Cyflwynwyd yr ymateb i ymgynghoriad y Pwyllgor Iechyd a Gofal Cymdeithasol ar Gwella mynediad at gymorth i ofalwyr di-dâl

This response was submitted to the Health and Social Care Committee consultation on Improving access to support for unpaid carers.

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Creu model hunaniaeth gofalwyr di- dâl ar sail eu profiadau byw

Constructing a carer identity model based on the living experience of unpaid carers.

Summary

Mae'r erthygl hon yn archwilio elfennau o hunaniaeth gofalwyr di- dâl er mwyn creu adnodd i adnabod eu hanghenion. Ystyrir canfyddiadau'r gwaith o ran mabwysiadu neu wrthod hunan-adnabod fel gofalwr, rhesymau dros ofalu a'r newid yn y berthynas gofal a'r effeithiau a ddilyn ar batrwm bywyd, iechyd a lles y gofalwr. Tynnir yr elfennau ynghyd i greu model sydd yn amlygu agweddau amrywiol o roi gofal. Mae'r model yn cydnabod natur perthynol a deuol (diadic) gweithgareddau gofal a sut y mae profiadau gofalwyr yn rai hylifol. Cyflwynir teipoleg chwe math gwahanol o ofalwr: gofalwr annibynnol; gofalwr achlysurol 'galw heibio;' gofalwr cyson; gofalwr wedi ei drochi; gofalwr wedi difreinio a gofalwr colledig cudd. Gwneir argymhellion ar gyfer ymchwil pellach ac ymarfer.

This article explores elements of the identity of unpaid carers to create a resource to identify their needs. Work findings are considered regarding the adoption or refusal of self-identification as a carer, reasons for caring and the change in the care relationship and the effects that follow on the pattern of the carer's life, health, and wellbeing. The elements are pulled together to create a model that highlights various aspects of caregiving. The model recognises the relational and dual (dyadic) nature of care activities and how carers' experiences are fluid. The typology of six different types of carers is presented: independent carer; occasional 'drop-in' carer; constant carer; an immersed carer; disenfranchised carer and hidden lost carer. Recommendations are made for further research and practice.

Keywords

Unpaid carers, Identity, Caregiving, Policy, Support, Relationships, Family, Gender.

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I would like to sincerely thank those who shared their living experiences with us. Their voices have inspired us on to look for ways to put our understanding into action and developing the model.

1. Introduction

Self-identification as a Carer

A carer is an individual who provides care outside of employment and without having had any relevant professional education (Larkin, Henwood and Milne, 2018). Providing care, especially intense care, is often rooted in dual (dyadic) long-term relationships with over a quarter (26%) of all carers caring for a spouse or a partner (Larkin and Milne, 2014). In this group, more than half (52%) provide care for their parents or parents-in-law and 13% provide care for their son or daughter (Larkin and Milne, 2014). Most carers are female and aged over fifty, a quarter are aged 65 and over and around 2% are young people (Becker and Becker, 2008).

It is estimated that 12 per cent of the population of Wales are carers, and this figure could increase to 16 per cent by 2037 (Welsh Government, 2021). By 2037, it is predicted that there will be 9 million carers across the UK (Buckner and Yeandle, 2011) and the demand for care from partners and adult children in England and Wales is likely to almost double over the next twenty years (White, 2013).

Key tasks carried out by carers include preparing meals, shopping, cleaning, washing clothes as well as administering medication, and personal care tasks (such as bathing and dressing). Carers offer social and emotional support, keep an eye on the person they are caring for, take them out and arrange professional care (Larkin and Milne, 2014).

Examples of long-term conditions that place particular demands on carers are dementia (including Alzheimer's disease) and diabetes (Larkin, 2012). Caregiving and care also 'evolve over time', changing during the care 'journey' and due to broader factors. One example is changes in the care setting for people with long-term conditions, from care in hospitals and care homes to care in the community. This has significantly increased the demand on family carers as they are expected to carry out tasks that are equivalent to semi-nursing activities; They are also expected to care more intensively and for more significant periods of time (Larkin and Milne, 2014).

Many carers note that caregiving has a negative and lasting impact on their physical and mental health (Carers UK, 2019, Welsh Government 2021).
Carers living in rural areas provide more care than carers living in towns and find it more difficult to get formal support (Crouch, Probst and Bennett, 2017). Health status among rural carers is significantly weaker than the general population but so far, there is no strong evidence that it is worse than the health of other carers (Carroll et al 2019). Higher levels of anxiety and distress were found among those caring for individuals living with dementia compared to the general population with possible consequences in terms of developing illness and long-term conditions themselves (Vedhara et al 1999).

Support for carers became a policy aim for the UK Government with the adoption of a National Strategy for Carers (1999). There were similar developments in Wales and Scotland (Welsh Government, 2000, Scottish Government, 2010).

In 2014, the Care Act (Her Majesty's Government, 2014) was passed, which gave all carers the right to have their needs assessed. Where it was deemed that carers did not meet the criteria, a right was established for carers to receive support to meet their needs from the local authority. In 2018, the Carers Action Plan 2018-2020 was published, which included the aim of identifying carers, and in particular carers of individuals living with dementia, more effectively (Department of Health and Social Care, 2018).

