

Future Research Directions for Unpaid Caring in Wales



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Contents

Key points summary	3
Introduction	4
About this report	5
Reviewing the literature	6
Identification	6
Carer Assessments	7
Pathways through Support	8
Unpaid Carers from Minority Ethnic Groups	8
References	10
Appendix: Literature search on Social Care Online database	12

Key Points Summary

Identification

What we know:

- Unpaid carers often do not ask for help as early as would be beneficial
- Many unpaid carers are unaware of what support services might be available and what their rights and entitlements are
- Assuming the identity of a carer can be a slow process – many to whom the term ‘unpaid carer’ could be accurately applied would not use it to describe themselves

What we need to find out:

- What strategies for the identification of unpaid carers by health and social care agencies might work best? How and where can these be applied?

Carer assessments

What we know:

- Carer assessments by local authorities can be the gateway to welcome help and support
- Social workers may combine the assessment of the carer’s needs with that of the person cared-for
- Many unpaid carers express dissatisfaction with the conduct and outcome of their carer assessment

What we need to find out:

- How are the social services departments of the 22 local authorities in Wales assessing and responding to unpaid carers’ needs under the Social Services and Well-being (Wales) Act 2014? How can best practise be identified and disseminated?

Pathways through Support

What we know:

- Unpaid carers often find it difficult and frustrating to access services
- Unpaid carers struggle to obtain relevant information
- The needs of unpaid carers change and evolve over time

What we need to find out:

- What advice and assistance do unpaid carers receive from local authorities from the moment of their identification onwards? What is the impact of services they receive on their desired outcomes?

Carers from Minority Ethnic Communities

What we know:

- Unpaid carers from minority ethnic communities face additional barriers in accessing services
- Unpaid carers from minority ethnic communities are more likely to face financial hardship and to undertake higher amounts of hours of caring
- Understanding of illness and caring are framed by culture

What we need to find out:

- How can culturally sensitive services be developed to support unpaid carers in minority ethnic communities?



Introduction

This report follows on from the qualitative research commissioned by Public Health Wales and carried out by Cardiff University in 2021 on the experiences of unpaid carers during the COVID-19 pandemic (see Burrows et al., 2021: *Voices of Carers during the COVID-19 Pandemic: Messages for the future of unpaid caring in Wales*). In preparation, a one-off consultation workshop event was undertaken online with unpaid carers and representatives from Carers Wales, Carers Trust Wales, the Older People's Commissioner's Office for Wales, Social Care Wales, Public Health Wales and the Welsh Government. The workshop sought feedback from participants on the findings and recommendations of the report and explored their views on future priorities in research into unpaid caring.

Following that consultation and further reviewing of the literature, we have identified four key priority areas for future research development. In doing so, we note that there is ongoing valuable survey work conducted by Carers UK (e.g. Carers UK, 2021), Carers Wales (e.g. Carers Wales, 2020) and Carers Trust (work in progress) on the general experiences and perspectives of unpaid carers, and that Public Health Wales, in partnership with Swansea University, have been investigating the education engagement gap for young carers and the determinants of unpaid carers' mental well-being (see Huang et al., 2021a and 2021b). Further, Public Health Wales' recent creation of an e-cohort and innovative data linkage techniques will allow the ongoing capture of quantitative data on the health and well-being

trajectories of unpaid carers (Huang, Song and Davies, 2021). This report seeks to identify research work to supplement what has been accomplished so far, to identify ways to improve the health and well-being of unpaid carers.

The recommended areas for future research focus especially on the provision and delivery of services that provide direct support for carers. While carers' experiences and views are relatively well documented, a recurring theme is frustration with the services provided (see e.g. Carers UK 2019; Carer Wales 2020; Carers UK 2021; Burrows et al., 2021). We therefore outline an agenda for research to examine the interactions between services and unpaid carers, exploring the identification of unpaid carers by statutory services; the assessment of carers' needs by local authorities; and carers' pathways through support. Further, we note that unpaid carers from minority ethnic groups experience particular challenges and outline a participatory approach that will de-centre Eurocentric perspectives and facilitate meaningful partnerships between services and communities through research.



