## Theme 6: Caring relations: toward sustainable arrangements with wellbeing outcomes

| 6A | Concepts and caring democracy |
| 6B | Care worker wellbeing         |
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| 6D | Caring, Society and Policy    |

**Release date:** Wednesday 20th April

### Theme 6: Caring relations: toward sustainable arrangements with wellbeing outcomes

#### Session 6A: Concepts and caring democracy

**Chair:**

**Discussant:**

**Sandhya Duggal**

**Asset-based approaches and the ethics of care in the UK: A shift towards relational practice**

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This paper conceptually draws upon the ethics of care to examine how asset-based approaches represent a shift in caring relations in practice.

Asset-based approaches represent a fundamental shift in focus towards the relational and away from the transactional understandings of how care and need are conceptualised. This shift from understanding care within a dyadic relationship between carer and care receiver, or a commodified purchase from services, towards the multidimensionality of care (Barnes, 2015) has been achieved through new conservations about ‘what would a good life look like for you’. Asset-based approaches centres the ‘care receiver’ through co-production within a ‘doing with’ rather than ‘doing for’ relationship. By allowing people to explore the right care for themselves, asset-based approaches promote relational autonomy (MacKenzie and Stoljar, 2000).

This paper draws upon recent research findings with beneficiaries and those providing formal/informal care, to reveal how asset based approaches may achieve a shift in caring relations in practice. Its aims (to respect and support the rights, skills and opportunities of all people in communities to be valued, active, contributing citizens) place care relations within broader themes of; citizenship, community, and wider societal responsibility. By doing this, asset-based approaches move away from the paternalistic structures of care ethics, and towards equality of care through the recognition of people’s assets, resilience and capacity.

Our discussion also includes how improvements to personal wellbeing are contextualised within natural relationships and personal networks, which can reduce service dependency and service costs.

**Selma Kadi**

**Gender in the care-mix: ideals of care of older parent - adult child care dyads in Austria**

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Relationships are an important element of care cultures. Care relationships have been conceptualized around the notions of caring about and caring for and moral predispositions to care, such as defined by the ethics of care literature (Tronto 1993). These notions are profoundly linked with gender relations. Questions such as who is involved in a caring convoy (Kemp 2013) and which tasks are performed by whom are not only shaped by economic constraints and available social networks but also by ideals of care. The cultural norms are also present in the provision of bodily care, which involves touch and creation of intimacy (Twigg 2004). At the same time, caring relationships include a power dimension defined around mutual dependencies such as need for care and access to financial resources (Kittay 1999). Through the analysis of semi-structured...
interviews with 24 dyads (older parent user and adult children carer) who buy some care (and thus have the option to outsource certain tasks), we investigated ideals of care to better understand the prevalent care culture in Austria. We found four different care ideals (family, personal preference, involvement in decision-making, gendered) which occurred across low, middle and high SES groups. Women described one version of the family care ideal more often than men.

Weronika Kłocz-Nowak

Grandparenting in Poland in the age of (restricted) mobility: how COVID-19 pandemics affected the practices of local and transnational grandparents

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The proposed presentation is based on the results of a project on grandparenting attitudes and practices’ adaptation to spatial mobility (both internal and international) bridging the gap between the literatures on transnational families and contemporary transformation of family practices. It contributes to understandings of transnational care networks, at a time of ‘unsettling events’ (Kilkey and Ryan, 2020) and to the more realistic view of transnationalism (Dahinden 2005). Recent events such as the pandemic and Brexit, have revealed the fragility of transnationalism, by creating barriers that migrant families need to navigate in their efforts to maintain caring relations at a distance.

The presentation will be based on the analysis of the focus group interviews conducted in 2020 with grandparents living in Poland, where society combines strong intergenerational and family care obligations with intense outmigration. We will present the perspectives of the non-migrant grandmothers and grandfathers on the emotional care and maintenance of ties with their grandchildren living in different locations in Poland and abroad during the coronavirus pandemic. We identify how having grandchildren abroad made the experience more difficult. Some of the visiting and communication practices related to grandchildren in transnational families are based on the experience and ICT skills which have been acquired earlier on, since the adult children’s migration. As the FGIs were conducted after the first wave of the COVID-19 pandemic they shed light on how the isolation measures affected grandparenting practices, disrupting the old ones and potentially leading to new patterns emerging.