The first step and the foundation for ensuring support for carers is self-identification - that is, a carer needs to identify themselves to support services and be given an assessment in order to be given support. In England, self-identifying as a carer is the first step in accessing many formal and informal support services. *A Strategy for Unpaid Carers* by the Welsh Government (2021) notes that early identification of unpaid carers is essential in order to ensure suitable support for them and reduce acute problems and the cost of treating those problems.

The Social Services and Well-being (Wales) Act 2014 states that local authorities have a duty to offer a carer needs assessment to those who need support in their caregiving role (or if they are likely to need support in the future). The emphasis on assessment in order to provide timely support has increased with *A Strategy for Unpaid Carers* Welsh Government (2021) emphasizing the economic and well-being case for ensuring early intervention (Welsh Government, 2021). However, in England and Wales, and across European countries, there is increasing evidence that a considerable number of those providing care to an individual do not receive an assessment as carers (Paddison and Crellin, 2022; Ambugo, et al. 2021).

Research by Burrows et al (2021) found the following on the experiences of unpaid carers in Wales:

> People often do not realize that they can be identified as carers until they have taken on significant responsibilities for a long period of time. The feeling of not being able to ask for help, or not expecting help to be given easily, contributes to carers feeling isolated and devalued (Burrows et al 2021 p. 51).

While organizational reasons for not identifying or assessing unpaid carers cannot be ignored, some groups of people who provide care choose not to self-identify as carers. Older carers in particular "fail to self-identify and/or resist contacting services" (Larkin et al. 2022 pp. 4-5). Women are more reluctant to request an assessment of needs or support from services than their male counterparts (Milne and Williams, 2003). Older carers looking after their older spouse tend to resist 'intervention' from 'outsiders' (including services) because they usually do not self-identify as 'carers'. This group feels that accepting a recognized role as carer undermines the 'care contract', which is the basis of a long-term marriage (Milne and Hatzidimitriadou, 2003). Some carers of African descent and other ethnic minorities consider that care is a term that does not reflect their social and cultural norms (Lloyd, 2006) and asking for help can be seen as a failure, as action that undermines family relationships and this can carry a stigma (Seabrooke and Milne, 2004).

Research gaps

An effort was made to synthesize and evaluate the diverse literature on caregiving by Mary Larkin and her colleagues (Larkin, Henwood and Milne, 2018). The authors of the review conclude that although there is considerable information about working carers, young carers, sons and daughters caring for an older parent, and about those caring for individuals living with dementia, much less is known about older carers or those caring for someone with multiple needs. A striking feature of this research is the focus on caregiving as a set of tasks, rather than as an aspect of a relationship between two people that is often a fundamental one, such as the relationship between a parent and child or between two partners. Although the negative health effects of long-term caregiving are well documented, they argue that the links between caregiving and carer outcomes are neither linear nor inevitable and will vary in both depth and nature.

This asymmetry in knowledge about carers appears to reflect a methodological divide (Milne and Larkin, 2014). The authors note that most of the existing evidence derives from policy needs and focuses on describing and quantifying the profile of the carer population; recording the impact and outcomes of cariegiving; and evaluating support for carers (Milne and Larkin, 2014). The value of an intervention will usually be understood in terms of cost-effectiveness in enabling carers to continue caregiving. Milne and Larkin argue that the assessment tools used within that tradition fail to address the complexity of the caregiving role. On the other hand, there is a tradition of research that aims to develop concepts and theories that focus on exploring the lived experiences of carers. Although this theoretical work can identify aspects of support that are valuable to specific groups, it is rarely implemented in a practical way.

Within their more recent work, Larkin and her colleagues propose that the strengths of both research traditions should be combined and that this approach would facilitate the integration of information from a range of sources, encourage the use of mixed methodology, and extend understanding of the practical and emotional nature of caregiving (Larkin, Henwood and Milne, 2018).

The 2021 research study by Burrows et al. recommends the need for health, care and social work workforce to 'develop a model of intervention by social services to be offered as part of a care plan following a carer assessment' (Burrows et al., 2021, p. 66).
Caring is a fluid process. People can move in and out of care and the care they give can vary in intensity during this process. The support offered needs to reflect this. It needs to be responsive, flexible and agile enough to reflect the changing nature of the care provided. No two situations are the same and the support offered must be able to recognise this in its approach (Banks 2022).

Research Objectives

As very little research has examined the process of self-identification as a carer (Funk, 2019, Morgan et al., 2021), I wanted to understand why and how this could be done. I wanted to explore how the caregiving role could change and to recognize the relational nature of that role (Larkin, Henwood and Milne, 2018). Additionally, I wanted to respond to the challenge of Larkin and her colleagues and try to use research to understand the depth and meaning of caregiving on the life experiences of carers to create a practical resource that can be tested and used in practice on a wide scale. Our intention was therefore to create an intervention model, as it was called by Burrows et al. based on their work during the pandemic (Burrows et al., 2022).