About this report

Stakeholders were invited to attend a single online workshop. Representatives of the following organisations were able to attend:

- Social Care Wales
- The Older People's Commissioner's office for Wales
- Carers Wales
- Carers Trust Wales
- Welsh Government policy division
- Public Health Wales

Additionally, some unpaid carers participated. The workshop broke into two smaller roundtable discussions, which were followed by whole group feedback. After an icebreaking exercise, questions for the first roundtable discussion were:

- What particularly resonated with you or interested you from the research findings presented?
- Did anything surprise you?
- In the light of the findings presented today, and your own experience, what policy developments do you think will be particularly important in the near future?

Following a plenary discussion, the second roundtable discussion asked participants to consider:

- What is not being said about unpaid carers and caring that policy makers, service providers and the public need to know about? (What is being overlooked?)
- Are there forms of unpaid caring, or categories of unpaid carers, that are not being talked about?

- Who needs to know more about unpaid caring, and what type of information do they need?
- What kind of research might help? Can we identify specific research questions?

A final plenary discussion ensued, in which the general discussions were summarised, and facilitators sought general agreement on key issues for future research. Four key areas for further research were identified:

- Carer identification – There was a consensus that unpaid carers often do not receive the services they need in a timely fashion. There is a need to explore how health and social care agencies identify carers and where the opportunities might lie for improving early recognition and support.
- Carer Assessments – Discussions in the workshop noted continuing frustration around the delivery of services to carers by local authorities. There is a need to explore in depth how the provisions of the Social Services and Well-being (Wales) Act 2014 are being implemented in practice.
- Carer pathways – The workshop noted that lack of data collection and collation results in limited knowledge of how services provided to carers meet their identified needs and desired outcomes.
- Carers from minority ethnic communities – There was broad agreement in the workshop that carers from minority ethnic communities face additional challenges, which are not well understood. Carers Trust Wales are currently conducting research in this area, and the research proposed below would build on this.

Reviewing the literature

Following identification of the key themes through the workshop, a rapid search for literature was undertaken using the Social Care Online research database to explore what research has been conducted in the last five years. We scanned titles and abstracts to establish whether our proposed research outlines in each topic area would replicate studies already undertaken (see appendix). We emphasise that our approach would not match the rigour or thoroughness of a systematic review or even a full rapid review – rather, we have been seeking to determine whether the research projects we suggest have already been addressed in recent publications. We are confident that the suggested projects would contribute new and much-needed knowledge around the provision of support to unpaid carers in Wales.

Identification

Identifying unpaid carers to ensure that appropriate provision is made available to them is a substantial challenge for agencies across the social care, health and third sectors. This challenge originates from several linked but distinct issues: first, that many people caring for family members perceive the caring that they do to be a natural aspect or extension of their existing personal relationship, rather than as a specific role that may require external recognition and support (Carduff et al., 2014). This may lead them not to recognise that they fall into the category of unpaid carer. Second, that cultural, gender or personal barriers may exist that cause carers to reject the title ‘carer’: within some cultural traditions and social locations, even the most extensive caring can be perceived as a normal and expected role in a family, particularly for women. This leads unpaid carers to be reluctant to assume a title that suggests they are taking on duties above and beyond what is normally expected in society (Eifert et al., 2015; Molyneaux et al., 2011). Third, unpaid carers may experience peaks and troughs in the amount of care they provide, depending on the availability of wider social supports and the condition of the person cared-for, meaning that it can be difficult for both professionals and carers to be certain as to how well they match eligibility criteria for services. Finally, carers may simply not realise that specialist support is available from health and social care services for their caring role due to a lack of awareness,

or may be suspicious of the consequences of accepting such assistance, fearing that the person they care for may be rehomed or that professionals will otherwise interfere in their lives in undesirable ways (Moriarty et al., 2015). Nevertheless, given the extreme strain on well-being and additional life challenges that unpaid carers face, and substantial benefit to society and the economy that unpaid carers offer, it is critical that all those offering ongoing care to family and community members are identified at the earliest point possible to ensure that support structures are in place.

