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EXECUTIVE SUMMARY

Carers Trust Wales wanted to listen and further understand experiences of unpaid carers from Black and minority ethnic communities in Wales to identify, raise awareness and highlight solutions to specific challenges and requirements.

After conducting interviews with 23 unpaid carers from Black and minority ethnic communities, the following themes were identified:

• The overarching theme is a ‘lack of fit’ between the support and services available and the needs of unpaid carers from Black and minority ethnic communities.

• There are practical barriers to receiving support. These include:
  • A general lack of awareness of carer rights and services that might be available.
  • Language barriers for some carers and/or the person they care for which hinders access, understanding and opportunities to benefit from any support on offer.
  • A lack of reliable support at home. Care providers would often be late or not arrive at all, leading to more stress than if they had not been allocated in the first place.
  • Inappropriateness of service support. There were often challenges meeting the cultural needs of individuals concerned such as ensuring time was set aside for prayer or meals were made using halal food.
  • A lack of cultural sensitivity on the part of providers. It is not just the more practical elements of providing support that might prove to be a barrier. A lack of understanding of the service provider to the manner in which the family live their lives can lead to misalignment and a breakdown in communication.

• Differing concepts of what constitutes ‘care’. By having a different understanding as what it is to ‘provide care’ in the first place is also likely to produce difficulties in reaching common ground when it comes to organising care provision. In western culture, care can be organised around ‘time’ and ‘tasks’. This often does not resonate with communities who have a more holistic sense of care.

• There are cultural expectations within the local community regarding the carer role. This has an impact on the capacity to seek support. Barriers include:
  • Care as part of ‘family responsibility’. Many tasks associated with care are deemed synonymous with the role of the family and therefore not regarded by the community as ‘additional’ or requiring external support.
  • Community pressure to both undertake care work without complaint, particularly in public. This can make the opportunity and motivation to reach out for additional support challenging.
  • Gendered roles and responsibilities. Whilst an increasing number of males in the family contribute to care tasks, the expectation predominantly lies with females and, as a result, communal reaction to women undertaking care work differs to men.

• Perceptions of what it is to be a carer means that many carers do not access support. Lack of self-identification as a carer is an issue amongst the wider population but this is particularly prevalent amongst unpaid carers from minority ethnic communities.

• This has an impact on the health and well-being of the carer. Many would struggle with both their physical and psychological health rather than access suitable support.
• There are also different perceptions and understandings of illnesses and conditions e.g. dementia and autism. These may be understood as a part of the natural life cycle or behavioural rather than a medical issue. A competing narrative leads to a conflict when it comes to considering an appropriate response.

• There is a general lack of trust in service providers, particularly social services, to offer appropriate support.

• It is felt that there are misplaced assumptions about the carer and their capacity to interact with services which leads to poor communication and decisions made without consultation.

• There are also felt to be assumptions regarding background, availability and willingness of individuals from minority ethnic background to be able to provide care. This means many feel they have little choice to do so, left to undertake care with less support and resources than carers from the wider population.
The Social Services and Well-being (Wales) Act 2014, defines a carer as someone who provides unpaid care to an adult or disabled child. The cared for person may be a family member or a friend, who due to illness, disability, a mental health problem or an addiction cannot cope without their support.

In Wales, it is estimated that there are currently 370,000 carers (ONS 2011), with over 100,000 people providing over 50 hours of unpaid care per week. This is likely be an underestimation. As has been well documented, many potential carers do not necessarily identify themselves as such, despite undertaking many of the duties that tend to constitute a care role (Corden et al. 2010, Hughes N et al. 2013, Carers Trust 2018).

Unpaid carers play a crucial role in supporting others with illness and disability. They are key to underpinning the health and social care system in Wales. It is estimated that unpaid care saves the UK economy £132 billion per year (Carers UK 2019). In Wales this figure stands at £8.1 billion (Welsh Government 2021). Carers come from all ages and backgrounds with a growing percentage from minority ethnic communities.

According to the 2011 Census, there were approximately 600,000 Black and minority ethic carers in England and Wales. In Wales this figure is approximately 9000 (ONS 2011). Overall, this population is younger than the White British population with the majority of carers from ethnic minority backgrounds being of working age, providing unpaid care whilst in employment (Yeandle et al. 2007; Carers UK 2011, Greenwood 2018). Furthermore, many carers from minority communities care for longer hours and are more likely to be struggling financially (Greenwood 2018).