Therefore, our objectives were as follows:

- exploring the life experiences and needs of carers,
- understanding and explaining the identity of carers and interpreting the meaning of different caregiving activities and
- disseminating knowledge and understanding of the various experiences of carers over time and introducing suitable resources to support carers' assessment

2. Research Methods and Methodology

In-depth interviews with un paid carers in rural areas in Anglesey and Gwynedd were used over a period of 2 years. Participants were recruited by RhL through a community group in 3 locations, and through an agency that offers "sitting" support with the person who needs care so that the carer can have a break or undertake other tasks. While around half of the participants (7) received support by attending a group, the rest (6) received support at home. In accordance with the grounded theory method, purposeful sampling and theoretical sampling were used to interview people who had specific characteristics that were of interest to us in understanding the experience and creating a theory based on our analysis (Charmaz 2006). The sample included 11 female participants and 2 male participants, their ages ranged from their 50s to their 70s. 7 of the participants were daughters caring for a parent, 4 were wives caring for their husbands and there were 2 husbands caring for their wives. 12 participants were caring for a person living with dementia and one was caring for a person who had had a stroke. The preferred language of 6 participants was Welsh and the preferred language of 7 participants was English. Interviews were conducted in the participant's preferred language, reflecting the important principle of the active offer within social services in Wales (Social Care Wales 2023). [See Table 1].

This research was presented as the principal investigator's (RhL) doctoral study and she was therefore responsible for collecting the data. The research methods were approved by the College of Healthcare and Medical Sciences at Bangor University.

A narrative method was chosen in which the interviewer opens the conversation and then tries to avoid interfering to enable participants to lead the conversation (Wiklund, Lindholm. and Lindström. 2002). This was a suitable method as we wanted to understand the feelings, complex experiences and meaning of caregiving activities. Responding to specific questions could be difficult and painful. I also wanted to understand the meaning of these experiences for the participants and therefore wanted to give them the opportunity to consider and express that without unnecessary interference (Squire et al., 2014).

Table 1: Characteristics of participants and those receiving care

Participant number	**Relationship and age**	**Preferred language**	**Person receiving care**	**Recruitment point**

Carer 1	Daughter, 50s	Welsh	Father, 80s, Dementia	Sitting service.
Carer 2	Daughter, 60s	Welsh	Father, 80s Dementia	Sitting service
Carer 3	Wife, 70s	Welsh	Husband, 80s, Stroke	Sitting service
Carer 4	Daughter, 60s	Welsh	Mother/80s Dementia Disability Physical	Sitting service
Carer 5	Daughter, 40s	English	Mother, 70s, Dementia	Community group
Carer 6	Wife, 70s	English	Husband, 70s, Dementia	Community group
Carer 7	Wife, 60s	English	Late husband, 60s, Physical Disability and Dementia[1].	Community group
Carer 8	Wife, 70s	English	Husband, 70s, Dementia	Community group
Carer 9	Daughter, 40s	English	Father, 60s Dementia	Sitting service
Carer 10	Daughter, 50s	English	Mother, 70s, Dementia	Community group
Carer 11	Husband, 60s	English	Wife, 60s, Parkinson's Disease and Dementia	Community group
Carer 12	Husband, 70s	Welsh	Wife, 70s, Dementia	Community group
Carer 13	Daughter, 60s	Welsh	Late Mother, 60s. Dementia[2]	Sitting service

Analysing the Data and Creating the Model

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[1] Her husband had been deceased for over 5 years

[2] Her mother had been deceased for over 8 years

The data was analysed using grounded theory. Central to this process is the relationship between data collection and analysis and an understanding of the literature, as the researcher or research team identifies concepts and tries to test them through interviews with new participants that may take a new direction. The process continues until no new themes arise (Charmaz, 2006).

In order to allow new elements to emerge and guard against the researchers' assumptions, the first step involved analysing (and coding) the data line by line and sometimes word for word. The codes were compared across interviews several times, obliging the research team to see the material in new ways that were closer to the experiences of the participants. This was joint work, stimulating in-depth discussion and offering new insights into the participants' life experiences (Charmaz 2006). We went on to organize the data according to theme (or focus) across the interviews, keeping in close contact with the data in order to allow change and refine our understanding. Concepts from the literature were used to confirm and deepen our understanding. This process is the basis of our analysis of carers' experiences below. We went on to use concepts from the literature as well as our understanding of the data to create a theory or model of carers' experiences and needs that is described below.

3. Results

Analysis: Exploring the living experiences and needs of carers.

Four themes were identified and developed by analysing the data: adopting a carer's identity, understanding the reasons for caregiving, changes to the carer's lifestyle and the carer's understanding of their own well-being.

Adopting a Carer's Identity

A participant considered it natural and inevitable that they take care of a husband or father as part of a family relationship agreement between them.

Carer 3 explained that her relationship with her husband was one of complete trust and as a result her husband would not allow anyone else to look after him:

> *Wel ia fyswn i ddim yn licio, sa neb arall yn cael gwneud iddo fo chwaith de, teip yma de, ydy o de?..Mae o'n ŵr i mi tydi…Dyna ydio de. Dwi hefo fo ers 54 o flynyddoedd. Felly mai de, a fysa fo ddim yn gadael i neb arall wneud na fysa*?
> (Well yes I wouldn't like it, and he wouldn't let anyone else help him, that's the type of man he is.. He's my husband isn't he...That's how it is. I've been with him for 54 years. So that's how it is, and he wouldn't let anyone else help him would he?)

