Caring as a determinant of health –preliminary findings of a literature review

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Our Context

- In August 2024 Kaz asked people from across Cumberland what they thought were important research questions.
- Joanne proposed we had an issue with hidden carers and care and wondered whether we understood what they needed enough and whether there was enough support for them. Kaz and Elaine both have experience of being carers and agreed it was an important topic – a project was born!
- A first step was consultation with Cumberland Council's Carer forum. They were keen that we did something useful and practical and that we didn't duplicate anything that had already been done.
- Elain secured a small grant from the University of Cumbria's Policy Fund (£2.5K) for a literature review to find out 'the who, what, why, where and when of caring'. This would help us to understand what is currently known about carers internationally as a basis for any future research plans.
- A small but growing team from the University of Cumbria and Cumberland Council led by Elaine were part of the literature review. Our search was for academic research papers linked to 'carers', 'caring', 'care giving' and 'informal carers' 'experiences', 'journeys', 'perceptions', 'stories'.
- We only included research about people providing care in a home setting, we excluded any research during Covid-19 as it was an exceptional period of time, and only looked at papers that were exclusively focussed on carers.
- We looked at any paper published in English from 2016 onwards.
- This search yielded 10,533 papers. This was rather daunting!
- We have reviewed all the abstracts (introductory paragraphs) and found that only 511 papers are actually relevant. This paper summarises what we know from the abstracts alone and comprises a set of very preliminary findings.

Credit for this work goes to the entire reviewing team: Kaz Stuart, Elain Bidmead, Sally Frost, Katie Goodall, Guy Casy, Daniel Gibbons, Peter Kelly, Doug Hope, Lianna Barrie, Kristine Zepa.

Our Starting Point

We found this review by Larkin, Henwood and Milne published in 2016, summarising literature up to 2015. Our literature review picks up from this timepoint onwards adding to what is already known.

This paper concluded that:

- “There is an extensive but fragmented body of knowledge and evidence about carers and caring”.
- “Increasing numbers of carers, and the complexity of their role, has led to growing interest in carer research”.
- Two largely separate research paradigms dominate the field (explorers doing traditional quantitative studies and theorisers doing qualitative research on subjective experiences).

“Existing work reveals significant deficits in information about:

- The profile of carers
- The impact of caring
- Interventions and support”.

Key Findings

Our findings are grouped into the following sections and we presented and discussed each at the Policy Event on the 9th July 2025 with 20 stakeholders from across Cumbria:

- Carer characteristics
- Stages of care
- Care tasks
- Causes for care
- Impact on carers.

Carer Characteristics – who is doing the caring?

Carer characteristics could be summarised by these seven variables:

- Age
- Gender
- Ethnicity
- Socio-economic status
- Social capital
- Rurality
- Cultural norms of family care.

We will analyse how positively or adversely these affect carers when we do the full review.

From your experience, personal and professional – how do you think each of these would affect a person's experience of and ability to provide care?

- Age might be important as being a young carer might impact on school and friendships, whilst being an older carer might impact on work or home circumstances.
- Cumbria has an aging population so age might be the most important factor to consider.
- Working whilst being an adult carer is a real challenge, there are some employer implications in this work.
- Cultural norms might affect whether you have older parents live in, or whether they would be cared for in a home. Specific groups might also be more or less open to help, for example Gypsy Roma Travellers.
- Rurality is a key issue in Cumbria – there might be challenges travelling to support services for the cared for and the carer, and a rural area presents challenges for care service delivery too.
- Gender acts out here too, with daughters being expected to care more than sons.
- Being a carers can be a huge shift of identity, especially if you lose employment as a result.
- In marriage we might pledge 'in sickness and in health', but we can't really imagine what caring for a sick spouse will involve.

Stages of Care

We often think of care as a single activity, but reviewing these abstracts revealed that there are distinct 'stages' of caring. These are not in a chronological or linear order as they may vary so much by condition and by individual.

- Diagnosis
- Management of issue
- Progression of issue
- Hospitalisation/s due to issue
- Care home for period of time
- Palliative care
- Bereavement
- Post-care giving.

