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A critical evaluation of research associated with Carers' Organisations since the start of the Carers' Movement

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A critical evaluation of research associated with Carers'

Organisations since the start of the Carers' Movement

Abstract

Purpose Since the start of the Carers' Movement research into unpaid care and carers has been used to advocate for policy change. The purpose of this paper is to address the changes in research into unpaid care and carers since the start of the Carers' Movement and to explore the relationship between these changes and social policy.

Design/Methodology/Approach This research paper is based on a qualitative study of documents within the Carers UK archive.

Findings Research into unpaid care and carers has changed focus from caregiving as an identity and lifestyle to an interruption to 'normal' life and employment. Changes in research are intertwined with changes in policy, with research evidencing advocacy for policy change and policy change fuelling further research. Changes in the methodology of this research exposes transition points in the Carers' Movement and in social research more broadly.

Practical implications This paper contributes to critical understandings of the relationship between research into unpaid care and caring and policy. The paper also contributes to debates on methodology, exploring how the methodological zeitgeist presents in archived research.

Social implications Understanding how current research into unpaid care and carers has been developed and acknowledging the role of policy in research development brings available data on unpaid care and caring under scrutiny.

Originality/value This paper is original in developing a critical analysis of the relationship between research into unpaid care and carers and social policy.

Keywords carers, unpaid care, caring, carers' movement, Carers UK

Paper type Research Paper

Introduction

Beginning in 1963, the Carers' Movement started as an advocacy push for the social and legal recognition of unpaid carers¹ and caring activities. Since then, the Carers' Movement expanded to campaign for a wider remit of carer, financial support, and a greater understanding of the carer population, seeing great success in all areas, including putting carers on the policy agenda. Since the start of the Carers' Movement there has been a push for research into the provision of unpaid care and carers in the UK. Carers have advocated for research as ammunition to change policy through exposing the amount and nature of the unpaid work carers do. This need has been met by research carried out by the organisations at the heart of the Carers' Movement and central government (Carers UK, 2014c, Carers Trust, 2021, ONS, 2001). This paper uses original findings from the archive of Carers UK and its predecessors (collectively referred to as the Carers' Organisations) alongside broader research to understand how research into the provision of unpaid care has changed from the start of the Carers' Movement to present day.

Transitions within the Carers' Movement are visible in changes of direction in research into provision of unpaid care. By dissecting the framing and methodology behind this research, transitions in the Carers' Movement are exposed, evident in amendments to definitions of 'carer', methodological framing, and through the evolving focus on what aspects of the carer identity are deemed worthy of research. The grounding of these changes in the Carers' Movement and research more broadly contextualises what we know and have known about the carer population and highlights the construction process behind carer research.

Whilst the UK continues to be a world-leader in articulating the complex role of the carer, evidence from other countries such as Japan, Sweden, and Canada suggests there is a lag in addressing this in UK policy (Yeandle, 2016). International data on carers is inconsistent (Tur-Sinai et al., 2020), meaning national data is vital for progressing international strategies such as the Human Rights approach to care and caring (Yeandle, 2016). Knowledge of the context that frames the data researchers use, past and present, should influence decision-making about the type and source of data that researchers use. This is particularly potent in research into unpaid carers' which, as this paper will demonstrate, has had an iterative relationship with the Carers' Movement both socially and politically.

¹ The term 'carer' is not rigidly defined, as this paper shows with discussions of definitions past and present. Carers UK currently defines a carer as someone 'looking after family or friends who are older, disabled or seriously ill' (Carers UK, 2022b)

The following research questions structure this research, looking first at the evolution of research into unpaid carers and following this through to implications for social policy:

1. *How has research into unpaid care and carers within the Carers' Organisations changed since the start of the Carers' Movement?*
2. *How does research within the Carers' Organisations relate to other social research during the same period?*
3. *How does research into unpaid care and carers intersect with political change during the Carers' Movement?*

Beginning with a brief history of the Carers' Movement, this paper situates large-scale government research and research from the Carers' Organisations within the Carers' Movement to demonstrate the iterative nature of carer research and policy development.

Background: The Carers' Movement

The push for increased support for unpaid carers is a continuing movement in the face of an ageing population and pressurised health and social care budgets (Carers UK, 2014b). Since the start of the Carers' Movement, the discourse surrounding unpaid care has changed (Cook, 2007). These social and political changes, such as changes to the definition of the term 'carer' and legislative recognition of the term, have been predominantly motivated by the efforts of the Carers' Organisations (Cook, 2009), alongside efforts of key politicians such as Hywel Francis (Carers UK, 2021) and Malcolm Wicks (Carers UK, 2014b). It is also relevant to note that social care services have been in long-term crisis over this period, resulting in privatisation and financialisation, arguably shifting the priority from quality of care to profit (Bayliss and Gideon, 2020).