In this case, the carer refused to adopt the identity of a carer in order to maintain the relationship between the two partners.

Carers experience satisfaction, enjoyment and empowerment when caregiving and there may therefore be health benefits when undertaking caregiving duties (Carroll et al,, 2019). Overall, participants felt that the stress of caring for a partner was alleviated by the closeness of the relationship. A wife who had been caring for her husband for some years said:

> Yes, but you're a part of me aren't you, it's different when it's your own, to when you're listening to other people. I listen to those dementia patients that are really bad, I mean I wouldn't know what to do with them to be honest, but when it's your own husband or your own wife you know what to do. (Carer 8)

Reasons for caregiving

The interviews were peppered with references to mixed feelings towards caregiving: responsibility, duty and guilt were mentioned most. These were reasons for caregiving and gave meaning to caregiving activities at the same time.

According to carer 3:

> *Cyfrifoldeb ydy o fwy de, ag os dwyt ti ddim yn fodlon de, weithia pan dwi'n weld o ar y soffa yn fanna a dwi'n watchio television, Duw, dwi'n fodlon de. Mae o yn fanna de, dwi'n fodlon de.*
> (It's more of a responsibility than anything, and if you're not happy, sometimes when I see him on the sofa there and I'm watching television, well, I'm happy. He's there, and I'm happy.)

As seen above, the feeling of being responsible for a partner can be positive as it gives the carer a status and a purpose. This relationship also aligns with the role of mother and daughter in rural societies similar to Anglesey and Gwynedd (Heenan, 2000, Wenger, 2021).

Others understood their reasons in very different ways. Carer 2 who looked after her father explains:

> *Ond mae o'n gwneud lot o emosiynau yno chdi fel person; mae'n gwneud i chdi deimlo euogrwydd, mae gen ti euogrwydd na fedri di ddim gwario mwy o amser hefo Dad, euogrwydd bod chdi ddim adre dy hun yn gwneud pethau hefo'r gŵr ag euogrwydd wedyn bod fi ddim yn gwario gymaint o amser hefo'r plant a'r wyrion a'r wyresau. Wedyn ti'n teimlo, dwi'n teimlo euogrwydd lot fy hun ag yn poeni am bawb arall, ag 'oh os dwi ddim yna, ydio'n iawn?*
>
> (But it creates a lot of emotions in you as a person; it makes you feel guilty, you feel guilty that you can't spend more time with your Dad, guilty that you're not at home doing things with your husband and then guilty that I don't spend as much time with the children and grandchildren.) (Then you feel, I feel very guilty myself and I worry about everyone else, and 'oh if I'm not there, is he OK?)

There are also implicit expectations of the role of mother and daughter in this quote. With the number of middle-aged carers increasing, middle-aged people are increasingly expected to be carers for their parents and partners (Larkin, Henwood and Milne, 2018). In these cases, the overwhelming majority of carers are female and often the pressure of looking after two generations (and perhaps maintaining a relationship with a partner, as seen above) leads to the carer leaving work early (Larkin, Henwood and Milne, 2018). Female carers are less likely to be in full-time work. They are more likely than men to reduce their working hours, stop working altogether, or pass on opportunities for promotion or training due to their caregiving duties (Burr and Colley, 2019). Women who are carers are also more likely to retire early compared to men (Burr and Colley, 2019).

As might be expected in the case of voluntary activity within a close relationship, there is evidence of carers' emotional effort to understand and accept their role. According to the Carers' UK survey that surveyed 7,500 carers:

> Caregiving can lead to a complex range of conflicting emotions - alongside feelings of love and duty, carers report feeling trapped, hopeless and angry at their situation but then guilty about these feelings (Carers UK, 2014).

Changes to carers' lifestyle

Caregiving has a significant impact on the life patterns of the participants in terms of their work and their other relatives, but also in terms of their social engagement. For example, carer 1 explained that caring for her father affects every aspect of her life:

> *Ond dwi'n teimlo os dwi'n clymu fy hun i lawr i fynd i rywle dwi'n teimlo fatha mod i'n cael fy nhynnu yn ddau, dwi isio bod adre hefo dad, ti'n gwybod be dwi'n feddwl. Os dwi'n comitio fy hun i wneud rhywbeth dwi'n teimlo fod o'n bwysau ag yn gyfrifoldeb arall...*
>
> (But I feel that if I commit to go somewhere I feel like I'm being pulled in two directions, I want to be at home with dad, you know what I mean.) (If I commit to doing something I feel it's a pressure and another responsibility...)

Her commitment - and indeed her desire - was to be with her father. It was her choice to prioritize this over other activities. The other activities and the caregiving are understood as both responsibility and pressure.