Which might be the most challenging and why?

- It would be difficult to manage all the different stakeholders involved in each stage as a carer; GP, NHS< Council, third sector.
- It depends on the illness, the support in place, and the situation of the carer.
- They all flow into one another and all involve a wide range of care tasks.
- These stages might be prolonged by waiting lists.
- There might be a snowball effect of issues building.
- We need to support awareness of the 'issue' alongside formal 'diagnosis'.
- The carer and the person needing care need to manage all these stages.
- Finding the right support for each stage is a challenge and might vary on your economic situation.
- The Council aims to get the right information to the right people at the right time but it is hard to manage it before people reach crisis.

Carer Tasks

The review of abstracts revealed nine different types of tasks that carers delivered to the people they cared for. The type of care task varied by the stage of care and the reason for care being needed. The types of care tasks included:

- Company
- Emotional support
- Personal administration
- Advocacy
- Home care (cleaning, shopping)
- Feeding
- Personal care (washing, dressing)
- Giving medication
- Medical procedures
- Physical movement (lifting).

From your experience, personal and professional – which of these might feel the most challenging to a new carer and why?

- There can be dignity issues with personal care. But you might just have to get on with it. It can be excruciating for the carer and the cared for, or you might not be bothered.
- The ability to pay for support will influence how many of these a carer has to do themselves.
- Advocacy can be really challenging in the health setting, for example being informed of what is happening medically for the person you care for.
- Gender roles might have an impact in personal care.
- Some of these challenges are universal and others unique to the situation.
- ALL these can become normalised meaning that an individual would not ask for support.
- These can easily build up into a crisis point.
- The level of challenge will depend on who you are and what your skills and preferences are.
- The person you are caring for may not accept that you do these tasks for them adding another layer of challenge.

Causes of Care

The review of 511 abstracts revealed a range of reasons why care was needed. These included:

- Illness (34 different types)
- ‘Older age’ diseases (3 types; Parkinson’s, Alzheimer’s, Dementia)
- Special educational needs and disabilities (4 types; cognitive / intellectual impairment, sensory impairment, physical disability, learning disability)
- Neurodiversity (2 types; ADHD and ASD)
- Injury / trauma (3 types; brain injury, spinal injury, unspecified disability)
- Mental health issues (6 types; unspecified mental illness, schizophrenia, psychosis, bi-polar disorder, anorexia / bulimia, delusional beliefs)
- Substance use.

We now know that care is needed for a variety of reasons, involves a wide range of care tasks across different, unpredictable stages of care, and is provided by a wide range of people in the population.

Providing support with this degree of variation is inevitably challenging.

Next we reviewed the abstracts for evidence of the impact of being a carer on a care givers life.

The Impact of Being a Carer

Seven different themes emerged from the abstracts, one of which was positive. These overlap and are intersectional, creating powerful webs of impact for the individual carer:

- Mental health
- Physical health
- Sleep
- Emotions
- Finances
- Relationships
- Positive impacts.

Mental Health

There were five ways in which being a carer acted negatively on mental wellbeing. These included, in order of prevalence:

Stress – worrying about every aspect of caring and one's wider life

Anxiety – about the future and one's ability to cope

Depression – at multiple personal losses and the hopelessness of the situation

Suicidal ideation – at times when it all became too much, accompanied by the knowledge that it was not an option as that would leave the cared for without a carer

Emotional contagion – as the emotional state of the cared for affects the carer, particularly the case when caring for people with mental illness.

Poor mental wellbeing is a serious consequence of caring and is not restricted to the mental domain. Research conducted in 2001 showed the chronic stress of caregiving suppresses the auto-immune function of carers – they literally produce less white blood cells (Makaley, 2001).

Physical Health

The tasks of a carer and the time it takes to be a carer both impact on the physical health of the carer. The abstracts detailed eight different ways this happened:

- Manual handling – physical strain or injury
- Injury from violence
- Lack of exercise – due to no time for self
- Poor diet
- Lack of self-care
- Unable to take rest leading to exhaustion
- Inability to attend to own illnesses as no time for own appointments.

