targeted psychoeducational resources. However, the development and provision of psychoeducational materials alone is unlikely to be sufficient for Black racially minoritised communities; effective outreach should involve connecting with communities directly. Rivera et al. (2021) [74] highlighted psychoeducational interventions specifically tailored to individuals within Black racially minoritised communities for stigma reduction were feasible to implement, and acceptable to recipients. Information was readily received when interventions included active collaboration between trusted community figures, such as faith group leaders and local organisations [53, 75]. This approach emphasises the importance of partnerships that resonate with communities to achieve greater engagement levels and increased satisfaction with the support provided [76].

The development of a racially and culturally informed and competent approach to support of informal carers in psychosis from Black racially minoritised backgrounds was indicated. A racially and culturally tailored approach would help address unmet sociocultural needs and expressed dissatisfaction reported by Black informal carers. Adaptations will be varied but likely to include consideration of language, culture-specific belief systems, the context and delivery of services, and integration of cultural practices [77–79]. The integration of culturally tailored training for professionals to better support Black informal carers would also address specific cultural beliefs and practices that influence caregiving and help-seeking behaviours. Edge et al.'s (2016) [80] feasibility study protocol of implementation and acceptability of a Culturally-adapted Family Intervention (CaFI) for Black racially minoritised individuals diagnosed with schizophrenia and their families addresses the disparities in engagement and clinical outcomes through culturally relevant approaches. The feasibility study highlights potential for improved communication with clinicians with prospects for earlier access to care and reduced costs associated with longer inpatient stays. While Edge et al.'s study primarily focuses on the feasibility and acceptability, findings from Webster et al. (2023) [81] evidenced culturally tailored services for Black and South Asian carers of dementia improved outcomes as well as long-term economic benefits and cost effectiveness. These studies highlight the rationale for further research, development and implementation of culturally relevant interventions for Black informal carers of psychosis.

### Limitations

This review has some key limitations. Firstly, several of the studies included in the review had modest sample sizes, which may limit the representativeness and generalisability of their findings to the broader population of Black informal carers. This is important as Black individuals represent diverse ethnic and cultural backgrounds, globally, and not a homogenous group. The conclusions drawn from the limited samples may lack the depth required to make meaningful declarations about the experiences of Black informal carers.

Secondly, reviewed studies varied in their categories of reporting race and ethnicity. While some studies included differences in ethnicity (i.e. Black Caribbean, Black African) others did not. Furthermore, studies that did have ethnic classifications failed to report differences in their lived experiences. Similarly, many studies did not distinguish between ethnicity and culture in their findings. For instance, 'black magic' is a cultural and religious phenomenon rather than that of ethnicity. The inconsistent approach invariably limits the ability to capture the nuances and diversity of experiences within Black communities and draw comparisons.

Thirdly, the CASP appraisal tool [34] found eight of the eleven included studies demonstrated some risks in the CASP evaluation. There were notable shortcomings in addressing the relationship between researchers and participants, as well as addressing any consideration of ethical issues. These limitations suggest insufficient reflexivity. Future research should prioritise these aspects by fostering reflexive practices to enhance the quality and validity of studies.

A key consideration for any study investigating the experiences of informal carers is that many individuals may not recognise themselves as carers. This is particularly relevant within Black communities who may view their relationship as spousal or kinship support as opposed to carer support [28]. Therefore, it is possible many informal carers may not be captured in carer-based research for this reason and therefore caution is required in any conclusions drawn.

## Conclusions

This systematic review explored the qualitative accounts of informal carers from Black racially minoritised backgrounds supporting someone with psychosis. The review highlighted several key findings about their experiences and how entwined it is with their culture and ethnicity. Several studies gave prominence to significant gaps in knowledge and information in mental health and access to mental health services, difficulties in navigating mental health service providers, pervasive metal health stigma, and negative interactions with the police. Addressing these issues are vital for the promotion of equitable access and support for Black informal carers. This presents implications for clinical practice around tailored support and delivery for Black informal carers, where their ethnicity is valued and considered.

Future research is needed to extend existing literature on the lived experiences of Black informal carers of someone with psychosis and helpful support interventions. Within clinical practice, there is likely to be merit in the development of racially sensitive support services for informal carers to mitigate stigma and improve trust between Black communities and service providers.

## Supplementary Information

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Supplementary Material 1: This file contains the full search strategy used across all four databases, including Medical Subject Headings (MeSH) search indexing terms, 'free text' search terms, and Boolean operators.

### Author contributions

AK contributed through co-designing the systematic review; co-developing research questions and aims; conducted database searches, title and abstract screening, full text review, data extraction, risk of bias quality assessment; conducted qualitative data synthesis; and preparing an initial draft of manuscript and editing. Angela.Kibia@kcl.ac.uk JL contributed through conducting title and abstract screening, full text review, risk of bias quality assessment, and data extraction. jiarui.3.li@kcl.ac.uk KA contributed through conducting the risk of bias quality assessment. kalya.aung@kcl.ac.uk JO was responsible for overall study conceptualisation including co-designing the systematic review; co-developing research questions and aims; consultation of full text review and risk of bias quality assessment; and editing and revisions of manuscript. juliana.1.onwumere@kcl.ac.uk.

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**Data availability**
No datasets were generated or analysed during the current study.

## Declarations

**Ethics approval and consent to participate**
Not applicable.

**Consent for publication**
Not applicable.

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The authors declare no competing interests.

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