Carers' physical and emotional well-being

There were visible effects of providing care over a period. Carer 12 explained:

> Mae hi’n [ei wraig] drwm yndi a dwi wedi blino de, wedi blino ambell i ddiwrnod de. (She [his wife] is heavy isn’t she and I'm tired, tired on some days.) Dwi’n gorfod gwneud llnau a bwyd a bob dim rwan de... Mae’n job galed ond dyna fo, dim physically ond mentally llu de.
>
> (*I have to do the cleaning and the cooking and everything now...It's a hard job but there we are, not physically but mentally.*)

And carer 13 says:

> *...es i’n sâl fy hun wedyn, ath ‘na flynyddoedd fel yne, ond pan es i’n sâl fy hun wedyn roedd yn rhaid i mi gael operation...*
>
> (...I got sick myself then, it went on for years like that, but when I got sick myself then I had to have an operation...)

In the two cases above, and across the sample, sickness and fatigue were accepted as the inevitable result of caregiving. There was no sense that stress and illness could be avoided by seeking support. Receiving respite care when a participant developed cancer was mentioned and it was all organized by the hospital specialist.

A change in the relationship between the carer and the individual being cared for could also affect the carer's well-being. Carer 8 considered her experience of caring for her husband whose character had changed and who could behave aggressively at times:

> It’s tough, tough, rough (tearfully) …so I find it very very difficult, very difficult...Of course the situation as it is differs from day to day; but you’re a part of me aren’t you, it’s different when it’s your own...

As mentioned above, caregiving gives rise to complex feelings that are often in conflict with each other and you may hear an echo of dislike, love and guilt, as well as despair, in these words.

Carer Identity Model

As described above, the purpose of our research was to create a resource to improve carers' assessments and to increase self-identification rates by better understanding carers' living experiences and asking more relevant questions using more suitable concepts. We therefore set out to look at the themes produced through the analysis, and re-examine the data and consider how these patterns were reflected in the literature in order to create a carer identity model typology based on the experiences of unpaid carers.

Independent carer

An independent carer is someone who provides care to another person intermittently when the need arises. This type of caregiving does not disrupt the carer's normal life pattern and as a result they are able to continue working and socialising. However, the awareness of the care relationship can be there constantly. The individuals who provides independent care do not usually see themselves (self-identify) as carers.

For example, carer 1 felt that she was able to continue with her work and personal responsibilities, by calling on her father as needed. She emphasized that taking the responsibility "wasn't a pain". But even though she felt quite independent, that responsibility was at the back of her mind. She went on to describe how she would react immediately if the situation deteriorated:

> *...yndw dwi yne, a tasa rhywbeth yn digwydd dwi yne, ond fedrai ddim stopio dim byd ddigwydd iddo fo ti'n gwybod.*
>
> (...yes I'm there, and if something happens I'm there, but I can't stop it from happening, you know.)

There is also perhaps a suggestion that the participant feels the need to protect her independence from possible expectations as she refers to her inability to protect her father from his condition.

Occasional 'drop in' carer

While an independent carer drops in when necessary or intermittently, an occasional carer has begun to follow a pattern of dropping in regularly. The move from being an independent carer to being an occasional 'drop-in' carer may be one that the individual does not notice and may seem to evolve naturally into a way of life. The overwhelming majority of carers are female (Larkin, Henwood and Milne, 2018). If the individual is a daughter, it is likely that this pattern of dropping in to see a parent will be taken as natural by those around her (Burr and Colley, 2019, Wenger, 2021). In these cases in particular, neither the person providing the care nor those around her would often see this role as that of a carer. However, caregiving can sometimes demand more time and lead to a change in the carer's life pattern, often without them realising.

Carer 5 felt that giving this care was like some kind of informal family agreement that is naturally expected between one generation and the next.

I care for my mother ... who has dementia. Then you just feel that all your spare time is spent running there ... at least when I'm there I can do
things, make sure she's safe, the house is clean and she's clean and she's got everything that she needs in the house. (Carer 5)

Carer 13 explained that in the beginning she 'popped in, dropped in' to check that her mother was okay. She said:

> *...roeddwn i yma, roeddwn i'n agos ati, geographically dwi'n sôn rwan.. roeddwn i'n gallu cadw llygad fela…*
>
> (...I was here, I was close by, geographically I mean, now.. I could keep an eye on her like that...)

Carer 13 explained that it was a "natural" concept for her to "fall into the role" of dropping in and caring for her mother. She emphasized that "*nes i ddim meddwl peidio neud o*" ("I never thought of not doing it"). The belief that it was her duty to take care of her mother was deeply ingrained in her.

Constant carer

A constant carer provides caregiving every day or at specific times during the week. As a result of the increase in the intensity and frequency of caregiving, the person providing care can begin to self-identify in the role. The shift in life pattern or acknowledging the role is not always welcomed, as the individuals providing care have to adjust other aspects of their lives in order to be able to offer constant care.

For some carers, caring for someone constantly changes the fundamental nature of their relationship with that person. By undertaking constant caregiving, we often see a shift from interdependence to dependence, which can be very obvious in the case of two partners. Accepting the identity of a carer was part of understanding that change. The two stages of the change in relationship and becoming a carer were highlighted by carer 13:

> *Oedd roedd o'n amlwg... y berthynas wedi newid sbelan doedd. Achos hi bron iawn oedd y plentyn te a finnau yn gofalu: gofalu am ei dillad hi, gofalu bod hi'n 'molchi yn iawn, gofalu bod hi'n cael bath...Wedyn mi ath y cof, a doedd hi ddim yn gwybod pwy o ni, dwi'm yn meddwl bod hi'n sylweddoli mod i'n ferch iddi, ond odd hi'n gwybod bo fi'n rhywun oedd wedi bod yn bwysig yn ei bywyd hi, fel yna fyswn i yn rhoi o.*
>
> (Yes, it was obvious... the relationship had changed quite a bit, hadn't it? Because she was almost the child and I was taking care of her: taking care of her clothes, making sure she washed properly, making sure she had a bath... Then her memory went, and she didn't know who I was, I don't think she realized that I was her daughter, but she knew that I was someone who had been important in her life, that's how I would put it.)