As can be seen from the list above the time it takes to be a carer means carers cannot care for themselves, creating risks for their long-term health.

Sleep

Sleep is an aspect of physical health and may be included in that category, but reference to a lack of sleep was so prevalent we kept it separate. A lack of sleep was caused by:

- Physical disturbances caused by care giving (e.g. cared for cries out, falls, needs medication)
- An inability to sleep due to the mental strain of caring.

This highlights that whilst a physical issue, a lack of sleep intersects with both the care tasks demanded and the stress of caring.

Emotional Impacts

A list of emotions was extracted from the abstracts reviewed. This comprised a list of 32 emotions:

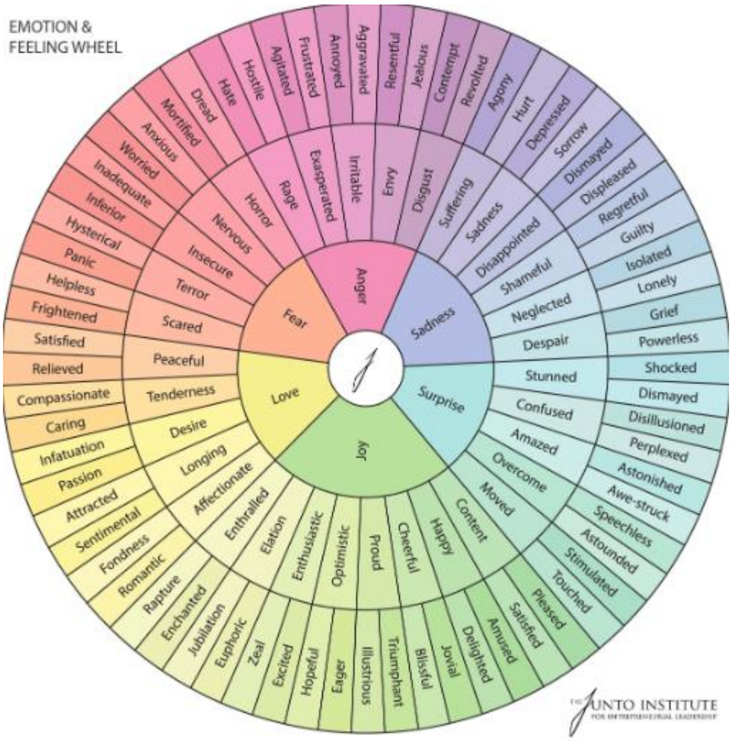
- Guilt
- Resentment
- Loneliness
- Isolated
- Invisible
- Anxious and hypervigilant
- Worried
- Distressed
- Stigmatised
- Disorientated
- Conflicted
- Frustrated
- Angry
- ‘Wishing they would die'
- Helpless
- Hopeless
- Insecure
- Inadequate
- Uncertain
- Lack of confidence
- Overwhelmed
- Overburdened
- Unprepared
- Burnt out
- Self-sacrificing

- Loss of self
- Restricted
- Loss of personal life
- Grief
- Love and devotion
- Determined
- Indebted, dutiful.

These varied by individual, by task, by stage of care and each carer could experience multiple and quickly changing emotions. There is an overlap here with mental wellbeing.

We have not yet analysed which are the most common or whether there are correlations to other aspects of the carer and caring.

We used a model called the ‘wheel of emotions’ to contextualise this list:



This model (which is not academically proven) suggests there are 130 different human emotions, in which case, caring can provoke over 25% of these, and predominantly those we might label as ‘negative’.

Finance

Financial impacts were also well documented, either due to carers having less ability to earn themselves and / or due to the cost of care, treatment and equipment.

Relationships

Being a carer was documented to have an adverse affect on relationships. This included both a loss of relationship and / or intimacy with the person cared for, and the loss of connection between the carer and their wider friends and family as they have less time for social connections.