Our research and consultation suggest that there are missed opportunities to identify and support unpaid carers currently unknown to support agencies. Third sector charities supporting carers argue that the primary opportunity often missed appears to be at the point of delivery for health provision, such as at the GP, pharmacy or hospital, either for the person cared-for or the carer themselves (Carers Trust, 2018; Macmillan, 2013). Further potential points of identification include educational institutions, workplaces, community locations such as libraries, leisure centres, religious centres, and community hubs, and online. Where efforts to identify carers are made, they may be applying language that obstructs self-identification by the above groups, using the ‘carer’ term too prominently or not accounting for cultural and language differences.

We propose an action-based research strand that seeks to involve people from the groups above who missed identification for some time at the start of



their caring journey, and third sector organisations (e.g. Carers Wales and Carers Trust) who are experts in understanding the barriers to identification. Identification strategies should be developed with these stakeholders and trialled at the points listed above. This will enable us to understand what strategies are most successful in identifying unpaid carers.

Carer Assessments

Under Section 24 of the Social Services and Well-being (Wales) Act 2014, unpaid carers are entitled to an assessment of their needs by their local authority and their needs should be given equal consideration to that of the person who is being cared for. The assessment should explore not only the carer's ability and willingness to continue to provide care, but also outcomes that the carer wishes to achieve and whether services are required to support them in achieving those outcomes. Within the Code of Practice for the Act (Welsh Government, 2015) considerable flexibility is afforded to local authorities, since it is stipulated that the assessment "should be proportionate to the request and/or the presenting need" (p.8), providing discretion for the local authority over the format and substance of the assessment produced. Further, the Code of Practice endorses carrying out combined assessments of the carer and person cared-for where the local authority considers it appropriate to do so, which means that there is considerable flexibility in how social work practitioners engage with carers, assess their needs and plan services. It is likely, therefore, that the 22 local authorities across Wales have developed diverse ways of assessing carers' needs. It should be borne in mind that the development of assessment practices has occurred within the context of significant reductions in the availability of funds to spend on social care services (Gray and Barford, 2018), meaning that the numbers of practitioners available to carry out assessments are often limited. Lipsky's (1980) theory of street-level bureaucracy indicates that, when under pressure, frontline practitioners are likely to find work-arounds and rules of thumb to make their work as straightforward and easy to process as possible. It is therefore to be anticipated that the nature and quality of carer assessments vary considerably.

Knowledge of the way local authorities have implemented carer assessments and combined assessments under the Act is limited. Carers Wales (2020) found that, even before the pandemic, only ~15% of unpaid carers responding to their survey indicated that they had even received an assessment. A recent evaluation of the Act has found that there is wide variety in the satisfaction expressed by carers who have had an assessment, with some finding their assessment to be an important moment of recognition and a gateway to much-needed services, while others find them disempowering and frustrating (Llewellyn et al., 2022). Our research (Burrows et al, 2021) and subsequent stakeholder consultation indicated that some carers experience considerable frustration when seeking services, finding that their own needs are given little priority and that assessments focus only on the extent to which they can continue to provide care. There is a need to find a way to ensure that the messages from unpaid carers influence practice in local authority social work departments. Templeton et al.'s (2021) recent rapid review of evidence related to unpaid carers' needs assessments highlighted the relative abundance of data related to carers' views and experiences, but there appears to be little in the way of research that captures the practices and perspectives of those who carry out the assessments in Wales under the Act.

We suggest mixed methods research to map the nature, format and quality of carer assessments across the 22 local authorities of Wales, focussing on the practices of social workers. There is a need to understand the decision-making processes of social workers around approaching the assessment of unpaid carers and what social workers' expectations are of the possible benefits of completing a carer assessment. Further, there is a need for qualitative interviews and focus groups with social workers to explore their understanding of unpaid carers' perspectives and needs, to help identify existing strengths and barriers for good practice in working with carers. It may be possible through this work to construct a typology of social work approaches to assessing and planning support for unpaid carers. This should be completed alongside surveys with carers who have received either a carer or combined assessment to measure their satisfaction with the process and outcomes. This has the potential to help identify good practice if a correlation should emerge between particular local authority approaches and carer satisfaction.