Kofi Awuviry-Newton

Older adults’ lived experience regarding their Long-term care in Ghana during the COVID-19 pandemic: A descriptive qualitative study

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Introduction: Adult children have been burdened providing long-term care (LTC); however, it is unknown how the COVID-19 pandemic with its associated social distancing measures have affected the LTC care older adults receive in Ghana. The current study aimed to explore older adults’ lived experiences regarding the LTC during the COVID-19 pandemic in Ghana.

Methods: A descriptive qualitative approach employing semi-structured interviews were used to collect data from 15 older adults from southern Ghana. Employing NVivo (12), a descriptive first cycle and focused second cycle coding were employed to analyse the data.

Results: The analysis of the interview data resulted in five interrelated themes; 1) long-term care sources and nature during COVID-19 pandemic, 2) older adults’ long-term care satisfaction level during a COVID-19 pandemic, 3) LTC alterations during COVID-19, 4) feelings of neglect regarding LTC, and 5) older adults’ resilience in LTC during COVID-19.

Discussion: These findings have revealed how LTC for older adults has been heavily impacted following the COVID-19 and its related social distancing measures in Ghana. We recommend that for the sustainability of LTC needs of older adults in Ghana can be ensured, the state should assume authority to devise a practical policy and programs to promote the health and social care needs of older adults and their primary caregivers.
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<td>Cate Goodlad</td>
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<td>Not all Superheroes wear capes: Job quality for care workers in UK home care</td>
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<td>It is often stated that domiciliary home care work is precarious, characterised by a combination of long hours, minimum wage rates of pay, being unpaid for travel time, zero-hours contracts and a lack of sick pay, as well as being misunderstood and undervalued by the general public. As part of the Sustainable Care programme (ESRC award ES/P009255/1, Sustainable Care: connecting people and systems, 2017-21, Principal Investigator Sue Yeandle, University of Sheffield), we are concerned with how care practices can be made sustainable for all stakeholders, including care workers, care recipients and their families, which includes a focus on improving job quality for paid care workers. Here we report on findings from cross-case analysis of four ‘innovative’ agencies who provide care at home (including interview, observation and document analysis). We examine how these companies variously create job quality to enrich employment opportunities for care workers and the strategies they employ to support them in their work. We include the voices of care workers to illuminate how components of job quality can produce sustainable care.</td>
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<td>Hareth Al-Janabi</td>
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<td>The costs and benefits of healthcare delivery for carer wellbeing in the UK</td>
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<td>There is an aspiration to consider family carer wellbeing in delivering high quality health and social care. However, we know little about the impact (costs and benefits) of healthcare delivery on carer wellbeing. This paper will draw on a 4-year research programme on carer wellbeing and economic evaluation, focusing specifically on two interlinked studies. In the first study, we established six mechanisms by carer wellbeing is affected by healthcare services and organisational changes. This was based on in-depth interviews and focus groups with carers and care professionals. The mechanisms (summarised by the mnemonic ‘IMPACT’) were ‘Information’, ‘Management of care’, ‘Patient outcomes’, ‘Alienation’, ‘Compliance’, and ‘Timing/location’. In the second study, the Delphi technique was used to identify likely costs and benefits of healthcare delivery for carer wellbeing. This involved surveying 65 experts remotely at two points, followed by a face to face meeting. This revealed a tendency to think that healthcare services would have a positive impact on carer wellbeing, while organisational changes would have a much more negative impact. Overall the studies provide some guidance as to when health and social care may be most likely to impact on family carer wellbeing and what those impacts might be. For a sustainable care system, practical ways of considering carer wellbeing in policy and care decisions is needed.</td>
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<td>Petra Ahllund</td>
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<td>Intimate care work - challenges in formal elderly care in Sweden</td>
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| The Social Service act in Sweden states that elderly in need of care should be allowed to live a dignified life, in practice for example manifested by being given support in their own homes in spite of conditions such as disability, frailty, illness or dementia. Essential, but rarely talked about, is intimate care (for example maintaining hygiene, changing diapers, brush one's teeth), tasks that can be a challenge for the actors involved. Intimate care requires good relationships between caregivers and care recipients in order to safe-guard integrity and wellbeing. With the aim to describe and analyze care workers experiences of providing intimate care, in this ongoing study so far twelve caregivers working in home help care in Sweden been included. Overarching goals is to identify components that can be used in education and introduction for care workers as well as influence policymakers. Preliminary results show to make the person feel safe and included caregivers use different strategies and skills for different caretaker. Important is that the personnel know the care receiver's routines and preferences. Maintaining a good relationship
is described as hard work, which requires time, ongoing discussions with both colleagues and care receivers. It takes time and effort to build a caring relationship but is important for sustainable care work in the future.
Tronto’s ‘Caring Democracy’ (2013) challenges us to re-think the current economic domination in human life to make caring more democratic and democracy more caring. A growing body of scholars are using care ethics to critique individualised responsibility and withdrawal of state resources within neoliberal welfare restructuring. Based in a relational ontology care ethics provides a theoretical framework for understanding the significance of care in sustaining human wellbeing. This paper draws on a study informed by care ethics as a theoretical framework and relational participatory research approach, to investigate the relationships between risks and responsibilities for older people who are funding their own social care. We argue that the current policy orthodoxy based in market principles and individualised notions of autonomy inevitably generates inequity. But further, for the older people in our study, it generates potential risks to their health and wellbeing through their care needs not being adequately met. The lack of older people’s voices and understanding of their lived experiences of care within dominant policy frameworks illustrates that neoliberal economic framing is both failing to meet social care needs through marketised care and limiting knowledge about care. We consider how researching lived experiences of care can help us challenge this purely economic account based on rational calculations and we argue that this is necessary if we are to move towards the ‘caring democracy’ envisaged by Tronto.