Positive Impacts

The literature also documented a range of positive impacts, particularly for young carers where caring often coincided with the developmental task of adolescence. Positive impacts included:

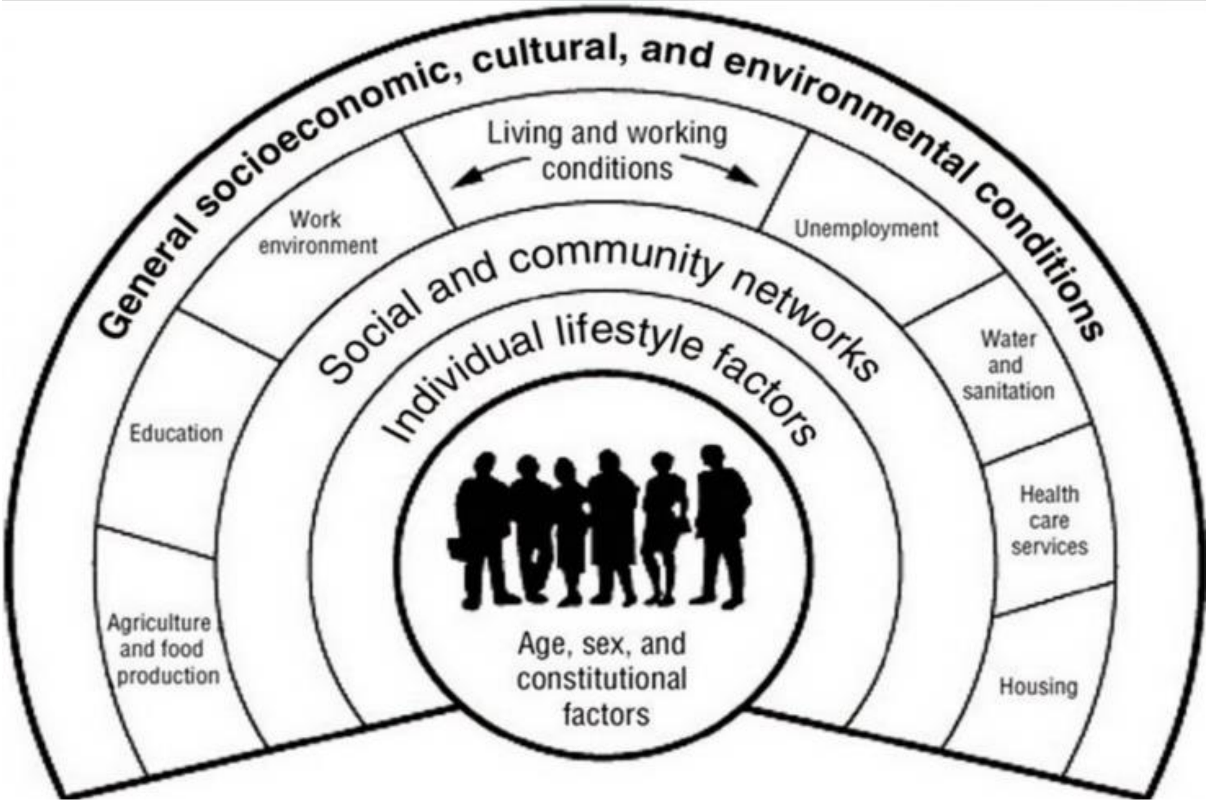
- Increased resilience
- Greater coping mechanisms
- Increased self-efficacy
- New or renewed purpose / life satisfaction
- Post-traumatic growth
- Spirituality, renewed or newfound faith
- Increased maturity.

Caring as a Determinant of Health

Reviewing these impacts made us consider caring as a determinant of health itself.

As the World Health Organisation (2025) states: "Many factors combine together to affect the health of individuals and communities. Whether people are healthy or not, is determined by their circumstances and environment".

A key model that shows all the Determinants of Health was written by Dahlgren and Whitehead in 1991 and is still in use today, as shown below:



Age, sex and constitutional factors – these are all the individual carer characteristics we mapped out. We probably need to add the health of the carer (their constitutional factor) to the list we developed from the abstracts.

Individual lifestyle factors – however healthy a carers life choices might have been prior to being a carer the literature suggests these are impaired by the time and toll of caring with carers showing less self-care and less healthy behaviours.

Social and community networks - caring has been shown to reduce social connections and so a carers social capital will be impaired due to the loss of time to access these networks however strong they were initially.