Pathways Through Support

One of the primary challenges for unpaid carers identified through our research and consultation was a sense of confusion and disappointment regarding the outcomes of assessments and the subsequent support that was offered. There was often a disjuncture between the expectations of carers and the provision that emerged subsequently. According to our own and other studies, carers frequently report expressing specific needs that were not met, leading to a disillusionment with organisations offering support (Burrows et al., 2021; Dunne and Rogers, 2013; Ridley et al., 2010). In our research, this was compounded by a lack of individual accountability for decisions made by organisations regarding support provision, so that carers were unsure whom to speak to or seek assistance from. Further, the processes for accessing support where it is available for specific needs are often extremely tiresome and confusing for carers due to a lack of clear information and guidance, or perceived professional unhelpfulness in arranging support (Arksey and Hirst, 2005; Giebel et al., 2021; Greenwood and Smith, 2015). In our research, some reported that the constant negotiation of a 'maze' of phone numbers and email addresses was one of the most exhausting parts of being an unpaid carer, and the thing they would most like to change about their services. Finally, as there are little or no data gathered on carer pathways through support that capture services required relative to services delivered, there is little information available to understand the outcomes of current provision (Spiers et al., 2021). These concerns were echoed within our consultation, and it was agreed by those attending that we need to better understand carer pathways through support to evaluate the efficacy of provision and the degree to which carer needs are being met. There was a concern that many unpaid carers, despite being identified as such, are 'falling through the gaps' of provision due to the above factors, with subsequent detrimental effects on their health and well-being, as well as that of the person for whom they care.

A research strand assessing and improving current data collection regarding carer pathways through provision would be valuable in addressing the above issues. This research should seek to understand what carer needs are at the point of assessment, and how these evolve throughout their caring journey, whilst capturing: what services were delivered to address these needs;

which organisations provided these services; what needs were unable to be met and the reasons for this; whether, as carers' needs changed over time, services were responsive to this with refreshed assessments and adapted provision; and carer response to services offered and their ongoing well-being. Challenges to capturing routine data on people accessing social services within local authorities are well known (primarily lack of resource and time), however a research project involving a handful of local authorities funded to capture these additional data could lead to generalisable insights that could inform the improvement of carer services across Wales without the need for full-scale national data capture.

Unpaid Carers from Minority Ethnic Groups

When undertaking our study into the experiences of unpaid carers during the pandemic, we found that we under-recruited participants from minority ethnic backgrounds. Due to lockdown restrictions at the time of data collection (January – April 2021) we relied on promoting the research through social media online, and through contacts in organisations that work directly with carers, including local carer centres, Carers Wales, Carers Trust Wales and Alzheimers UK. While we acknowledge that we may have had more success had we been able to have a physical presence in geographical locations in which minority ethnic communities are concentrated, our difficulties with recruiting respondents from such communities constitute a reminder that unpaid carers from minority ethnic backgrounds are less likely than white carers to access services (Greenwood, 2018). Previous research suggests that unpaid carers from minority communities are more likely to be struggling financially and that they do more hours of unpaid caring per week (NHS Information Centre, 2010). This means that there is a need for specialised services for unpaid carers to be available for people within minority ethnic communities. However, cultural differences and misunderstandings, stereotyping and language barriers all create additional difficulties for access to services, resulting in further disadvantages (Greenwood et al., 2015). In Wales, the evaluation of the impact of the Social Services and Well-being (Wales) Act 2014 indicates that unpaid carers from minority ethnic communities tend to feel let down by their local authority social services, articulating feelings of lacking

a voice and concerns about racism in the allocation and delivery of services (Llewellyn, 2022).