Carer 11 had been caring for his wife for over ten years he says:
"The biggest thing is boredom, feel like that takes over ... you can start neglecting your health ... Make sure you eat properly and sleep, sleep can be a real problem ... weeks ... on 2 hours a night, because of problems ... you can't sleep properly you just cat nap a lot of the time." (11)

Immersed carer
An immersed carer provides care to the person being cared for, almost 24 hours a day, all year round, without interruption. Immersed care includes completing tasks, offering support and supporting the person being cared for. Immersed carers will almost invariably self-identify as carers.

The transition to being an immersed carer can happen instantaneously due to illness, accident, or it can happen gradually as the burden of caregiving increases due to a long-term or terminal condition. Consequently, becoming an immersed carer means adopting a new reality, which replaces one's former way of life.

Carer 13 described the impact of becoming an immersed carer on her and on her marriage:

> *Ia tair blynedd fues i'n byw hefo hi [ei mam] ...Doedd o ddim yn hawdd, doedd o ddim yn hawdd am y rheswm syml wel... oeddwn i'n cael fy nhynnu dwy ffordd, roedd gen i briodas o ryw fath (chwerthin), roedd trio cadw honno i fynd, ella bod o'n rhywbeth hawdd i ddweud 'oh ia I'm with you through thick and thin 'ella...Ond mi nath o, do mi nath o neud pethau yn galed rhyngwn ni, doedd pethau ddim yn hawdd, ond dyna fo muddled through fysa'r Sais yn ddweud…*
>
> (Yes, I lived with her [her mother] for three years ... It wasn't easy, it wasn't easy for the simple reason, well... I was being pulled in two directions, I had a marriage of a kind (laughs), I was trying to keep that going, maybe it's easy to say 'oh yes I'm with you through thick and thin'...But it did, yes, it made things difficult between us, things weren't easy, but we muddled through...)

The pattern of an immersed carer's day revolves entirely around the person being cared for. Carer 12 explained:

> *dim bywyd ni ydi o, ond bywyd [enw'r wraig], gwneud be mae [enw'r wraig] isio gwneud llu de,.. mae mywyd i wedi newid rŵan.*
>
> (It's not our life, but the life of [wife's name], what does [wife's name] want to do,... my life has changed now).

In the case of immersed carers, their own health can become secondary to maintaining the caregiving arrangements and because of personal and practical reasons in terms of getting help. Carer 13 explained how she timed medical treatment for a serious condition around the availability of respite care for her mother. She recalled the conversation with the hospital specialist:

> 'You need another operation,' [said the doctor]. 'Well can I book my respite in?,' [she asked]. 'Book your respite in, make sure you've got that first, and then come back to me and I'll give you a date within that fortnight'... *Ac fel yna gwnaed yr ail waith, fy op yr ail waith..*
> (And that's how it was done the second time, my op the second time...).

Health status among rural carers is significantly weaker than among the general population (Carroll et al 2019). It is worth considering to what extent this is exacerbated by the lack of palliative services.

Disenfranchised carer

When there is a change in the situation of the person being cared for, the carer can consider returning to paid work, re-engaging in a social life and responding to wider opportunities (Larkin 2009). But they may also miss the caregiving role, especially when it is an implicit part of an important relationship.

A carer is disenfranchised when the tasks and actions of caregiving or the carer's identity are not recognized, acknowledged or supported by society. This can happen due to a change in the situation of the person being cared for, for example going into residential care, nursing or residential treatment in a hospital or through the death of the person being cared for.

Carer 13 continued to feel like a carer when visiting her mother at the nursing home and identified with the work of the staff at the home and became "friends with the girls there". This huge change in role was hard to accept and carer 13 continued to feel like her mother's carer. But she was no longer able to claim self-identification as a carer. Participant 7 described herself as a carer and continued to attend a carers' group even though her partner had died over 5 years earlier.

Despite the recent exposure given to the condition, caring for a person living with dementia is still associated with stigma or shame (Kim et al 2019). Carer 5 (who was also employed as a support worker) described how some carers tried to protect the person being cared for from the stigma of living with dementia by not acknowledging their role as a carer. She says:

> Well, there's stigma to it (dementia) isn't it, ...But if the ones who's got dementia, a lot of people think stigma is attached to it and they don't say anything. So, if they don't say anything it's not happening, is it? It's just protection isn't it.

In order to protect a partner or parent from (supposed) public scrutiny and to protect the self-respect of the individual being cared for, these individuals choose to hide the fact that they are providing care and choose to become disenfranchised carers. For some, there may also be an element of denying the true nature of the situation.