General conditions:

Agriculture and food – the foods the person you care for may or may not be available and a carer may neglect the food choices they need as they are busy caring (e.g. avoiding allergens).

Education – the carers level of education might influence how well they can navigate the care system and advocate for the person they care for and might also be impaired by caring. Professional development plans might be abandoned; young carers may not be able to get to university.

Work – the type of work a carer does may help or hinder them in that role, and caring might impact on the work they can do, perhaps even leading to a loss of work altogether.

Living and working conditions – these might influence the person's ability to care. They may change as the demands of care change (for example having less money to pay rent) and may be directly influenced, for example, by having to move in with a parent.

Unemployment – may be more likely due to the demands of caring.

Water and sanitation (bathroom circumstances) – might be significant challenges depending on the type of care needed, for example frequent bathing, dressing changes, managing incontinence).

Health care services – a carer may have less access to these personally due to time restrictions.

Housing – may need to change to accommodate new financial realities and / or living situations.

The congruence of the findings of the literature review with this model explains why we are positioning caring as a determinant of health.

We were then curious about how much each factor might influence a carers life.

The Human Cost of Caring

We turned to a new body of literature to answer this question and our answers so for are indicative snap shots rather than a comprehensive review of evidence.

- The presence of a mental illness as reducing a person's lifespan by 10 to 20 years.
- A lifetime of physical inactivity was evidenced to shorten a lifespan by up to 35 years.
- Poor sleep was associated with a 29% increase in mortality.
- Long term stress was shown to reduce lifespan by 2.8 years.
- Living in absolute poverty reduces lives by up to 10 years.
- Loneliness, often the result of the loss of relationships, increases mortality by 26%.

These are shocking statistics that indicate the severity of the impact of caring on a healthy lifespan, particularly when cumulative effects are considered. More research is needed in this area to see if any evidence is specifically related to carers rather than the whole population, and also to see if there is evidence of how quickly negative impacts can be ameliorated.

References:

Mental health – Risks of all-cause and suicide mortality in mental disorders: a meta-review - Chesney - 2014 - World Psychiatry - Wiley Online Library

Physical health – fitness - Does Physical Activity Increase Life Expectancy? A Review of the Literature – PMC

Sleep - Sleep Trajectories and All-Cause Mortality Among Low-Income Adults | Public Health | JAMA Network Open | JAMA Network

Stress - Stress and Life Expectancy: How Does One Impact the Other? » Online Graduate Programs in Innovative Aging Studies » College of Medicine » University of Florida

Poverty - Impacts of Poverty and Lifestyles on Mortality: A Cohort Study in Predominantly Low-Income Americans – PubMed

Loneliness - A systematic review and meta-analysis of 90 cohort studies of social isolation, loneliness and mortality | Nature Human Behaviour

So What?

Carers have different characteristics which might help or hinder them in their care giving. They provide care in different stages or phases according to the needs of the people they care for. Care tasks were multiple and varied by the need of the people they cared for. There were many different causes for care to be needed, each with its own stages of progression and care tasks. Impact on carers fell into seven different categories, six of which are negative which has led us to consider caring as a determinant of health itself.

Now we turn to the practical question – so what? What does this mean for us as people providing care to loved ones or friends, what does it mean for us as professionals supporting carers, and what does it mean in the organisations we work in and national policy framework we live in?

The 22 participants at the policy event explored the following questions in a world café format. Ideas were captured on flip charts and are written up verbatim here.

What does this mean for practice?

- Partnership working with our providers
- Shared learning
- Shared training
- Resources to tackle disconnect
- Multi-agency relationships and communication
- Joint panels like MASH
- Establish strategic carers board
- Improve advice, information, advice and guidance centrally with a one stop shop
- Community delivery and working
- Accessible resources
- Improve connectivity internally and externally
- Clearer information on statutory and non-statutory support
- Commissioning evidence based practice
- Sustainability of providers
- Relationship based practice is important
- Need non-judgemental services
- Need to hear the carer’s voice and whole family approach
- Stronger relationships with partners and stakeholders
- Therapeutic groups
- Social and support groups
- Drop in sessions
- Advice and guidance co-produced with community

- Networking
- Improved technology
- Improved access
- Reduce duplication and the number of people involved in each case (whilst still collaborating)
- Seek to understand gaps in provision.