Beginning in 1963, the Carers' Movement saw success in recruitment, funding, and influence on a much larger scale than could have been predicted (Cook, 2009). The expectation that women should give up their own aspirations to care for a sick or elderly parent was at odds with the principles of the Women's Liberation Movement of 1960's Britain (The British Library, no date), providing a catalyst for the Carers' Movement and the progression of carers' rights. By increasing the visibility of care work, feminists aimed to expand women's professional horizons while simultaneously 'seeking greater respect and financial rewards for women's traditional activities in the home and helping professions' (Gordon et al., 1996 p.263). The first iteration of Carers UK, the National Council for the Single Woman and her Dependants (NCSWD), was formed in 1965 (Carers UK, 2014b).

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5 The NCSWD saw quick success with the legal recognition of unpaid caring responsibilities in
6 Dependant Relative Tax Allowance (Henwood, 2015). The subsequent introduction of Invalid Care
7 Allowance in 1976 (Legislation.gov.uk, 1976) was regarded by many as the completion of the
8 NCSWD's objectives (Cook, 2007). From 1981 the NCSWD faced competition from the Association of
9 Carers (AoC), an organisation formed to support carers in the community (Cook, 2007, Carers UK,
10 2014c). This competition could have fuelled advocacy for political change during this time as
11 political change would have been a tangible success to use as both charities competed for donations.
12 Following recognition of a broader definition of 'carer' (Lloyd, 2004), the NCSWD rebranded as the
13 National Council for Carers and their Elderly Dependants (NCCED) in 1982 (Carers UK, 2014b). This
14 rebranding brought the alignment of the NCCED and AoC closer together, culminating in a merger in
15 1988 to form the Carers National Association (CNA), prioritising an evidence-based approach to
16 campaigning for legislative change for the support of unpaid carers (Carers UK, 2014b). The CNA was
17 hugely successful, achieving legislative change in 1995 with The Carers (Recognition and Services)
18 Act (Carers UK, 2014c) and heavily influencing the government's National Carer's Strategy
19 (Department of Health, 1999). In 2001, the CNA absorbed Carers Scotland, Carers Wales, and Carers
20 Northern Ireland to form Carers UK, the UK's only national membership charity for carers (Carers
21 UK, 2014d). The evolution from the NCSWD to Carers UK has played a leading role in the Carers'
22 Movement from the early 1960s to present day. The advocacy push for government action leading
23 to the introduction of Carer's Allowance (Gov.UK, 2015) and Carers Assessment (Carers Trust, 2012),
24 along with the development of The Carers and Equal Opportunities Act (2004) (Carers UK, 2014c),
25 The Work and Families Act (2006) (HM Government, 2006), and the Care Act (2014) (Carers UK,
26 2014a) are among the greatest achievements of Carers UK to date.
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43 The Carers' Movement has been, and continues to be, the socio-political context in which research
44 into unpaid care is framed. Research into provision of care is inextricably intertwined with the
45 history of the Carers' Movement. This relationship is discussed in more detail in relation to findings
46 from research into provision of care across the Carers' Movement.
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52 **Methods**

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55 This research used the Carers Organisation archive: Records of the Carer's [sic] Association (RCA)
56 (Greater Manchester Lives, 2013b). The RCA is a collection of records donated to Manchester
57 Libraries, Information and Archives by AoC co-founder Sandra Leventon (CYWU, 2008) and Carers UK
58 (Holzhausen, 2016), comprising documents from the Carers Organisation from 1963-2008 (Greater
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3 Manchester Lives, 2013a). It is the only archive collection containing records from a carer
4 organisation during the Carers' Movement (The National Archives, 2018), making it the primary
5 source of documented research into care and carers between 1963-2008. The RCA Collection
6 comprises 23 catalogued boxes which were used for this research. The existing RCA catalogue, the
7 list of materials within the Collection, does not perfectly correspond to the Collection itself at Item
8 level² and is a patchwork of information from donors and cataloguing archivists (GMCRO, no date,
9 Archivist, 2016), thus Davidson et al's (2019) Breadth and Depth approach to 'big qual' data was
10 used.
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18 In a climate of budgetary restraint, the future of qualitative research lies in combining small-scale
19 qualitative data sets into larger-scale data sets for re-use, termed 'big qual' (Davidson et al., 2019).
20 Davidson et al. (2019) apply this theory to the use of archived secondary data however it has
21 applications to the archives more generally. Archived data, like Big Data, does not have a singular
22 use. Moreover, archive collections can be large, comprising millions of cubic feet in physical records
23 or hundreds of terabytes of digital data (Kitchin, 2014). There are over 3000 items in the RCA
24 Collection (GMCRO, no date) from numerous sources (several separate donations and organisations)
25 (Greater Manchester Lives, 2013b), qualifying it as a 'big qual' secondary data set as it exceeded the
26 resource capacity for this project (Davidson et al., 2019). Advancing Mason's 'scaling up' proposition
27 for the secondary analysis of qualitative data (Mason, 2002), Davidson et al. (2019) suggest working
28 across the data before digging into it in a 'Breadth and Depth' model.
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38 The RCA catalogue was initially used at Series level (the smallest level at which the RCA is able to be
39 requested to be viewed) (Greater Manchester Lives, 2013b), to survey the available data for
40 information-rich cases (Emmel, 2013, Patton, 2015): cases (items within the Collection) that
41 contained reference to primary research, defined as any instance of using participants. Series' were
42 selected based on the descriptions of Items within each Series, which were analysed for
43 keywords/phrases such as; research, question, questionnaire, help, answer (keywords were revisited
44 and revised as fieldwork progressed to account for dated language). Based on this criteria, Items
45 from three Series' were used for further analysis: Meeting Minutes, Newsletters, and Miscellaneous
46 Reports (Greater Manchester Lives, 2013b). Each Item was viewed and read including both 'the
47 more and the less promising' documents (Davidson et al., 2019 p.371). Purposeful sampling using
48 the recursive surface thematic mapping method of Davidson et al.'s (2019) Breadth and Depth
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60 ² Archive collections (known as fonds) are structured first by series (theme), then by file (group), and finally by
item (item or record) (Postal Heritage, 2013)