Research has explored experiences and support needs of Black and minority ethnic carers in the UK (Greenwood et al. 2014, Carers UK 2022) but more needs to be known about the situation in Wales. In Wales, with social care devolved, there are some similarities with the rest of the UK but there are also some unique challenges, issues and opportunities worthy of further exploration. For example, Wales has the highest proportion of Carers in the UK. It also has a typically older population and areas of particularly high economic deprivation. Whilst Wales is becoming more diverse, this is not evenly spread across the nation. 15.8% of residents in Cardiff identify as being from a Black, Asian or minority ethnic background whilst in Pembrokeshire for example, this figure is 1.3% (StatsWales 2022).
AIMS AND OBJECTIVES

Carers Trust Wales wanted to listen and further understand experiences of unpaid carers from Black and minority ethnic communities in Wales to identify and raise awareness of specific challenges and requirements¹. It was also crucial to highlight recommendations for service providers, Carers Trust included, and authorities to be able to provide optimum support as needed. The aims and objectives of the project were as follows:

- To understand the experiences of carers of all ages from Black and minority ethnic communities in Wales
- Recommend actions and activities for local authorities, Welsh Government, NHS Wales and the health and social care sector more widely to improve provision for carers from ethnic minorities
- Recommend actions and activities for Carers Trust Wales and other local organisations to support the provision for carers from ethnic minorities

¹It is acknowledged that using the acronym BAMER as a term in isolation is in itself problematic, perpetuating the ‘othering’ of individuals from such communities as well as suggesting all included can be considered a homogenous group. However, on discussion with stakeholders from within such communities, it was explained that it is sometimes necessary to use for functional purposes. Therefore, with this reassurance, the term will be used sporadically in this report for ease of read.
METHODS

Initially, a survey was undertaken with the ambition to explore findings further in follow up interviews. However, a poor response rate led to a change of protocol. The following adjustments were made to increase recruitment:

- After liaising with specialist support workers working in this space, all recruitment documents were translated into the most appropriate languages.

- Key stakeholders who might help with recruitment were identified and contacted for initial meetings to explain the aims of the research. This also helped to gain insights as to how to best recruit and build trust with many stakeholders then willing to personally assist.

- The value of face-to-face recruitment was realised. Carers Trust staff would attend meetings, awareness sessions and spend time staffing information stalls at locations such as GP surgeries in areas where there are a high proportion of carers from minority ethnic communities.

- A small incentive for taking part was introduced. A small hamper was offered to thank those participating which was much appreciated with anecdotal evidence that it played a role in encouraging others to take part.

Whilst the aim was always to produce rich information, the absence of survey data meant interviews gained added significance. In total, 23 in-depth interviews were undertaken. Of these, 16 interviews took place online via Teams or Zoom. Four were face to face, taking place at locations such as a local community centre or cafes; three were undertaken over the telephone. Interviews were recorded where possible with detailed notes taken on the three occasions they were not. All participants spoke English though one carer used a translator for her interview. Interviews lasted for between 34 and 88 minutes with the mean average length being 57 minutes. Interviews were thematically analysed. Analysis commenced after four interviews and ran concurrently alongside data collection, themes emerging from earlier conversations being explored and influencing later interviews. After 20 interviews, it was felt data saturation was being reached with the final three interviews confirming this.

22 of the 23 interviewees were female. Length of caring varied though most interviewees had been doing so for many (10+) years. Many supported more than one person. It could be a somewhat blurred picture, reflective of the fluidity of caring, with participants describing how they are the primary carer for an individual but also support others regularly. The conditions of those cared for varied and included those with autism, dementia and frailty but also rare multi-neurone, life limiting diseases.

Recruitment was diverse with carer ethnicity including those who were Somali, Pakistani, Nigerian and Tanzanian. The ages and circumstances of carers varied considerably. Some carers were 2nd, 3rd or 4th generation immigrants to the UK. Some had lived in the UK for over 50 years whilst others had moved only months earlier. Some carers were in college or university, some worked full or part time and others were not working or had retired. Though all carers were asked to provide information by way of background context, some carers did not provide all demographic details.

2 Despite an initial slow start, the adaptations made to the recruitment process proved successful and gathered so much momentum that we eventually had more volunteers than capacity to interview. Carers who were not interviewed were invited to take part in later stages of the project when it comes to operationalising recommendations and next steps.
LIMITATIONS

Whilst efforts were made to advertise as widely as possible, the most successful method for recruitment was snowball sampling\(^3\) particularly as many carers stated they were comfortable to participate after learning others they knew had done so. This though does mean that there may be some selection bias amongst interviewees.

Recruitment could not produce a representative sample of Black and minority ethnic unpaid carers in Wales. However, this was never the ambition. This is an attempt to give a rich, contextualised narrative, increasing our in-depth understanding of many of the experiences that people from minority ethnic communities face when caring for someone.

Black and minority ethnic groups should not be considered as a homogenous community. Whilst this was already apparent, during interviews there were many differences articulated. There are also multiple differences within communities with varied, individualised views, interpretations and experiences of carer situations. Individuals make meaning based on experiences, interactions and resources available. There are differences in language, education, relationship with religion, cultural and family dynamics. Location is also a significant factor; diversity in Wales is not geographically consistent across the nation and resources available reflect this. As discussed, some interviewees are 3rd or 4th generation immigrants and therefore have different experiences and expectations from their parents and grandparents. These factors, and many more, all have a bearing on the outlook the individual may have on their lives and carer role. The complexity of these nuances must be borne in mind when considering findings as well as when addressing potential opportunities and solutions to challenges identified. This does not render the task impossible. On the contrary, it makes it all the more important to understand why some ‘one size fits all’ strategies may be less effective. Appreciating the diversity between and within groups from the outset is more likely to lead to more considered and thus more successful outcomes.

