Convoys of Care: How do Carers Shape, Adapt and Utilise their Networks for Caring?

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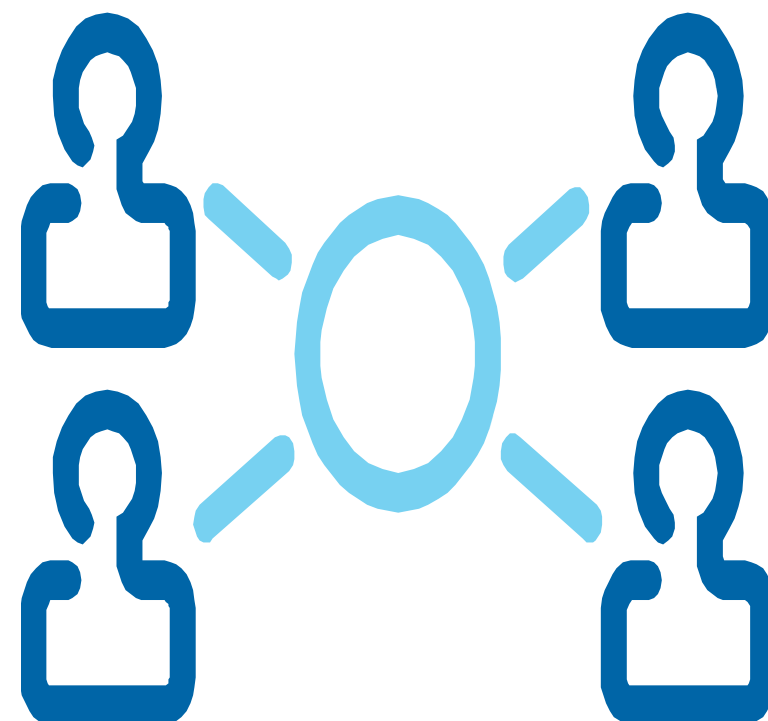
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Background

- In England carers have been part of Government Policy for 20 years (HM Government; 1995; 1999; 2008; 2012; DH, 2008; 2010(a-f))

- The recent Care Act (2014) changes legislative landscape

- Changing demographics, financial pressures and reduced funding for health and social care delivery is pushing the burden of care on to individuals, their families and friends (Independent Commission on the Future of Health and Social Care in England, 2014)

University of Hertfordshire UH

THE ONE HUNDRED UNDER FIFTY

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Background

- The numbers of carers is increasing and society will rely on the significant contribution that carers make (Wanless, 2006; ONS, 2013)

- Policy and discourse emphasise the role of co-production, personalisation, building community capacity and social capital, in developing and extending individuals' and carers' networks (Office for Public Management, 2009; HM Government, 2007, 2012; NHS England, 2014)

- How social capital and social networks influence and shape carers' lives and their role is relatively unexplored in the UK

- Furthermore there has been little exploration of the interplay between the different support networks particularly in relation to health, social care and the charitable, voluntary and community sectors

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The Study

Aims/Objectives

To determine:

- The structure of carers networks and their utility in the caring role

- The inherent resources within the network, including flows of information, leverage and how access is achieved

- Negative features within the networks that can be detrimental to the carers' role

- The presence of health and social sector services alongside other community provision within these networks and their role and function to the carer

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## The Study

Case Study Approach
- Twenty informal carers were recruited via Parkinson's UK

Data Collection and Analysis
- Initial self-administered questionnaire ascertains socio-demographic data and the participant undertakes a self-assessment using the COPE index (Balducci, et al., 2008)

- A questionnaire (based on an exchange approach), semi-structured interview and solicited diary elicit the carers' social networks

- Egocentric network diagrams are generated by the UCINET(v.6) programme (Borgatti, Everett and Freeman, 2002).