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3 approach gave a final selection of 82 documents: 30 meeting minutes, 29 newsletters, and 23
4 reports. The efficiency of identification of these documents was aided in part by the researcher's
5 prior understanding of predominant themes within the Organisation. These documents were then
6 subject to in-depth analysis, as described in the Breadth and Depth model:
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10 'An immersion in data at a scale that qualitative researchers feel uses the strengths of qualitative
11 analysis; that is, in being sensitive to changing context, multi-layered complexity and rich detail
12 to represent intricate social realities and produce nuanced social explanations' (Davidson et al.,
13 2019 p.372)
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18 By using Davidson et al.'s (2019) model a large qualitative dataset (the RCA Collection) was reduced
19 to a manageable amount of data without compromising on the 'distinctive order of knowledge
20 about social processes that is the hallmark of rigorous qualitative research, with its integrity of
21 attention to nuanced context and detail' (Davidson et al., 2019 p.365). Analysis iteratively combined
22 recursive surface thematic mapping and in-depth interpretation of the items within the collection
23 (Davidson et al., 2019), looking for 'rough trends and broken patterns' (demi-regularities) in
24 empirical data (Fletcher, 2017 p.185) exposing transition points in the Carers' Organisations.
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32 **Changes in research into unpaid care within the Carers' Organisations**

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34 Two key themes of change were identified: attitudes towards research and methodological
35 approaches.
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38 ***Attitudes towards research***

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40 As the Carers' Organisations evolved from the NCSWD to Carers UK so did the nature of the research
41 it conducted. Changes in social attitudes towards carers and research more broadly are reflected in
42 the evolution from the NCSWD to Carers UK. As the organisation changed to keep pace with
43 developments in the Carers' Movement, so too did the way research was discussed and documented
44 within the organisation and publicly.
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52 At the beginning of the Carers' Movement, the most valued aspect of a piece of research was the
53 person doing the research. There was often one person referred to by name at the start of the
54 project details e.g. 'approach to MH re: research...' (NCSWD 1966-1972 Minutes Dec 66), 'MK to
55 investigate...' (NCSWD 1966-1972 Minutes May 67), 'MS reported...' (NCSWD 1966-1972 Minutes
56 Sept 68). From the early 1970's the focus changed from the individual to the organisation doing the
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3 research. For example, 'several women's organisations' (NCSWD 1974), 'The National Joint
4 Committee of Working Women's Organisations has requested...' (NCSWD, 1977), 'Thameside Council
5 project' (NCCED 1987b). This change roughly aligns with the NCSWD's campaign for legislative
6 change with Attendance Allowance (Burchardt, 1999), showing attitudes towards research mimicked
7 the Carers' Organisations' transition from an inward focus on the carer population to a broader
8 outward look at where this population was positioned socially and legislatively. A similar shift can be
9 seen with reference to participants in research.

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16 Earlier newsletters referred to research participants with a casual, attentive approach:

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18 'Many of our readers have already applied on behalf of their dependants for the Attendance
19 allowance... the single woman concerned gave up her job some time ago because her dependant
20 could no longer be left alone during the day and the refusal of the application for the attendance
21 allowance has caused concern and disappointment.' (NCSWD 1971)

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26 This became more formalised and informal in later newsletters:

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28 'The National Joint Committee of Working Women's Organisations has requested that we
29 participate in researching data on the general topic "Health Care for Women", with particular
30 emphasis in the mental health area. At the moment we are not proposing to circulate a
31 questionnaire. For the time being we have decided to ask you to co-operate by indicating
32 whether or not the caring process affected your health adversely' (NCSWD 1977).