\(^3\) This is a non-probability sampling technique where existing participants assist to identify and recruit future participants.
FINDINGS

The following section describes experiences of unpaid carers from Black and minority ethnic communities. It highlights some of the barriers faced across all aspects of daily life, with particular emphasis on the capacity to access appropriate support for the carer and the person they care for. Importantly, interviews also explored ideas to identify opportunities which might improve quality of life. These suggestions are also considered here.

The following overarching themes were identified. Many of these issues overlap and caution must be taken not to oversimplify by only considering each in isolation. Whilst it has been necessary to separate here in order to consider in detail, where useful, attempts have been made to show how themes inter-relate and influence each other.

Challenges

• Practical barriers
• Cultural expectations within the community
• Perception of being a carer (or not)
• Assumptions from (and of) support services

PRACTICAL BARRIERS

Awareness

There is a general lack of awareness of potential support available. In addition, many carers explained that it had not occurred to them to seek support. Very few carers had ever had it explained to them what support might be available with some assuming their life circumstances would mean they were ineligible anyway.

CARER A: Because we both worked, we didn’t think we were entitled to anything. No one has ever sat us down to explain anything.

If carers are unaware of what service provision is available, let alone how to access it, they are never going to seek support. There was sometimes a lack of awareness and understanding of the role of service providers such as social services in the first place. Rather than identifying such services as a potential source of support, on the contrary, these services were regarded as a threat, an opportunity to ‘criminalise BAMER communities’ in the words of once carer.

CARER B: I don’t think many even understand social services. They’re only understanding is children are taken away by social services.

This lack of trust will be explored in more depth later but it is clear that oppositional experience or beliefs when it comes to services is likely to hinder access and support. However, it is not simply awareness which is the issue. As one carer states:

CARER C: Not as simple for us Asians or for other Black and minority ethnic people to just go on Google and read something and get what we need to get out of it. It doesn’t work like that.

As further findings will show, awareness of services has to be then mapped onto a range of other practical and cultural experiences and expectations which often means a lack of fit between support available and what is required.
Language

Language is another barrier reported, either for the carer or the person they care for. Whilst most carers interviewed spoke English, many other carers and, particularly older, family members might not. Even carers fluent in English reported having insufficient confidence to be able to fully understand medical jargon or the complexity of the social care system. This is a challenge to many aspects of the carer’s life, especially accessing healthcare appointments. This situation is already likely to be stressful and yet there is additional burden for the carer to act on behalf of both the cared for person and the professional to ensure information is understood.

CARER D: Once before I stayed with my mum for a week in the hospital but they did not appoint an interpreter for us so I was feeling under pressure because I could not understand every single word the doctors were saying. My English is not perfect, but they say its ok you can do it.

A lack of understanding, in addition to respect for health care professionals and therefore not wanting to add burden, means that there was a lack of questions or conversation, potentially leading to misunderstandings when it comes to care needs.

CARER E: There are times when I have clarified things and spoken to my mum in Punjabi, and she will say no it’s not that at all. There is a misinterpretation, and they [health care professionals] think that if a person can say yes and give their name and date of birth then they can speak English and understand what they are saying which is not right.

Whilst language barriers can be challenging, an assumed language barrier on the part of the service provider can also be restricting, a theme picked up in more detail further on. However, it is worth highlighting here that if there is an assumption of a language barrier, between carers and service providers, it is also likely to increase miscommunication.

Lack of reliable support

Many carers who did receive support through paid care workers, often complained of the lack of reliability of service provision. Whilst this is not exclusive to carers from Black and minority ethnic communities, it was such a regular concern that it is worthy of comment here.

CARER F: I can’t do this anymore. I couldn’t sleep worrying if a carer would come.

CARER G: They say they are coming but are late or don’t turn up at all saying they are not well. For me, having something like that, it is not worth having. Unless there is consistency.

CARER H: We say to any carers to come at 10 in the evening to put her to bed. Some come at 5 to put her to bed and if I say no, they force me.

The unreliability of support could potentially do more harm than good with many carers reporting that it would be stressful not knowing whether support would arrive as planned or at all.
Inappropriateness of service support

In addition to the unreliability of care services, interviewees reported that services available were often inappropriate, unable to meet cultural requirements. This was commented on by many interviewees, particularly when discussing respite opportunities.

CARER A: You hear these horror stories, especially as a Muslim woman. Like how would she find everyone else around her not being the same colour, not speaking the same language?

CARER B: (There is) no day centre that meets his cultural needs so that is a responsibility for my mum and so we have to step in. There are no services available that meet the needs. That is huge for us. He wants to be speaking in Somali and doing what he knew as a child...there is nowhere they can go and talk about what is important to them...those services are not available which is really sad and in this day and age, do you think that is acceptable? Personally, I don’t.

CARER E: (discussing respite opportunities) There is no mosque nearby. I am not going to get halal food. They don’t cater for that.

Interviewees often assumed they would lack anything in common with those present, including the staff as well as fellow service users. There is a barrier around cultural expectations in seeking support which will be explored shortly but it was felt if influential individuals in the community came forward first, it was likely to encourage others.