Elements of the disenfranchised carers' experiences are common to those suffering disenfranchised grief (Doka, 1989). Disenfranchised grief can occur when the individual feels that society is denying their need, right, role and eligibility to grieve. As a result, the person who has suffered a bereavement is not allowed to mourn publicly or be supported by society.

Hidden lost carer

Participants saw themselves as the partner, husband, wife or daughter of the person being cared for and accepted caregiving tasks as part of that role. Carer 2 explained that she did not see herself as a carer: "Wel dwi ddim yn cyfri fy hun fel gofalwr achos dad 'da ni'n edrych ar ôl." ("Well I don't count myself as a carer because we're looking after dad."). Being a carer was completely different and conflicted with her and her sister's relationship with their father.

When the relationship between the participant and the person being cared for was a marital one, participants also related caregiving with the family relationship. Carer 11 said: "I don't consider myself a carer, I'm [*his wife's name*]'s husband, that's how I look at it." Caregiving tasks were part of the marital relationship.

Carer 3 explained that caring for her husband was part of the marital contract:

> *y gŵr ydi o de. Da ni wedi priodi do. In…Be ydi o?… In sickness and in health.*

> (he’s my husband, isn’t he. We’re married aren’t we. In… What is it?… In sickness and in health.).

We therefore suggest that it is not only traditional ideas about femininity that account for the idea that self-identification as a carer undermines the family relationship.

Individuals who provide care may choose to minimize their problems by pretending that they are coping for fear of their unity and their relationship being ruined (Morgan et al 2021). In some cases, the individual decides to refuse to self-identify as a carer and adopts 'radical hope', which is the hope that the relationship will continue in the same way as it has in the past.

A hidden lost carer considers tasks that we consider to be caregiving as an extension of the relationship that already existed between them and the individual being cared for. As a result, these individuals do not self-identify as carers - they are hidden - and so it is very likely that they will also be lost in terms of not receiving help from relevant services.

4. Discussion

Caregiving continues to be taken for granted within the family (Wenger, 2021, Burr and Colley, 2019, Burton 2008, Heenan, 2000). Our data suggests that caregiving expectations of middle-aged women who begin caring for their older parents are particularly strong and this is echoed in other rural settings (Wenger, 2021; Heenan, 2000). In research on rural carers, a sense of pride in being able to look after a member of their family is noted (Carroll et al 2019, Gibson et al, 2019). Heenan's work with Northern Irish farmers’ wives goes further, stating that the provision of care is seen as part of a bilateral relationship with an element of repayment for childcare and care as the individual being cared for (usually the mother) grows older. In this group, there was a sense that the term 'carer' was meaningless. The women who were questioned had no intention of asking for official help (Heenan, 2000). Although our participants self-identified to some extent as carers, there was a similar sense that caregiving was natural and part of a lifelong relationship with the person being cared for.

Family members or partners start providing care because they feel that it is natural to do so, because of duty and guilt (Morgan et al., 2021). Others, including older men choose to provide care in order to protect their relationship and protect the privacy of the person cared for, especially in the case of neurological conditions (Larkin, Henwood and Milne, 2022).

Although our sample self-identified as carers to the extent that they attended a community group or received help and support from a "sitting" service, not all the carers considered themselves as carers (Burton 2008). The role was rejected by participants who contrasted it with a marital or family role. This was consistent across the sample, including female and male carers and children and partners providing care.

We developed a carer identity model typology in order to implement our understanding. We have introduced six different types of carer: independent carers, who are just starting to provide care; occasional carers, who are developing a pattern of caregiving; constant carers; immersed carers, who have been immersed to provide intensive care 24 hours a day throughout the year without interruption; disenfranchised carers, who have lost or do not have carer status using Doka's (1989) concept of disenfranchised grief; and hidden lost carers, who choose to refuse to self-identify as carers It is necessary to understand the origin of this last group's opposition to self-identify as a carer in order to encourage more of them to have access to preventive support.

As our sample consists of carers with experience of dementia (except one), and that dementia is a condition that tends to get worse, the model may seem like one where the carer and the person being cared for move inevitably from different types until they reach the condition of the disenfranchised carer as the person being cared for moves to residential care, hospital or dies. However a carer can move between the “types” of the model. It will be important to relate the model to other serious conditions where a cure is possible such as cancer, and to examine the journey of various carers.

5. Implications for policy and practice

The research was partly motivated by the need to understand why individuals do not self-identify as carers and to try to offer ways to identify and support them. However, all the participants had self-identified to some extent. But, as we see from the discussion on hidden lost carers, some participants refused to describe themselves as carers. This study therefore suggests how acts of caregiving should be described in other ways and be proactive in identifying carers at the start of the process.

Implications for policy and practice

The research develops knowledge, understanding and meanings to self-identify as a carer and introduce the complex identity of caregivers. It is suggested that the different types of caregivers are flexible and fluid as individuals who provide care identify with being a particular type of caregiver at different times in their lives. The Carer Identity Model is intended to focus on the importance of assessing the needs, care and support of the individual providing care by offering 'early intervention and prevention work' (Welsh Government 2021: p. 5). The model is intended to prioritise and give equal status to the carer reflecting the main principles of the Social Services and Well-being (Wales) Act 2014.