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37 This exposes a transition where the Carers' Organisations shifted focus from a collection of individual
38 carers to a single collective movement. As the organisation expanded to support research from
39 other organisations, reference to research became disconnected from the organisation:

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42 'Thameside Council is carrying out a major survey into caring in the community to find out how
43 many people in the borough currently look after dependant relatives and friends. More than
44 17000 households are to be asked to take part in the survey which has been promoted by
45 concern about the hidden number of carers in the community. The council will use the results of
46 the postal survey to review its policies and services.' (NCSWD 1977)

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52 Internal requests for participation became a simple call for participation without detail:

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54 'Would you please cooperate in answering the following questions and return the form to NCCED
55 AS PROMPTLY AS POSSIBLE' (NCCED 1985)

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3 The cultural shift in research suggests that as they grew, the Carers' Organisations were less able to
4 do large scale research. Research became less of a priority than it had been previously. This
5 coincides with the appointment of the first paid director of the organisation, Roxanna Arnold,
6 described as 'a tough, practical, unsentimental campaigner' (Carers UK, 2014c). This also aligns with
7 the increase in political activism in the early 1980's [see p2]. These changes are reflective of a shift in
8 attitude in social research more broadly. Whilst person-centred qualitative approaches to academic
9 research were developed and popularised in the 1950's and 1960's (Calhoun, 1987), the perceived
10 superiority of academic social science over market research led the two to develop detached from
11 each other (Savage and Burrows, 2008). Approaches used by the Carers' Organisations were closer
12 to the increasingly popular market research in the 1970's. This is echoed in methodological changes
13 to research within the Carers' Organisations.
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23 ***Methodological changes***

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26 A demonstrable change in epistemology is evident in the way that carer research is presented and
27 discussed over time and in a change in attitude towards how research is conducted. These changes
28 in methods follow changes in broader attitudes towards research (and research participants)
29 discussed in the previous section. Initially, snowball sampling was used through local churches and
30 GP's (Greater Manchester Lives, 2013b), however once the NCSWD gained momentum, members
31 were used as the sample for research, followed by outside organisations (Greater Manchester Lives,
32 2013b). The sampling strategy changed again to qualitative 'case histories' following the 'second
33 return' of qualitative research in the 1960's. This period saw symbolic interaction and
34 ethnomethodology (Gobo, 2005) drive a more inquisitive society to be interested in the
35 differentiation of social groups through individual positions (Jovanović, 2011). This period would be
36 relatively short-lived following the development of software able to analyse large-scale quantitative
37 data (Gobo, 2005).
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48 There is also a marked change in the information available about methods in the RCA Collection.
49 Through the very nature of being archived, the items within the RCA Collection are deemed to hold
50 historical significance (Steedman, 2002), suggesting that each individual item in the RCA Collection
51 was of value. From this, it is inferred that the presence or absence of research material is a
52 testament to its perceived importance. Prior to the outsourcing of research in the late 1970's there
53 is little detailed information about the methods used by the organisation (NCSWD 1966-1972).
54 Information about questionnaires includes response rates and recommendations but no research
55 aims or information on the target population (NCSWD 1966-1972). This is perpetuated in the
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meeting minutes which do not detail any discussion of, or justification for, the research methods used (NCSWD 1966-1972, NCSWD, 1967-1974), indicating that the results of research were more important to the organisation than the methods producing them. This changed as research was outsourced, leading to a consistent report format with the clear provision of information such as sample size, target population and methods (NCSWD 1978a). This is in-line with the development of social research at the time and an increasing focus on research as a process in its own right. However, the most noticeable change in direction followed changes to the very fabric of the Carers' Organisations.

The NCSWD was a publicity campaign aimed at increasing awareness of the single woman with unpaid caring responsibilities and solidified its place in history by achieving legislative change with financial support for unpaid carers (Carers UK, 2014c). However, the research in this initial period was ad-hoc, and although the minute books show efforts to increase the research outputs from the NCSWD, these efforts were often unsuccessful (NCSWD 1966-1972). Research was small-scale, in-house and focused on respite and targeting loneliness (NCSWD 1966-1972). The NCSWD consciously changed their campaigning efforts to be more evidence-based in the 1970s (Carers UK, 2014c) and the focus of research shifted to financial needs and support (NCSWD 1966-1972, NCSWD, 1967-1974). After the implementation of Invalid Care Allowance in 1976, research done by the NCSWD changed in focus again to what would become its predominant focus from 1978-present: evaluation research.