CARER G: What happens with BMEs is that if there are no other BMEs who say look I’m going to be there (they are unlikely to go.) I know at (Support group) sometimes some of them wouldn’t go but then I would say I’m going and then they would come along.

CARER B: A cruel positive is ignorance is bliss. I think my mother (fellow carer for father) would be very sad if she knew all these things was available...but did not meet...her needs.

CARER B: A cruel positive is ignorance is bliss. I think my mother (fellow carer for father) would be very sad if she knew all these things was available...but did not meet...her needs.

If interviewees do not expect services to be appropriate, or have experiences which confirm this, they feel discouraged from reaching out in future. One carer even commented that she purposefully hid advertised support from family members for fear that it will simply raise hopes only for them to be dashed later.

CARER E: (discussing respite opportunities) There is no mosque nearby. I am not going to get halal food. They don’t cater for that.

Cultural sensitivity

Sensitivity of cultural needs was also discussed as a barrier to receiving adequate support. This goes further than appropriateness of services. Cultural sensitivity is about understanding the values and behaviours within certain cultures and recognising practices that people hold in high regard. Whilst these cultural practices can be learned to an extent, it was not felt to be something that had been fully recognised by many support services.

No amount of awareness raising will necessarily increase attendance and access to support if a carer does not feel confident that it is ‘for them’ so having staff with common interests or members of the community willing to help them take the first step would make a big difference.
CARER E: I think services are insensitive to people’s needs

CARER H: I know one person who asks people to leave their shoes outside but they will not. This makes her very upset.

CARER H: Sometimes they come during prayer time but she says not to come at this time.

Whilst the above examples are tangible in terms of behaviours and outcomes, they offer a representation of the ‘lack of fit’ when different cultural practices come into conflict. Recognising these differences, when organising support and carrying out support roles, would improve trust.

Different concepts of considering what constitutes ‘care’

Many carers discussed a different understanding of the concept of what constitutes care and the manner in which it is organised. The westernised use of time and space to organise care was not helpful to many nor was the division of care into tasks to be accomplished. For example, a carer described how the morning routine was an important part of the day for her father but, due to time constraints, was simply a task to be accomplished by paid carers.

CARER B: It is a bit of porridge chucked in the microwave or a little flannel wash. My father doesn’t do that. The reality is we have to treat people how they want to be treated. It’s not us bringing what we want and changing the way they have lived all their lives...why should they have to change the way they have been all their lives?

CARER I: We have to also recognise that if the system is not fit for us then we have to change and how else can we look at it. I know I would not put my dad in respite for 6 weeks to give me a break but...what else can we do?

CARER E: I don’t really think people, services, policies, structures lend themselves to being flexible enough to be able to cope...It’s too big and they don’t want to open a can of worms and delve into it because it’s too hard. It easy to do the tick box things like carers needs assessments but it’s harder to delve into what somebody actually needs as a carer because it is a bit different from the norm.

This misalignment when it comes to concepts of care means that there is again likely to be a lack of common ground where it comes to organising support. As a result, carers felt that they had to offer guidance to paid carers to the extent that it provided little respite; in fact it often meant more work for the unpaid carer with little additional value to the person they care for.

The practical barriers to providing support for carers has been discussed. However, these do not take place in a vacuum and in the next section, community attitudes and expectations regarding care will be explored.
CULTURAL EXPECTATIONS WITHIN THE COMMUNITY

Care as part of ‘family responsibility’

Interviews took place with carers from a variety of communities and backgrounds. However, there were several commonalities and cultural expectations from the community was a theme frequently mentioned. Tasks associated with unpaid care work was often bound up in family responsibility. Members of the family, especially females, were expected to undertake tasks that constitute care work. This was part of their everyday duties. Such is the lack of recognition of caring as a role in its own right, one carer explained:

CARER E: In some languages like Urdu and Punjabi there is no words to translate into what a carer is. The word carer doesn’t manifest itself in the dictionary.

Without a definition, tasks that constitute a care role are not determined as something worthy of specific attention and, by extension, support. Carer E also explained that, not only does this have cultural ramifications, but also practical ones. When adverts offer services to ‘unpaid carers’, many would not recognise themselves as eligible, as much due to the terminology used as self-identification. The carer described this type of misalignment as ‘cultural incompetence’ on the part of service providers and is perhaps another illustration of cultural insensitivity as already discussed.

CARER F: I feel this is my duty, I have to do it. I can’t enjoy myself. I can’t put my responsibility on the back burner and do something for myself which is one of the things that has been instilled in me because of the community, culture and religion as well.

CARER C: If a white person decides to go out and work the social and economic situation is completely different to if an Asian, Pakistani woman decides to go out to work while having children because that is thought to be neglecting, I’m not doing what I am supposed to be doing.

The assumption that providing care is an expected part of life is not in itself necessarily a barrier to accessing support. However, by not recognising the role as ‘different and worthy of support’ it is likely to decrease the chances of doing so. Attitudes may be starting to change and it was felt that the tacit knowledge to care for older relatives was not something recognised so much by younger generations.