A Carer Identity Model is presented which builds and develops on existing carer assessment, which is a 'what matters' assessment and working in partnership with carers (Welsh Government 2014). The Welsh Government states:

Nor are [assessments] as effective as they should always be... (Welsh Government 2023: pp. 20–21).

The model aims to carry out an assessment of a carer's best outcomes with a focus on the wishes and feelings of the person giving care. By carrying out the assessment, the caregiver is empowered, and their well-being and resilience maintained. This is an essential element of the assessment because carers' support needs, may be more dependent on their own motivation in the caring situation, than on the stress of managing a caring task (Clemmensen et al. 2021).

The model provides a foundation for unique bespoke assessments for workers in health, care, and social work.

Risk assessment – implementing a preventive care plan.

Recovery and maintenance assessment– implementing a recovery plan and maintaining the well-being of individuals providing care.

Crisis assessment – implementing an intensive care and support plan.

The challenge of reaching out to lost, hidden carers continues. If a carer partially rejects a carer's identity, one strategy is to offer an assessment as a couple of the individual in question and the partner being cared for. (Morgan et al. 2021).

It is recommended to focus on couples as a joint unit of care rather than looking at their needs individually. This coincides with the shift in mindset about relationship-based care that is increasingly being addressed in chronic care and palliative care models (Wadham et al. 2016). A couple assessment will give professionals the opportunity to check that when one partner has access to the care and support system; the care, support and support needs for the other partner as well are assessed (Ewing et al. 2018).

Conducting a couple's assessment, with their consent, would be a way to promote self-preservation strategies as a couple. In addition, the needs of the carer do not slip through the net (Morgan et al., 2021). Presenting an assessment as a couple would avoid having individuals pretend to be coping to avoid disrupting their relationship with their partners (Morgan et al. 2021).

6. Implications for further research

It was important for us to carry out research in a rural, bilingual area as this is the nature of our local community and this is where the main researcher works. We can place experiences within the context of the (relatively limited) research carried out in similar locations (Wenger, 2021, Heenan, 2000) and consider them in the context of research in urban locations and where population changes are very different from the rural areas of Anglesey and Gwynedd. However, comparative research needs to be carried out in other rural areas.

The situation of disenfranchised carers needs to be understood (Larkin, 2009). Where the relationship between the carer and the person being cared for is not recognised, as in the case of some older LGBT couples, it is unlikely that there will be an understanding of the carer's role and needs (Addis et.al, 2009). This would contribute to the Welsh Government's policy objectives expressed in their LGBTQ+ Wales Action Plan (Welsh Government 2023). Particular risk points in terms of defining carers are the access of the person cared for to residential or hospital care or death (Addis et al., 2009; Larkin 2009).

Rates of self-identification as carers are low among ethnic groups in England and Wales (Office for National Statistics (2023, Carers Trust Wales, 2022). This may be due to a decision to be a hidden lost carer for reasons pertaining to the relationship or the cultural context (Lloyd, 2006, Seabrooke and Milne, 2004). However, low rates of self-identification can also result in a lack of awareness of the need for assessments in terms of services and agencies or ineffective assessments. In such cases, the carers would have been disenfranchised. When a patient needs a translator in a health context, it has been reported that patient satisfaction is lower, outcomes in terms of condition management are less favourable and there is a reduction in the numbers attending appointments to manage the condition (Heath, 2023). There is therefore a need to investigate the experiences of carers of individuals living with dementia from ethnic groups including those who need translators. This research should give specific recognition to a cultural understanding of caregiving (Burrows et al., 2022), also recognizing that cultural normality is not experienced in the same way across any community and that experiences will vary.

7. Limitations of the research

A relatively small sample is used here. However, data collection continued until no new themes emerged [theoretical saturation]. In addition, we used a data analysis method that was intensive and suitable for a small sample and that, we believe, was successful in terms of understanding experiences to enable us to generalize somewhat to create the model.

As a high number of carers in the sample had experience of caring for an individual living with dementia, it was inevitable that some common aspects would emerge. The focus on one condition is a strength as it allows us to see any differences in terms of the period of care without the complexity of experiences stemming from other conditions. However, it is a weakness in terms of our understanding of the experience of carers when those being cared for suffer from other conditions. These conditions, such as cancer, can follow a very different pattern and it should be checked whether the model is relevant in these cases.

8. Conclusion

The role of gender and ideas about the nature of the family were considered in terms of creating expectations about caregiving among a group of unpaid carers in rural areas in Anglesey and Gwynedd. A model was proposed that describes 6 typologies of carers' identity based on our work. These include four identities that reflect the frequency and intensity of contact, namely: *independent carers, occasional carers, constant carers, and immersed carers*. These reflect patterns in terms of support needs. They also reflect the likelihood of the carer asking for support through self-identification as a carer. The first, *disenfranchised carers* describes an experience in which the role of the carer is not recognized or acknowledged by society, while the latter i.e. *hidden lost carers* describes the experience and perspective of those who refuse to describe their role as that of a carer. The final identities of the model, i.e. *disenfranchised carers* and *hidden lost carers,* call for more research with specific groups in new settings.

END.

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