

The PATHFINDER Study:

Exploring Informal Caring Practices And Support Mechanisms For Ethnic Minority Isolated Carers



Why the study was conducted

Across the UK, approximately 5.7 million people provide unpaid care for family members, friends, or neighbours living with long-term illness, disability, or age-related needs. While unpaid caregiving is widespread, significant inequalities exist in access to support, particularly for carers from ethnic minority communities. Carers from Somali and Gypsy and Traveller (GT) communities often face additional barriers when engaging with health and social care services. These barriers include limited awareness of available support, cultural expectations around family caregiving, language barriers, geographic isolation, and a lack of culturally appropriate services.

Despite these challenges, the lived experiences of carers from these communities remain under-represented in research, resulting in services that may not fully reflect their needs or cultural contexts. The PATHFINDER study was developed to address this gap by exploring the experiences of carers from Somali and Gypsy and Traveller communities and identifying ways services could better support them. These groups were specifically selected as they experience a higher rate of caregiver burden, but continue to be underrepresented in caregiver research.

Aims of the study

1. Explore informal caring practices among isolated ethnic minority carers, focusing on Somali and Gypsy and Traveller communities.
2. Investigate barriers to accessing health and social care support.
3. Identify how services could be adapted to become more culturally appropriate and accessible.
4. Facilitate multi-agency workshops with stakeholders to explore factors contributing to low engagement with support services.
5. Develop resources and guidance to support culturally informed approaches to supporting ethnic minority carers.

What we did

We conducted 12 narrative interviews with female carers using a story telling approach (a type of unstructured interview) enabling participants to share their experiences at their own pace. We spoke with:

- **Gypsy and Traveller carers (n=5)** supporting parents, spouses, or relatives with long-term conditions
- **Somali carers (n=7)** supporting parents, disabled children, extended family members, or community members

In addition, two multi-agency co-production workshops were held with health and social care commissioners, service providers, social prescribers, and voluntary and community sector organisations to reflect on the findings and explore ways to improve engagement with services.

Key findings

The study identified several shared themes across both Somali and Gypsy and Traveller (GT) carers.

Care as a cultural expectation

Caring for family members, particularly older relatives, was widely understood as part of the **“circle of life”**. Providing care was seen as a natural responsibility within the family and community.

Gendered caregiving roles

Caregiving responsibilities were largely gendered, with women typically expected to take on the primary caring role within the household.

Stigma and shame around seeking support

Seeking support outside the family may be viewed negatively, as caring for relatives is often seen as a family responsibility and asking for help can be perceived as neglect.

Isolation and emotional strain

Many carers described experiencing social isolation and emotional burden, particularly where caregiving responsibilities were largely managed within the family and where external support networks were limited.



Community-Specific Experiences

THEME	SOMALI CARERS	GYPSY & TRAVELLERS (GT) CARERS
Meaning of caregiving	Caregiving often shaped women's identity and daily lives, particularly when supporting elderly relatives. Some carers described finding meaning and purpose in the role.	Caregiving was viewed as a strong family duty, particularly for women, with expectations that relatives care for their own family members.
Experiences of isolation	Mothers caring for children with disabilities sometimes experienced social isolation due to stigma surrounding disability within the community.	Isolation was more often linked to mistrust of external services and a preference to manage care within the family.
Role of culture and religion	Islamic values emphasising compassion, responsibility, and helping others played an important role in shaping caregiving practices and providing emotional support.	Cultural traditions emphasised family loyalty, privacy, and independence, shaping expectations that care should remain within the family.
Barriers to accessing services	Some carers lacked awareness of available services or were unsure about eligibility for support. Cultural and religious considerations also influenced service use.	Mistrust of services, fear of discrimination, and concerns about privacy discouraged engagement with formal care systems.
Conditions for engagement with services	Carers were generally open to support when services demonstrated cultural awareness and respect for religious practices.	Engagement was more likely when professionals demonstrated respect, cultural understanding, and built long-term relationships with GT communities.

Recommendations

The PATHFINDER study highlights the importance of culturally informed and trust-based approaches when supporting carers from marginalised communities. Improving engagement with services requires:

- **Greater cultural awareness and sensitivity** among health and social care professionals.
- **Community-informed service design**, involving carers and community organisations in the development of services.
- **Improved outreach and information** ensuring carers understand what support is available and how to access it.
- **Gender-sensitive care provision** where cultural or religious practices shape caregiving roles.
- **Long-term relationship building** with communities to develop trust and improve engagement with support services.

By centring the voices and experiences of Somali and Gypsy and Traveller carers, the PATHFINDER study provides important insights for developing more equitable, culturally responsive health and social care services.

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