CARER H: Some children don’t. My sisters children don’t for example. Her husband is from a different culture. It is the family as well. I don’t know how they’ve been brought up.

In turn, this was potentially creating issues further down the line. There may be assumptions from support services that the family would pick up caring responsibilities as needed, something that will be explored in more depth later, but, without the same expectations, this could either leave a gap in care provision or produce a sense of resentment. In addition, the historical lack of awareness or resistance to accessing services means carers are left without resources to support them; again, there is a ‘lack of fit’.
Community pressure

The stereotype of a close-knit community emerged as a key theme across many interviews. Whilst some participants praised the support this offered, many carers highlighted the additional pressure to subscribe to social norms which added further stress. As part of these expectations, there was an overarching attitude that one does not publicly voice concerns or discuss negative family issues in public. Doing so is considered socially unacceptable. It was often reported that everyone in the community knew each other’s business. This served to reinforce commonly held beliefs and expectations regarding attitudes and behaviour, making any alternatives to these attitudes’ problematic.

CARER I: People do not want to have these conversations for fear they are being judged by others. It is not something that we do.

CARER E: I do think that it’s almost like it’s kind of like shunned. You wouldn’t put someone in a care home and if you did eyebrows would be raised because it’s almost like you are not competent or not responsible as children or as husbands or wives or whatever. It’s almost like you are not accepting that responsibility. It’s almost like testing to see you are not competent enough to care if you did that.

Seeking help was seen as lacking strength; if a carer requests support, they are regarded as incapable of performing their duties. Others within the community feel entitled to pass judgement and participants reported this being something they both perceived and experienced.

CARER I: He had to be in a care home whilst this (adaptations to the family home) was being prepared for him but the amount of people who said ‘why did you put him in a home? We don’t do this.’

CARER A: (Members of our community) usually look after them at home until the end. It was a really difficult conversation. There were a few tears. What are people going to say? In the end we had to disagree and then agree. It wasn’t very nice. It’s still not very nice to be honest.

CARER C: Are you a carer or is that a motherly duty that you should be doing anyway? In Pakistani culture or most south Asian cultures, if you are looking after your ill parents, child, brother or whatever you should be doing that, and people are quite blatantly making a point in front of me about it. They say I can’t believe the government are paying money to parents who are just looking after their children when we are all doing that. Or an even more cruel version is, oh you get paid for it we don’t even get paid for it.

Even carers who may be less concerned about the attitude of their community still recognise the importance of public perception on behalf of the person they care for.

CARER A: They (cared for person) don’t want any finger pointed at them that their family did not do something in the right way.
Even where attitudes are changing, traditional cultural expectations are still prevalent and important, influencing support seeking behaviour.

Some participants associated the relationship of caring and seeking support with interpretations of religious scriptures. Several carers described how their faith helped them to remain humble, increasing their understanding of their place in the wider world, thus helping them to accept their situation. One carer however, felt her religion offered a different, less helpful perspective. When discussing the proposition of organising care:

CARER C: That may be ok and seem sensible in white, western culture but bring it in a Pakistani set up, and even though it is not religious but putting Muslim religion in it as people perceive it, if you are making those decisions, you are not trusting the creator. Your faith is weaker on the creator that is why you are taking the matter into your own hands.

This carer described how she was taught that Allah puts everything in place for a reason. It was not her position to question or seek to change these circumstances and to look to do so, by showing autonomy to influence the situation, is to show a lack of faith. This carer felt this unfair both as a misinterpretation of the Qur’an but also in an emotional sense. It presented a deeper, spiritual dilemma, an additional challenge to reach out for support.

The pressure to conform can be intense with several interviewees reporting that carrying this additional burden led to mental health difficulties.

CARER C: It was really claustrophobic. Holding me really tight.

Health and wellbeing of the carer will be explored in more depth later, but it is worth highlighting that interviewees would report that the pressure to care ‘in the right way’ was often a factor in producing poor health as much as the care work itself.
Gendered roles and responsibilities

Whilst females were often predominantly the primary carer, several participants described males within the family also providing care. However, this was infrequent and the role described differed in terms of duties and duration. It was also acknowledged that expectations differed between males and females. For example, one interviewee explained that whilst her daughter was in hospital, it was expected by others in the community that she be present all the time. Her husband did not have the same pressure. Likewise, when her husband took a break from caring duties, there was no issue but when she did the same, even for a short period, others felt she was neglecting her responsibilities.

CARER C: In that sense our culture can be quite cruel because we don’t give time and space for individuals, especially women. I would not say men are much better off, but a bit more than the woman.

By feeling this additional pressure, it meant that to take any break was often more stressful than any respite it provided so less, if any, breaks were routinely taken.

This section has considered how the wider community perceives caring and the impact this has on the care role and opportunities to seek support. How this maps onto the attitudes of the individual carer themselves will now be considered.

PERCEPTIONS OF BEING A CARER (OR NOT)

Whilst attempts were made to recruit individuals who may not have previously self-identified as carers, those interviewed were people who had largely recognised themselves as such. As discussed, many unpaid carers do not recognise themselves in these terms. Alongside the stigma of reaching out, lack of recognition influences the realisation of the possibility as well as the motivation to seek support.