Matthew Bennett
Informal care, wellbeing and chronic stress: A longitudinal analysis in the UK

This paper builds on the growing research using health and biosocial data to explore the link between informal care and health outcomes. Previous research has typically explored cross-sectional data and survey responses on wellbeing, however a growing body of literature from the medical sciences has looked at how informal care is related to biological responses and is concerned with longitudinal approaches that increase the credibility of causal inferences. This paper uses longitudinal data and blood samples from 409,031 person-wave observations (adults over time) from 1993-2017 in the British Household Panel Survey (BHPS) and UK Household Longitudinal Study (UKHLS) and explores how informal caring responsibilities are related to biomarkers associated with chronic stress (C-reactive protein and fibrinogen) and subjective wellbeing (GHQ – General Happiness Questionnaire). We hypothesize that informal carers are more likely to experience chronic stress and reduced wellbeing compared to those that do not have caring responsibilities. We also test for ‘dosage’ effects where a greater intensity of informal care will be associated with chronic stress and reduced wellbeing. Finally, we test for differences for those with caring responsibilities for people within the home compared to outside of the home; and whether there are differences between who is being cared for e.g. a spouse, parent, child or extended family member.

Patrick Hall
The ‘cyclical turn’ in UK social care policy? Temporality, modernisation and community

Comparative social policy research often implies a linear approach: placing nations in an order of ‘progress’ toward some ideal: normally defined in terms of maximum individual liberty. This linear account of time fits with the sociological understanding of modernity (e.g. Giddens, 1990) as a process of moving forwards, as the ‘displacement of everything that has gone before’ and ‘detraditionalisation’ (Heelas et al, 1996, cited in Hood et al, 2010, p10).
Modernisation is characterised by a ‘break with pre-bureaucratic governing principles and forms of authority, such as sovereignty or kinship’ (Margetts, 2010, p.41). This understanding of modernity is reflected in some feminist accounts of ‘defamilialisation’: a normative and descriptive concept of the process of ‘socialising’ care (through state provision) to maximise women’s individual freedom and choice regarding care.