Alongside issues with insensitive delivery of services for minority ethnic communities, there can also be challenges for people from minority ethnic communities to seek help, whether due to cultural differences in knowledge and beliefs around health and care, or due to a lack of trust in whatever services are available (Duran-Kiraç et al., 2022). It is important to be aware that phenomena that are described through the idioms of Western medicine may have widely different meanings and explanations in other cultures. For example, symptoms commonly understood in Wales to constitute dementia might be understood within African-Caribbean families as a more benign symptom of the ageing process (Berwald et al., 2016; Parveen et al., 2017) or within Chinese families as a spiritual malady (Low et al., 2010). Meeting the needs of unpaid carers from minority ethnic backgrounds necessarily involves attempting to understand their experiences through their perspectives and interpretations. There is, therefore, a need for research into the needs and experiences of unpaid carers from minority ethnic communities in Wales that is designed and framed within their cultural norms and understandings. It is essential that such research should not treat ethnic minority status as a homogenous category, but instead should

seek to understand the plurality of perspectives and experiences across the diverse range of cultures that make up contemporary Wales.

We would propose an initiative to engage multiple minority ethnic communities in framing, designing and conducting their own research in partnership with local services, to foster a shared understanding of their lived experiences of needing and giving care, and of receiving services. In doing so, it will be necessary to decentre Eurocentric knowledge and assumptions, in order to gain culturally appropriate and contextualised insights. This participatory work should involve the properly resourced engagement of local community representatives outside of identified carer support groups to reach people who may not have self-identified as carers already. We anticipate that this work would build upon and complement work currently underway led by Carers Trust Wales. In proposing this research, we recognise that targeting specialised support services at specific communities may not be appropriate in all situations, since unpaid carers in some communities might be put off accessing localised services for fear of meeting people they know, due to issues of stigma around illness, disability and receiving services. This is further illustration of the importance of research that centres the perspectives of the communities and individuals for which services may be developed.



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Appendix: Literature search on Social Care Online database

Topic	Search terms	Titles reviewed
Carer identification	<ul style="list-style-type: none"> • Carer [<ul style="list-style-type: none"> - AllFields:'carer' - OR AllFields:'caregiver' - OR AllFields:"care giver"] AND • Identification [<ul style="list-style-type: none"> - AllFields:'identification' - OR AllFields:'recognition' - OR AllFields:"first contact"] 	175
Carer Assessments	<ul style="list-style-type: none"> • Carer May 2022 [<ul style="list-style-type: none"> - AllFields:"unpaid carer" - OR AllFields:"informal carer" - OR AllFields:"family carer" - OR AllFields:'caregiver'] AND • Assessment [<ul style="list-style-type: none"> - AllFields:'assessment'] AND • Wales 2 [<ul style="list-style-type: none"> - AllFields:'Wales' - OR AllFields:'Welsh' - OR AllFields:"Social Services and Well-being Wales Act 2014"] 	70
Carer Pathways	<ul style="list-style-type: none"> • Carer May 2022 [<ul style="list-style-type: none"> - AllFields:"unpaid carer" - OR AllFields:"informal carer" - OR AllFields:"family carer" - OR AllFields:'caregiver'] AND • Pathways [<ul style="list-style-type: none"> - AllFields:'pathways' - OR AllFields:'outcomes'] AND • Support 2 [<ul style="list-style-type: none"> - AllFields:'support' - OR AllFields:'service' - OR AllFields:'intervention'] AND • UK [<ul style="list-style-type: none"> - AllFields:'UK' - OR AllFields:'Wales'] 	36

<p>Carers from minority ethnic communities</p>	<ul style="list-style-type: none"> • Carers [<ul style="list-style-type: none"> - AllFields:“carer” - OR AllFields:‘caregiver’] <p>AND</p> <ul style="list-style-type: none"> • Ethnicity [<ul style="list-style-type: none"> - AllFields:‘ethnic’ - OR AllFields:‘BAME’ - OR AllFields:‘BME’ - OR AllFields:‘minority’] 	<p>187</p>
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