- Data analysed using NVivo 10
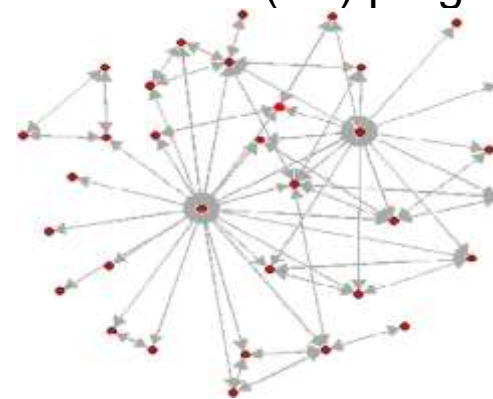
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Theoretical Frameworks

The Social Care Model (Cantor, 1979)
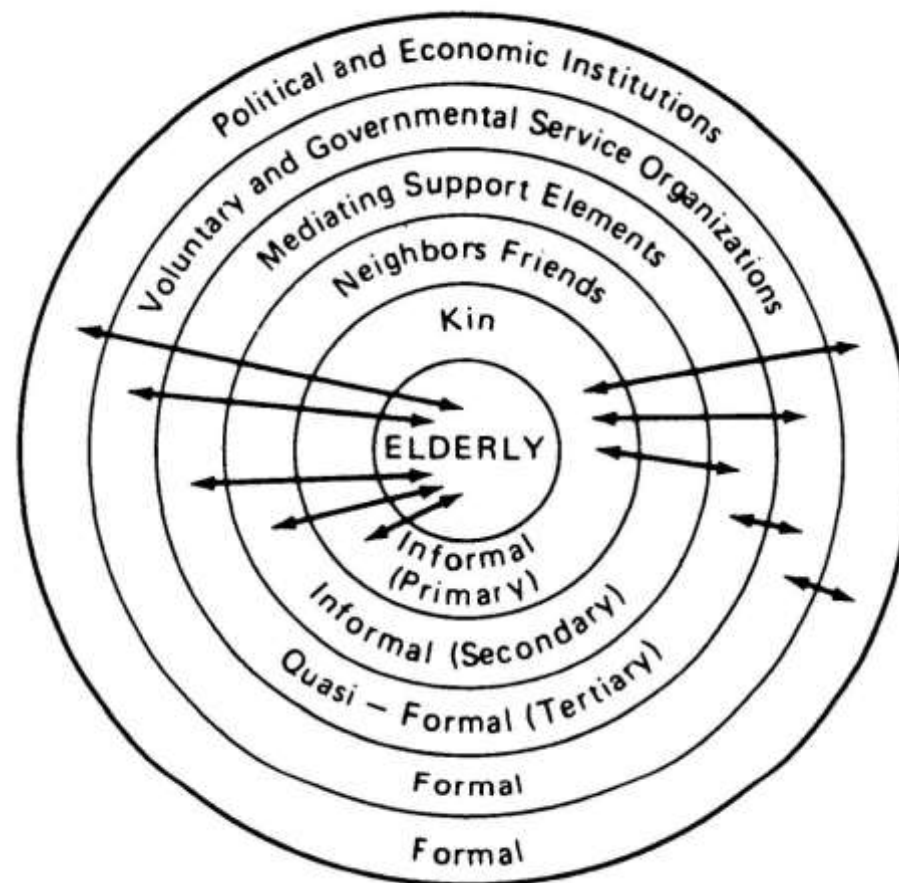
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Theoretical Frameworks

Adaptation of Cantor's Model (1979) by Say (2015)

Processes of exchange and interaction

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Findings

Personal Communities

- *By personal community, we refer to the set of personal relationships that a person considers important for him or her at a particular time* (Pahl and Spencer, 2010: 205)

Features that Shape and Adapt the Carer's Personal Community for their Caring Role

- Network individualism (Wellman, 2002) enables individual communication in cases of migration/ geographical distance
- Fusion (Pahl and Spencer, 2010)
- Reciprocity
- Ambivalence
- Cultural aspects
- Gendered expectations
- Stigma and the effects of a long-term condition on social relationships

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Findings

The Wider Community

Particular Features of the Wider Community that Support the Carer in their Role

- Faith based groups
- Neighbours/ Neighbourhood
- Transport and ease of access to facilities/ support services (health and social care alongside local voluntary and community groups)

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Findings

Third Sector Organisations (TSOs)

- *Third sector organisations is a term used to describe the range of organisations that are neither public sector nor private sector. It includes voluntary and community organisations (both registered charities and other organisations such as associations, self-help groups and community groups), social enterprises, mutuals and co-operatives* (National Audit Office, 2015).