What does this mean for communities?

- Potential to boost the social capital of carers
- Need a shift of attitudes and language to tolerance and compassion
- Need a better understanding of the needs of carers, and the specific things they can offer to help carers
- Can provide social connections to do fun stuff, to have conversations, to give carers a break, to have normal conversations
- Carers can access an existing or new community – how can the Council facilitate these with practical help like venues and transport?
- Support with points of life transition
- Some groups self-organise others need support
- Schools can be a place of community – particulary for young carers who have gaps in provision
- Day care is needed so carers can join a community
- Access to cross community services is needed (e.g. transport and respite).

What does this mean for policy?

- The new NHS 10 year plan offers opportunities for community hubs, community delivery of services, digital solutions and a preventative approach – how can we leverage these?
- Workplace policies vary – some are very compassionate and clear, others are less giving. Need for all workplaces to have a dedicated carer policy (not lumped into compassionate leave), flexible working, peer support, counselling support, volunteer days in care homes, flexible working in other settings (e.g. hot desk facilities in hospitals).
- Carer allowances need reviewing. £83 a week is not enough and the limit on earing of £196 a week does not incentivise employment for carers.
- Carer organisations need a higher minimum wage and better resources to pay for it to retain valued staff, and should provide support for their wellbeing – they are continually traumatised.

- Guaranteed interviews for carers and armed forces staff are helpful, but how often do they lead to employment?
- Need a strengthened multiagency partnership policy locally or nationally to pull support together seamlessly for carers. They should only tell their story once and be able to access everything through a carer support worker.
- Need GP's to have more time for appointments to ask carers how they are and to information share.
- Need a policy of No Closed Doors – removing all barriers, making carer wellbeing everyone's business and having a care support worker / navigator in all provider organisations.
- Need policy to link nurseries and care homes as it works overseas.
- Need to enable carers to have choices about whether they care and how they care (at home, with day care, with care home).
- Need a trauma informed approach to carers, with care, kindness and compassion given to their needs. They need to be dealt with as humans in challenging contexts, not a tick box assessment item.
- NHS needs more funding to reduce wait lists, to improve discharge protocols, and to lower thresholds.
- The Joy App could be a solution to some of these issues with a cradle to grave support.
- Policy mobilisation is a key challenge as people do not know what they are entitled to. A service map would be invaluable locally.

What does this mean for research?

- Research into carers rights
- Understanding the key influencers
- Access to information e.g. finances
- Understanding what shared data is available and how it is used
- Journey mapping – e.g. how are referrals happening
- Need data to understand the carer population better
- Understanding the impact of diversity and cultural norms on caring
- Understanding generational changes in attitudes to care
- Finding out what works for who in which circumstance – focussed on solutions
- Hearing carer stories – a resource to validate others experiences
- Research into gaps in support
- What are charities top ten questions from carers
- What AI opportunities are there, how can it help?
- What evidence is there to support new policies?
- What data trends are there in our aging population?
- What services are needed for our carers aged over 65?

- How to integrate services into one front door.
- How to implement making every contact count.
- Knowledge of successful interventions -what works?
- What can digital support look like – how many people could access it?
- Understanding the language carers would like used to describe them
- Understanding referral factors.

Next Steps

The research team will complete and publish the literature review, fully analysing the 511 full research papers. This will add more nuance to our findings and help us understand which factors are the most significant.

Once we have our findings we will share them with carers to see how well they resonate and to see what they would like us to do as next steps.

We will run another policy event sharing our full findings with everyone.

We would also like to start to build grant applications to both local funders and to research councils to continue this important research, with practical outputs in the future.

We would like to invite anyone to get in touch with us if you are interested in taking part in shaping, doing, or writing up any of this research.

Contact: Elaine.bidmead@cumbria.ac.uk

With thanks to the University of Cumbria for funding this research and the Policy Event and to all the participants who contributed to the day, we appreciate your passion, time and contributions.