CARER A: (We) don’t go out and cry for help and look for support.

CARER E: I don’t think anybody can look after their mother better than their own daughter and I don’t think there is anybody who can look after their husband better than their wife.

Even amongst participants in this project, self-identification as a carer was not necessarily something many found an easy concept to initially comprehend. Whilst this is typical within the wider carer population, given the themes already set out, it seems particularly acute amongst Black and minority ethnic communities interviewed.

Health and Wellbeing of Carers

Caring has undeniably taken a toll on many of the individuals concerned with nearly all interviewees discussing how tough it can be. Most spoke of musculoskeletal pain, exhaustion, isolation, anxiety and depression, even if not always using such terminology.

CARER J: A lot of us are sick. A lot of carers are ticking time bombs.
Many carers discussed how they have had to give up work or reduce hours, often due to stress as much as the logistical issues of providing care. Some carers described receiving support for suicidal ideations, such as the pressure they found themselves under. Despite the barriers faced, some carers reported that they had sought help, but the issues discussed previously in terms of access and appropriateness then play a part. One carer explained that she asked services:

CARER F: Would it take me to slit my wrists for you to do something?

There is previous evidence that mental health issues are higher amongst carers from some minority ethnic communities (Manning et al. 2014) than the general population. The issue was certainly apparent here with interviewees citing many of the other themes discussed as influencing factors. Despite the need for support themselves, carers reported frequently hiding issues from friends, family and the person they care for. For some this was because, without support or an alternative plan, they could not comprehend being ill. It simply was not an option.

CARER I: It was so tight. There was no space for anyone to get unwell.

CARER K: You are the carer. You are this foundation for these people. If you go down, who is going to be there for them? It is not easy. It is a huge burden. I am the eldest in my family. You have got to pretend you are strong, but I have had my cries. I have gone in the bathroom and cried my eyes out, washed my face with cold water and come out so it is not easy.

Persistent beliefs regarding social services again played a part as there was a fear that sickness reflected negatively on capacity to cope.

CARER J: If you’re sick the whole house goes down. Also, if you are sick social services steps in and says you are not a fit mother. Got to present yourself as fit and healthy which is itself exhausting.

The emotional toil of caring was also reported to be hidden so the person they care for does not feel they are a burden.

CARER E: I don’t want them to feel they cannot ask me when they need help.

There were concerns that the person cared for would feel guilty but also, in conjunction with community expectations, that they would be embarrassed for the role they have played in the cultural taboo of publicly declaring struggles by seeking support. Many of these factors come together to reduce any support sought. Interviewees
described other carers within their community and the impact care work was having on their health.

**CARER I:** Sometimes people put themselves in situations which are unbearable, they know they are going to get sick, just so they are not seen (in a certain way). Sometimes they make it worse for themselves.

**CARER K:** I see people struggling in the community and then there is no respite. They just have to get on with it.

Many carers recognised the irony and ramifications of not accessing sufficient support. However, barriers such as a lack of awareness and inappropriateness of services and cultural attitudes about both being a carer and seeking support all play a part in perpetuating the issue.

**Awareness and perception of certain conditions and disabilities**

It not only the social construct of ‘carer’ which goes unrecognised amongst some Black and ethnic minority communities. There was also a reported lack of awareness and acceptance of certain medicalised conditions in some communities. For example, one interviewee described the lack of recognition of mental health.

**CARER L:** We don’t even have words for mental health. My head hurts or I’ve hurt my head.

A lack of awareness and corresponding terminology of a condition present significant barriers to accessing support. Participants discussed how some conditions are also understood differently. For example, several respondents reported that whilst the term dementia was used, it was not recognised necessarily as an illness but part of the ageing process.

**CARER A:** I do think there is not enough dementia awareness in our community. They say it’s just old age. They are just getting on a bit.

Placing symptoms of dementia as natural and inevitable influences the perceived appropriate response. Whilst the medical discourse is only one interpretation, some interviewees felt that the alternative, societal response meant the person with dementia was often then ignored and hidden away. The fatalistic assumption that it is just something to be accepted means the person with dementia is less likely to receive external support. This will then also reduce the exposure of the carer to support services.

Attitudes towards some conditions lead to stigma, reducing the chances of seeking support even further. For example, an interviewee from Nigeria whose child has autism, explained how the condition was interpreted as a behavioural issue. This can have ramifications within the family structure. One interviewee reported being told autism was a failure on the part of parents, predominantly the mother, to raise the child correctly. Another described how her family believed it was an issue that could be cured with prayer or exorcism. Carer J described that, such is the feeling of shame, many men are in denial. This has tangible ramifications. For example, a father refused his wife permission to apply for disability living allowance as it would legitimise her view that their child with autism had a disability. This was seen as shameful. The beliefs of the father and the stigma of disability meant he left the family leaving the mother to cope alone. The interviewee explained this was commonplace.
The wider family, as part of the community and sharing these attitudes towards certain conditions led carers to be reticent from seeking support from them. Some carers reported they would not make the family aware that their child has a disability and, in one instance, a carer did even not tell the family that she had a child. There was a sense that it was easier to go without the negative comments and judgement. This also emphasises the strength of stigma and attitudes towards these disabilities which impact on experiences of the carer, providing yet more barriers regarding receiving support.