Over the next 15 years, the Carers' Organisations would have a dual approach to research. The primary focus was on evaluating policy (NCSWD 1978b, NCCED 1986a, 1986b, 1986c), providing the evidence to underpin the organisations' focus on campaigning for legislative change. Evaluative research at this time was premised on the 'experimenting society' (Campbell 1969 in Pawson et al., 2005 p.3), where organisations such as charities (like the NCSWD) had developed a mistrust of professional views of government-developed programmes and relied instead upon supporting evidence (Solesbury 2001 in Pawson et al., 2005 p.3). However, this was before the time- and cost-driven shift from primary research to systematic review in policy evaluation during the 1990s (Pawson, 2002).

The second approach to research by the NCSWD and its successors was a more investigative one. The organisation remained committed to knowledge production, with large-scale projects such as The Dynamics of Informal Caring (1979), Survey among Working Women with Dependents (1976),

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3 Home Help Survey (1978a), Carers in Transition (1984) and several less-formal enquiries within the
4 organisation such as Can a Carer Say No? (1987a) and Housing needs of the Single Woman with
5 Dependants (NCSWD no date). These research pieces are reflective of the roots of the organisation,
6 bringing new and current data on the carer population to underpin calls for legislative change (this is
7 discussed in more detail in the next section).
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13 Whilst research done by the NCSWD and its predecessors predates government research into
14 provision of care by some 20 years, academic research at the time was similarly focussed on
15 highlighting vulnerable populations. Poverty in the UK (Townsend, 1979), an examination of relative
16 deprivation covering various measures of living standards (PSE 2016), is regarded as a pioneering
17 piece in the development of research of vulnerable populations (PSE 2016). Townsend's study
18 predates projects like The Dynamics of Informal Caring (NCSWD 1979) and is one example of the
19 methods used by the NCSWD being used in academic research at the time. NCSWD research is
20 similar to Townsend's in that there is no justification for the methods, no discussion of ethics, and
21 the questionnaire length is longer than would be acceptable today (NCSWD 1979, Townsend, 1979).
22 However, Townsend's study feels somehow richer. There is more 'paradata' (context and
23 perceptions from in the field) (PSE 2016), and it is in these between-the-lines comments that more
24 advanced understandings are revealed. Face-to-face interaction with participants and Townsend's
25 own understanding of the social phenomena being researched contribute to a more detailed
26 understanding of the social phenomena. There is a qualitative element in Townsend's thorough
27 understanding of the target population that is missing from the research done by the NCSWD. This is
28 due in part to the NCSWD outsourcing research reports to a third party (NCSWD 1974-1979),
29 meaning a thorough understanding of the material is not engrained into the report as it is with
30 Townsend's study.
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45 Comparison between research by the NCSWD and Townsend's academic research highlights that the
46 NCSWD did not draw a distinction between research done for evaluative or investigative purposes.
47 This one-size-fits-all approach to methodology did not utilise the NCSWD's arguably unmatched
48 access to a rich source of information. However, the primary focus of the Carers' Organisations will
49 have been campaigning and advocacy over and above research. Thus, it is unreasonable to expect
50 that the Carers' Organisations could or would have been on par with academic research methods,
51 resources, and best practice. Discussion about the relationship between research from within the
52 Carers' Organisations and other research on unpaid carers is continued alongside the relationship
53 between research and policy.
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Relationship between research into unpaid care and carers and political change during the Carers' Movement

Policy has been an intrinsic connection between research within the Carers' Organisations and other forms of research, in particular Government research. This section looks at the interaction between policy and research in progressing the Carers' Movement.

Influence on and of Government research and policy

Access to the largest number of carers was (and remains) through large-scale Government surveys. Questions targeting carers were included in eight government surveys between 1963 and 2020: The General Household Survey (GHS) (1985, 1990, and 1995), the 2001 and 2011 Censuses, Carers in Households (2009), Understanding Society (2009-2013), and Life Opportunities Survey (2009). The advantage of these large population surveys is the ability to capture carers not engaged with carers organisations.

The style and number of questions varied across the surveys, showing parallels to the evolution of the Carers' Movement. The same can be said for policy developments during this time, as the rights acquired by carers in national social care and employment systems prioritised 'alleviating pressures on carers which might threaten their health or the sustainability of their care' (Yeandle and Buckner, 2017 p.307). Looking at the development of research and policy into unpaid care by the Government and Carers' Organisations there has been an iterative relationship, with the Government reacting to developments within the Carers' Movement with both research and policy, which then furthered the cause of the Carers' Movement with a shift in focus to the next advocacy push. The Carers' Organisations have also held the government accountable for the implementation of policies and evaluation as seen in press releases from Carers UK and the recent pressure on the government regarding the cost of living crisis (Carers UK, 2022a).