Communitarians (Wuthnow, 1993), care ethicists (Noddings, 2002) and social capital theorists (Bellah, 1994) have long highlighted to the importance of kinship and community as well as the dangers of undermining their normative importance in modern societies for the provision of care. Interestingly, where these processes of modernisation are most advanced, we can observe a process of a ‘turning-back’.

Emerging discourses of care (asset-based, co-produced, community-development) could be seen as a return to mutual aid and communal types of care which were replaced by modernisation (Duffy, 2014). Cottam describes professionals working in more asset-based and relational ways as going through ‘a stripping away of learned institutional behaviours and a recovery of purpose’ (2018, p.67). Our paper will discuss these ideas and present findings from our ‘Comparing UK Care Systems’ interviews regarding these discourses.

Amy Horton

Interdependence: Contested interpretations and experiments in alternative residential care in the UK and USA

Affiliation: UCL Geography

This paper explores ideas and practices of interdependence, as the basis for care systems. It aims to refine the conceptualisation of interdependence that has been developed in feminist care ethics (Clement 1996; Held 2005; Tronto 1993; Barnes 2006; Raghuram 2016) and by movements of care workers and service users. This theoretical work informs a proposed research agenda, which focuses on ways of implementing interdependence. Empirical material is drawn from analysis of care company reports, as well as interviews with diverse actors in the care systems in the UK and US, and observation of activist workshops. First, I show how interdependence contrasts with the fragmentation and financialisation that characterise care homes for older adults in England. Second, I draw out different interpretations of interdependence that have been deployed by movements of carers and older people: relational, economic and political. Third, I outline plans to research alternative ways of organising residential and nursing care that could better enact interdependence. The proposal is to study selected experiments in building an intergenerational movement around care; in developing democratic land ownership, capital investment and control of operational costs; and in the radical co-production of spaces of care.
The amount and quality of support available to the 8.8 million unpaid carers in the UK varies widely across the country. High quality and consistent support not only benefits carers’ health, wellbeing and resilience but also enhances the life of the person being supported e.g. it helps reduce hospital admissions and facilitate timely discharge.

The subject of this paper is the National Institute for Health and Care Excellence (NICE) guideline “Carers: provision of support for adult carers” that was published in January 2020. With increasing service integration, the significance of NICE recommendations on social care is now equal to that of their counterparts in in health service settings in the UK.

This guideline makes action-oriented good practice recommendations for professionals providing support that enhances the wellbeing, resilience and life experience of adult carers providing unpaid care for anyone aged over 16 with health and social care needs. Based on the best available evidence of effectiveness, including cost effectiveness, the recommendations focus on:

- helping people to recognise themselves as a carer and understand their right to information and support
- identifying and assessing carers
- providing information; practical, emotional and social support; and training
- supporting carers to remain in, start or return to work, training or education
- end of life care support

This paper will present these recommendations and stimulate discussion in the light of their implications for the sustainability of unpaid care, thereby addressing several conference themes. The NIHR recommendations can be implemented by anyone working with carers in order to ensure that the support they need is not just delivered but actively enhanced, both during the pandemic and as services adjust to post-pandemic life. To promote the debate about implementing further improvements in practice, the key research recommendations made by the guideline committee will also be outlined.

Liliya Zenina

Older people with disabilities during the COVID-19 in Russia: differences between the governmental and NGOs’ approaches

The ongoing state policy to engage nonprofit organizations to social service provision has translated into the Special grant of 2020 against the COVID-19 by the Presidential grants Foundation. The analysis of 223 projects for older people with and without disabilities revealed the paternalistic attitude towards older people, limited directions of help, issues with conceptualization and used terminology, which maintain exclusion and negative stereotypes. The language and ideas of the state anti-pandemic recommendations became problematic in context of equality and rights of older people. Restrictions imposed by the local governments in different Russian regions on older people have heightened issues of perception and self-identification of older persons and people with disabilities.