The picture is increasingly clear that these multiple factors overlap and interact to produce conditions which produce a lack of fit for the carer from minority ethnic communities to access formal and informal support. Much of what has been discussed has been the perspective of carers towards both services that may be available, and the relationship care has with wider cultural expectations and attitudes. The final section will address experiences and perceptions of carers towards support services and the way they are designed and operate.

Carers reported having to be ‘quite pushy’ to receive support, aware that many others would not feel comfortable to do this. Minimal support is not exclusive to carers from minority ethnic communities. The recent COVID–19 pandemic has increased waiting lists and put additional strain on existing support mechanisms (Hatherley et al. 2022, Audit Wales 2022). However, given the additional barriers faced, it was reported to be distressing when attempts were made to access support and it was not forthcoming. Perceived rationale for allocation of resources was also a contributing factor as will be discussed shortly.
Assumptions about language

Part of the reason for the lack of communication was the felt assumption from service providers of the carers capacity to speak English. Earlier, language barriers were discussed as a challenge to accessing services but it was felt that professionals sometimes assumed a poor grasp of English even if this is not the case. Time pressures and perceived difficulty to be able to fully explain diagnosis, prognosis and suitable options meant communication was felt to be poor.

One carer explained that she would purposefully select (or de-select) specific family members to interact with health care professionals based on their accent, feeling those who have a strong foreign accent are potentially not given sufficient information.

Regardless of whether this is an accurate assumption, this limits involvement of carers who may benefit from being involved.

Assumptions when it comes to organising resources

With availability of services in short supply, there was a sense amongst some interviewees that there were misplaced expectations which played a role when service providers allocate resources. Carers felt decisions can be made without consultation often with assumptions regarding cultural expectations that do not stand up to scrutiny. For example, it was reported that staff from social services often assumed there would be a large family available and willing to assist with care because it is part of the culture to do so. This meant that many carers felt compelled to undertake the role, even when it was incompatible with their lives.

The assumptions that support at home will be available reinforces the pressures put upon the family to assist when they may not be able to do so. By then providing care, this reinforces the assumptions and corresponding belief that it was a correct decision to leave it to the family.
Whilst prioritising in itself was understandable, some interviewees felt that stereotypical assumptions regarding available support meant families from other communities, with perceived less support, would often be prioritised. Many interviewees reported having small families with little additional support in the locality. Others described how family members might be working full time and therefore unable to provide assistance. Therefore, whilst the decisions made by social services may be organisational, decisions how to prioritise resources were felt to be misplaced and unfair.

CARER A: Sometimes I feel, and I shouldn’t say this, but because they know Muslim families will rally round, they take a bit of a backward step. They know the person is not on their own. It probably isn’t that but sometimes it feels like that.

CARER L: Not being funny but if you are white and live in a village, they’ve got the community there. Why is there not the same expectation on them and their families?

Limited support from social services may well be a reflection of scarce resources and funds. However, it is the perception of the rationale for such decisions that can be just as problematic and damaging as the decisions and actions themselves. If carers believe decisions are made from stereotyping leading to discrimination, it will reinforce hesitancy to make contact and negativity towards service providers.

CARER G: A friend said you have to be careful with them because they will twist things.

CARER G: They (other carers) feel that if you say that you’re having a hard time, something negative might happen. I think it is best to let them know. They need to hear all sides or how are they able to help you? Maybe people have had a bad experience or maybe it’s an attitude thing.

Lack of trust in Social Services

Experiences, such as those described above, reinforce beliefs that service providers are primarily motivated to police care and punish those unable to fulfil their role satisfactorily.

As already described, this influences experiences such as seeking support and potentially leads to withholding information and a lack of engagement when communicating with statutory services. This reinforces outdated attitudes that those from Black and minority ethnic communities do not want support, preferring to deal with matters within the community.
Having highlighted challenges and barriers when describing experiences of caring, potential opportunities and solutions were also explored with carers. Some ideas were discussed when asked explicitly whilst other emerged as part of the wider discussion. Suggested solutions offered by interviewees are as follows:

1. Reinstate or create community hubs. These can be places where someone can walk in and get everything they need regarding information for carer support services.

2. Awareness raising sessions. Support and service providers should go into the community where many within the target audience reside. Events should be hosted with stalls and information.

3. Those already influential in the community can help educate and raise awareness of both conditions that often carry stigma as well as helping to change attitudes towards seeking support as a carer. It was felt that those already in a position of influence within the community are best placed to provide these messages.

4. Culturally specific support groups should be introduced which would give confidence to carers and the person they care for that the offering was appropriate. Participants commented that they were more likely to go to something if they knew someone already there.

The next section will incorporate these ideas and set out multiple recommendations to support and influence change.