Amid the surge in competitive campaigning by both the AoC and the NCCED, the government included a 'Carers' module in the 1985 GHS (UK Data Service, 1985). Information was collected on both households and individuals via door-to-door interviews (UK Data Service, 2018, UK Data Service, 1985) making it the first Government survey to engage with carers face-to-face. This is reflective of broader social research methods at the time such as Townsend's Poverty in the UK

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3 (1979). Themes included; the relationship between the carer and dependant, the dependant's
4 disability and how it affected them, whether the dependant lived with the carer, and caregiving
5 activities (UK Data Service, 1985). The introduction of carers as a focus for research by the
6 government followed the publicity and campaigning of the NCCED and AoC in the early 1980's (see
7 p2). After the government's acknowledgement of the importance of carer data through its
8 collection, the CNA reacted with a more evidence-based approach to campaigning for legislative
9 change with the Speak Up, Speak Out report (CNA 1992) which, with 3000 respondents, was the
10 largest non-government survey of unpaid carers to date. Findings highlighted the negative health
11 and financial repercussions for carers, respondents' lack of awareness of their carer status, and a
12 desire for more recognition from family and friends and policymakers (CNA 1992). This incited
13 change with the incorporation of topics and questions from this research into the GHS.
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23 Between 1985 and 2000 the GHS ran the carer module on a five-yearly basis. The number and focus
24 of questions asked about unpaid care varied, including an expanded Carers module (UK Data Service,
25 1995) and additional topics that mirrored those from the CNA's Speak Up, Speak Out report (CNA
26 1992). In 1995 the Carers (Recognition and Services) Act was launched, giving carers a legal status in
27 the UK and the right to an assessment of their ability to care (Yeandle and Buckner, 2017).
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33 Following the Speak Up, Speak Out survey, The Government's Carers Strategy (1999) criticised the
34 GHS for 'cover[ing] only a small proportion of carers in Great Britain' and only having approximate
35 figures (Department of Health, 1999 p.21). Despite criticism of the data, the 1999 Carer's Strategy
36 was a catalyst for the development of respite care, emergency carer support, and support for
37 working carers (Clements, 2010 in Yeandle and Buckner, 2017). Also in 1999, the Employment
38 Relations Act introduced the right to take (unpaid) 'family emergency' leave and protected the
39 employment rights of carers who did so. Whilst modest, this was the first legislation to protect
40 accommodations for working carers without fear of dismissal (Yeandle and Buckner, 2017).
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48 The 1997 Census Test included a new question on unpaid care in preparation for the 2001 Census for
49 England and Wales (Department of Health, 1999). Consequently, the 2000 GHS module was shorter
50 than previous Carer modules and focussed on time spent caregiving and the activities involved (UK
51 Data Service, 2000). The Carers and Disabled Children Act was also introduced in 2000, giving local
52 authorities the option to provide any services for carers that would help them to continue to care
53 and maintain their well-being, as well as make payments direct to carers (Department of Health,
54 2005).
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5 The introduction of unpaid carer data within the Census for England and Wales influenced the
6 reduction and dropping of the GHS Carer module (UK Data Service, 2015, ONS, 2001), putting the
7 onus for more regular collection of carer data back onto Carers UK. This was in part an effect of the
8 introduction of the Government's Harmonisation Strategy (Government Statistical Service, 1998)
9 which aimed to streamline common topics in major government surveys from 2001 onwards, with
10 the objective of comparable outputs (Moss, 1999). However, in practice, different populations,
11 samples, and guidance notes has meant that data from the same questions across different surveys
12 are not directly comparable. The harmonisation strategy has stunted questionnaire design by
13 effectively freezing questions on unpaid care from the early millennium. At the time of writing the
14 questions continue to reflect the socio-political context of that time, focusing on the amount of time
15 spent caring, despite research repeatedly highlighting this as a problematic metric (McTaggart, 1908,
16 Brooks, 2012, MacDonald, 2014, Adam, 1994). This was relieved in part by the Carers in Households
17 survey in 2009/10.

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28 The Carers in Households survey (2009/10), commissioned by the Department of Work and Pensions
29 as part of the 2009 Carers Strategy (NHS Digital, 2010), was the most comprehensive survey of
30 informal carers at the time and remains the only government survey dedicated to unpaid carers.
31 Questions from the GHS and definitions from the 2001 Census were included under the
32 governments Harmonisation Strategy (Government Statistical Service, 1996). It contained 117
33 questions across eight themes: Household Information, Intro, Support for main cared for person,
34 Support for carer, Carer specific services, Impact of care-giving on carer, Impact of caring upon
35 employment prospects, and Demographics (UK Data Service, 2010). This showed a change from the
36 practical focus of the 1985 GHS to the support-focussed Carers in Households, mirroring changes
37 seen in the Carers' Organisations over the same period. The addition of the 'Impact of caring upon
38 employment prospects' section reflects the governments prioritisation of time, claiming to 'enabl[e]
39 carers to fulfil their educational and employment potential' (HMG 2010 p.5). This theme was echoed
40 in policy with the 2012 Welfare Reform Act, which shifted focus for people with long term ill-health
41 from supporting early retirement with Incapacity Benefit to supporting continuing employment with
42 the stricter Employment Support Allowance.