In this regard, I questioned whether activities of independent NGOs differ from the governmental policy during the COVID-19 pandemic in Russia.

Projects of NGOs and initiative groups supported by the nongovernmental grant operator the Timchenko Foundation and Raiffeisenbank differ in the used terminology, demonstrate a higher diversification and orientation on inclusion. The quarantine measures caused by the COVID-19 highlight the importance of horizontal connections of seniors with disabilities and involved NGOs, social workers, friends and relatives.

Promoted by the White Cane NGO, the concept of extratability overcomes the pitfalls of medical and social models of interaction. Interviews with experts and older people with disabilities raise issues of social cohesion and lifestyle changes acceptance due to the COVID-19, and describe solutions to tackle the COVID-19 situation as a hybrid format of online events and ideas for employment.
Maria Cheshire-Allen
Understanding family carer wellbeing in Wales during COVID-19

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This article aims to contribute to our understanding of wellbeing in the context of family care during the time of the COVID-19 pandemic within Wales, UK reporting on primary data based on 30 semi-structured interviews with family carers caring for older people. Based on a theoretical framing informed by contemporary critical theorists of care (Tronto, 2013; Barnes, 2012; Sevenjuisen 1998) and wellbeing (Cunningham, Cunningham, Litt and Robertson, 2019; McGregor and Pouw, 2017) it addresses the extent to which key aspects of current theoretical and policy debates on wellbeing are reflected in the lived experience of family caregivers during the time of the pandemic and reflects upon three central questions: 1) What does “wellbeing” mean to family carers of older people in the context of COVID-19? 2) How does this version of wellbeing relate to contemporary conceptualisations of wellbeing in care? 3) What specific aspects of carer wellbeing are affected by the COVID-19 crisis and what policy responses might ameliorate their situation? The authors reflect on researching with carers during the time of the initial lockdown in Wales where some participants report deep personal struggle and hardship due to restrictions on support. They discuss the application of a participatory ‘research with care’ approach (Barnes and Brannelly, 2020 forthcoming) that demands particular attention and an ‘integrity of care’ (Tronto, 1993.) Findings are discussed and applied to contemporary debates concerning ‘caring democracies’ within the context of Covid-19.

Outi Jolanki
Business as usual? The meaning of Covid-19 pandemic for the well-being of older people living in service housing in Finland

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The Covid-19 pandemic has affected the lives of each and every one, but due to their age older people have been subjected to most strict mobility restrictions. In Spring 2020 the health authorities and the Government of Finland recommended for people aged 70+ to avoid meeting other people and remain indoors as much as possible. The visits of family members or other outsiders in service housing were forbidden. In summer the restrictions were eased and meetings made possible outside the premises and finally again indoors, if the safety measures (30 minutes time limitation, distance, 1-2 visitors a time, masks) were taken. In this study we ask what has been the effect of the mobility and meeting restrictions on well-being and daily lives of older people living in service housing.

The study draws from theories of social well-being and geographical gerontology. Data come from phone interviews of 31 people conducted June – August 2020 (19 women, 12 men). The age range of the interviewees varied from 64 to 96. Interviews were recorded and transcribed. Data is analyzed with a positioning analysis and environmental positioning analysis. In the analysis we study the descriptions of service housing in the interviews of people living in service housing (9), and of those visiting them on a regular basis.

The results showed that the Covid-19 pandemic had not much affected the daily routines and care delivery. The residents portrayed the life within the walls of the premises largely unchanged with one important exception. Social life of the residents had seriously impoverished and loneliness had increased. Digital technology alleviated the hunger for social contacts for some, but did not replace the longing for meeting people in person and the need for a human touch. The meeting restrictions meant to save lives were seen to bring unnecessary suffering for people with memory problems and those unable to spend time with their dying family members. The service housing unit was portrayed as a place which met the basic needs of the residents, but social and mental well-being required contacts with people outside.