4 Whilst this approach was popular and suggested by several interviewees, it was also commented by some, albeit less, that they would not like to access any support where they are likely to be recognised by others within their community. This only emphasises how issues are complex and responses need to be multi-faceted as well.

RECOMMENDATIONS

The aims of this project were:

- To understand the experiences of carers of all ages from Black and minority ethnic communities in Wales
- Recommend actions and activities for local authorities, Welsh Government, NHS Wales and the health and social care sector more widely to improve provision for carers from ethnic minorities
- Recommend actions and activities for Carers Trust Wales and other local organisations to support the provision for carers from ethnic minorities

Having collected experiences and suggestions from unpaid carers, it is clear that this is a complex issue with multi-faceted, often overlapping issues that present barriers to accessing appropriate support. Therefore, any response needs to reflect this recognising that a ‘one size fits all’ solution is insufficient. The following are recommended actions and activities for Carers Trust, local authorities and the health and the social care sector more widely to consider:

**Carers Trust**

- Support Carers Trust Network Partners to collect ethnicity data as standard and monitor reach in comparison with local population prevalence
- Ensure lessons from successful services reaching carers from minority ethnic communities, funded under Making Carers Count, are captured and shared with the wider Network to encourage roll out

**Carers Trust Wales**

- Facilitate connections between carers organisations, organisations representing people from ethnic minority communities and local statutory partners to encourage the development of services tailored to the needs of unpaid carers from minority ethnic groups
- Raise awareness of findings
Network Partner Organisations

- Consistently capture service users’ demographic data, including ethnicity, and report on reach in comparison with the local population prevalence annually.
- Consider alternative avenues and methods of advertising services and support. This includes identifying a variety of different locations and mediums used by different communities.
- Proactively engage with organisations representing ethnic minority communities locally to partner in services tailored for minority ethnic carers.
- Specific drive to recruit support staff from minority ethnic communities. This will not only encourage a change in attitude and understanding of available support, but also promote services and make them more attractive for others within the community who recognise it as appropriate to their needs.

Local authorities, health boards and Regional Partnership Boards (RPBs)

Awareness raising

- Undertake a targeted and appropriate awareness raising campaign to change perceptions of the role of statutory social services. This includes increasing communication from service providers in terms of support available, entitlements, what can and cannot be expected from providers and clear communication as to how decisions are reached.
- When services are culturally appropriate, ensure this is widely promoted, using appropriate language and terminology, to encourage awareness and take up.
- Work with influential people within communities, such as faith leaders, to raise awareness and promote understanding and acceptance of different disabilities, conditions, the role of the carer and the positive aspects of seeking support.

Communication

- Offer information in a variety of different languages during routine communications. In advance of meetings and appointments, make sure necessary translation services are available and allow sufficient time and space for information to be understood.

Planning

- Ensure a person-centred approach to the organisation of service provision and support. Where possible, be flexible and innovative to different patterns of care that best suit the needs of both the individual in need of care and the person who cares for them.
- In commissioning services, ensure they include meeting the needs of minority groups.
- Consider a central point, accessible at the heart of the community, to provide all information regarding unpaid care.

Welsh Government

- Ensure findings are considered by working groups delivering the Welsh Government Anti-racist Wales action plan and strategy for unpaid carers.
CONCLUSION

This project has highlighted the experiences of unpaid carers from Black and ethnic minority communities in Wales, particularly regarding accessing appropriate services and support. Some of the experiences share many of the challenges of the wider care population. However, many of the barriers are exacerbated, and others unique due to practical issues, cultural assumptions and attitudes towards caring and disability. This is compounded by a sometimes strained relationship with the services that are designed to give support. As one carer states:

**CARER J:** Unpaid carers from ethnic minorities are islands in their own right.

Some challenges seem to be particularly problematic within certain communities and not in others. This highlights the complexity and multifaceted nature of the issues and how the practicalities of care interact with culture, language and personal experiences.

The use of in-depth interviews in order to gain a detailed, rich narrative has allowed underpinning attitudes and concepts to emerge through thorough exploration. There is often reported to be a ‘poor fit’ when it comes to service provision for many in the wider carer population. This report highlights that whilst this may be the case, for many carers from Black and minority ethnic communities, it might be better to describe the situation as ‘no fit’.

This project gives evidence as to why previous, more generalised, solutions have not necessarily had the desired impact. This is not a simple, singular issue to address, and potential solutions need to reflect this. The recommendations are multiple, designed to target different aspects and agencies of the care landscape, reflecting the need for changes at a policy, system, organisational level as well as influencing the everyday, micro-interactions that form understanding, attitudes and behaviours.

Many of the barriers are not exclusive to caring. There are systemic issues regarding attitudes towards Black and minority ethnic communities, feelings of being marginalised which are re-enforced from everyday interactions, assumptions made of the individual as well as issues regarding infrastructure and even legal ramifications preventing participation in wider society. Whilst it is impossible for one agency or sector to address all these concerns successfully, if unpaid carer support services can take responsibility for their space, it has the potential to make significant improvements to the quality of life of carers who provide such a vital part of the health and social care agenda.
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