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55 The feminist influence on the Carers' Movement has not permeated government research into care
56 provision. Efforts to look at the relationship between unpaid care and illness and/or disability in the
57 1997 Census Test were unsuccessful due to a high level of discrepancies when comparing responses
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3 to the Census Test and follow up evaluation survey (ONS, 2005a): 'respondents and their carers
4 sometimes had different views on whether care was being provided, leading to inconsistent
5 responses' (ONS, 2005b). However, this is not a consequence of harmonisation. Hughes et al. (2005)
6 argue that the framing of the term "care" within disability studies could not be reconciled with the
7 feminist positioning of care characteristic of the Carers' Movement. There is contestation between a
8 feminist framework which prioritises the giver and disability studies which prioritises the receiver,
9 both lacking recognition of interdependence and mutual need (Hughes et al., 2005).
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17 ***Current research***

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19 Large scale Government research is the main data used to affect change through policy. This type of
20 research predominantly uses a quantitative survey methodology, however research into unpaid care
21 was heavily influenced by the growing popularity and development of qualitative research
22 techniques in the 1960s. This golden age of qualitative research was characterised by a need to give
23 a voice to those who had previously been silenced through a growing distrust of authority and
24 authoritarian control (Given, 2008). These circumstances were the foundations for the Carers'
25 Movement and research into unpaid care and carers.
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33 As of 2019, the most cited data for unpaid carers remains quantitative, coming from the 2011
34 Census (Carers UK, 2014d). Although over a decade old, Carers UK justifies the continuing use of UK
35 Census figures 'as they are the biggest dataset concerning carers in the UK' (Carers UK, 2019). Carers
36 UK's policy briefing *Facts about caring* (2019), is a compilation of numerical facts. This includes
37 reference to qualitative data but is heavily reliant on measurable, quantitative attributes such as
38 hours spent caring or take up of support. This demonstrates that although qualitative research has
39 been done by Carers UK and its predecessors, when it comes to policy numbers are favoured. This is
40 reiterated by the introduction of The Carers (Recognition and Services) Act in 1995 following the
41 CNA's Speak Up Speak Out report (Carers UK, 2014d).
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50 Modern-day qualitative research on unpaid carers has primarily come from academia. Since the
51 early 2000's there has been a focus on the carer identity and the health/psychological effects of
52 unpaid caring (Montgomery and Kosloski, 2009, Corden and Hirst, 2011, Hughes et al., 2013) and the
53 dynamics of the caring relationship (Nakano Glenn, 2000, Al-Janabi et al., 2008). More recently,
54 academic research has championed qualitative methods in unpaid carer research, encouraging
55 carers to speak for themselves and in their own language (CIRCLE, 2019).
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3 Qualitative and quantitative research have developed through separate strands of the Carers'
4 Movement. This is not to say that one holds more value than the other, but to demonstrate that
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6 despite the growing volume of individual voices through qualitative research, it is large scale
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8 quantitative research that dominates publicity and policy campaigns. This is in part indicative of the
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10 evolution of the Carers' Organisations, moving to large scale quantitative research as the known
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12 carer population increased, and in part a reflection of the neoliberal attitude of a Government more
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14 interested in easily digestible groupings than rich qualitative accounts.
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16 17 Discussion

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20 The focus of research into provision of care has shifted from the practical, defining characteristics of
21
22 caregiving and positioning caregiving as an identity and lifestyle, to a focus on support, time, and
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24 how caring impacts the caregiver, positioning care as an interruption to a 'normal' working life. This
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26 is reflected in a broader policy shift towards better support for carers to remain in employment.
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28 Acknowledgement that the methods used for Government research into unpaid carers are not
29
30 completely representative of the broader field of carer research brings the wider socio-political
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32 context into focus. The RCA Collection provides intimate detail of research carried out by the Carers'
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34 Organisations, exposing transitional moments in research from the heart of the Carers' Movement.

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36 Just as academic and government research into unpaid care and carers has reflected social and
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38 political advances by the Carers' Movement, the methodology of research by the Carers'
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40 Organisations has converged with academic research. The RCA Collection demonstrated that
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42 research by Carers UK had similarities to academic research but diverged when it came to the
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44 details. More recent developments within the Carers' Movement have seen a focus on academic
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46 research as academic and policy research have become intertwined. Parallels can be drawn between
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48 academic and Carers' Organisation research in the 1970's, as research from within the Carers'
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50 Movement was more akin to marketing research. As evaluation research carved its place in
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52 academia towards the end of the 20th Century the evaluative policy focus of the Carers' Movement
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54 had its epistemology reflected in academia. Today, academic institutions are responsible for a large
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56 portion of research into care provision.

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58 Government research on provision of care is clearly aligned with turning points within the Carers'
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60 Movement. The introduction of questions on provision of care and changes to definitions of care and
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62 carer reflect the efforts of the Carers' Organisations. The introduction of new forms of data and
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64 legislation constituted completion of goals for the Carers' Organisations, necessitating development

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3 within the Carers' Organisations and wider Carers' Movement. The iterative nature of the
4 relationship between government research and the Carers' Movement is seen in changes to
5 research and legislation. The framing of research evolves in-line with the advancement of carer's
6 rights and the increasing politicisation of the Carers' Movement, as well as increased support for
7 carers to live a 'normal' working life. However, the synonymity between Government and Carers'
8 Organisations research diverged at the turn of the millennium with the introduction of a
9 Harmonisation Strategy for Government data collection.
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16 The introduction of the Government's Harmonisation strategy effectively froze survey questions
17 from 2001 onwards, meaning that developments such as the Carers (Equal Opportunities) Act 2004,
18 the 2014 Care Act, or the Carers Strategy (2014) and Carers Action plan (2018) are not reflected in
19 research, demonstrated in the repetition of the 2001 Census Question in the 2021 Census. There is
20 merit to harmonisation in the theory of comparable findings, suggesting that the same question
21 asked over a period of time will produce longitudinal trend data. However, harmonised questions
22 across different surveys have been preceded by varying criteria such as the updating of the
23 definition of the care recipient as 'sick, handicapped, or elderly' (UK Data Service, 1995) to suffering
24 from 'long-term physical or mental ill-health or disability, or problems relating to old age' (ONS,
25 2004) and, where surveys like the Census are repeated almost like-for-like, the chronological gap
26 between data means that the numbers are influenced by the fast-changing political landscape
27 forged by the ongoing Carers' Movement. The increase in the number of carers that will
28 undoubtedly be shown from the 2001 to 2021 Censuses are not protected from socio-political
29 changes by the equivalence of the question wording. Following the Carers in Households Survey in
30 2009/10 there have not been any Government surveys dedicated to carers. This could be due in
31 large part to widespread austerity measures cutting public funding for social care substantially from
32 2009/10 (Stoye, 2018).
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46 The expansion of carers research within academia has produced a wealth of high-quality research,
47 both nationally and internationally. Carers UK and academic groups such as CIRCLE (The University of
48 Sheffield) and YCRG (Loughborough) with their advanced skills and access to a community of carers,
49 are well placed to evaluate and investigate provision of care. The lack of government data on carers
50 could also be a political choice. It is easier to ignore a problem if the size of it is not reported (Ball,
51 2022). The Government's 'Big Society' theme of the 2010 election and beyond hinged on the idea
52 that society was somehow broken, drawing heavily on conservative ideas of active citizenship (Defty,
53 2014). This model has been heavily criticised as thinly veiled public spending cuts, including public
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responsibility for services previously provided by the state (Defty, 2014). Data has been no exception. It is easier for the government to criticise data from other organisations. Thus, placing the onus for carer data on Carers UK and other charities is beneficial to the government but detrimental to the cause as carers not connected to charities are more likely to be captured and represented in broader government surveys.

Conclusion

Research into unpaid care and carers has evolved since the beginning of the Carer's Movement in the 1960's. However, Government research which in the 1990s provided data on an untapped source of carers, has been superseded by the advancement of evaluation and policy research within academia and the fast-paced evolution of the Carers' Movement itself. The focused nature of Carers UK and academic research means they can follow the contours of the Carers' Movement because they are, in part, responsible for shaping the Carers' Movement. The success of the Carers' Organisations in changing the social, legal, and political status of carers demonstrates the power of an evidence-based approach to campaigning for change. The power of research as a tool to underpin and direct the Carers' Movement continues today with Carers UK, academic institutions, and similar international organisations challenging and influencing policy and policy makers with clear evidence-based claims. The development of research into care and carers by private and third sector organisations, necessitated by the reduction in Government research, pushes the boundaries of carer research and allows the research to keep pace with socio-political and research developments in a way that Government research cannot. The Carers' Movement is a dynamic and ongoing movement that continues to see success both because of its interconnection with and emancipation from Government research in this field. This rich history that continues to influence research into unpaid care needs to be understood by contemporary researchers using these data. An appreciation for this history will elevate the use of these data through an integral grounding in the socio-political landscape of the Carers' Movement and research into unpaid care and carers more broadly.

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