TSOs: Shaping and Adapting Carers' Networks and Aiding the Carer in their Role

- Bonding and bridging social capital are evident in this aspect of the network-information flows and access to further resources are enhanced by '*weak ties*' (Granovetter, 1973)
- Supportive exchanges are numerous with an emphasis on affective exchanges and activities that support physical and cognitive wellbeing

The TSO Network in Action

- Network/Boundary Spanners and Information Brokers can be identified
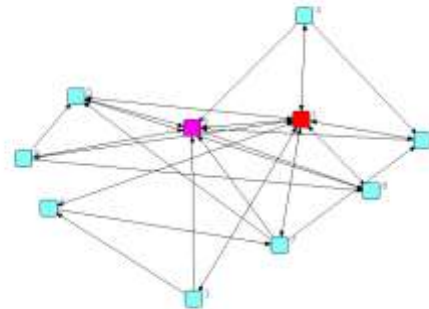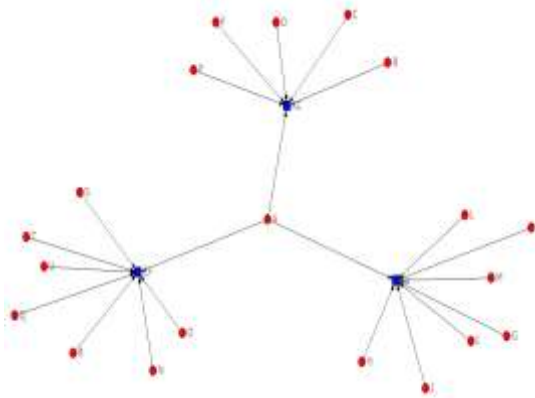
- The internet does act as an important entry gate to accessing voluntary/charity sector services

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Findings

Health and Social Care

Features that Shape and Adapt Health and Social Care Networks for Carers and Care Recipients

- Health and social care professionals need to be effective information brokers/network spanners

- Some carers are very pro-active in shaping the network in order to lever the health resources they need for the care recipient

- Linking social capital (Szreter and Woolcock, 2004) and an integrity of care incorporating attentiveness, responsibility, competence, responsiveness, trust and respect are key aspects of carer interactions with health and social care personnel (Tronto, 1993; Sevenhuijsen,1988 and Engster, 2007)

- Reciprocity, carer validation and navigation around the system are important features

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Findings

Personal Communities (relationships that are given vs. chosen)

Sibling support

For some carers their own siblings or those of the care recipient were vital in providing support. For others, family tensions with their siblings added to their difficulties in providing care

Old friends

For both childless couples in the study, their oldest friends were given as key people who would offer support in times of need

Ambivalence

Several carers were ambivalent about help from close family, including their children. One carer had step-children and her relationship with them was adversely affecting her role

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Findings

Bridging and Bonding Social Capital

Activity via the TSOs (e.g. Parkinson's UK and other carer groups) offers many benefits through 'bridging and bonding' mechanisms….

A1: *in the little break that we had with coffee I was chatting to the girl beside me ahh who's name was Nicky…, and you know you both say…well who do you care for…? Well her mother had PD and she said…oh my mother's joined this wonderful ballet class…and that was it.*

A1: *..yes, so it's a real mixture of people, a real mixture and there's something like 50 – 60 and I think now the numbers up to 70, people in the class...*
you've got someone who's a rocket scientist, you know and he's next to somebody who's a librarian and it, it's just, it's people from all walks of life err and everybody very, very swiftly develops a very easy rapport with each other, umm I've never come across a group like this actually, it's really quite amazing I mean I know you have the bond with this disability…

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Findings

Utilising TSOs
Homophily, functional specificity and stigma may affect which organisations are approached

… a discussion about a local, more general carers' group..

JS: *Oh this is the carers group……but you don't think you're going to go down to that at the moment…*

E5: *I don't know because…it's not as I said,.. just the Parkinson people…people with drug problem, alcohol problem…so I'll be nervous because they can be aggressive…*

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Findings

Accessing resources and support via TSOs

Emotional and wellbeing effects

D4: *Oh I love to sing…*

JS: *Tell me about the singing…*

D4 : *Singing is the best thing of all because when you are singing you can't think about anything else ……………*[the musician] *stomps around in his boots, with the group sort of beating out a melody…and…it's his method and he believes that singings is really good for ill people and singing is good for all sorts of things…*

JS: *Does Nathan enjoy it…?*

D4 : *Gawd yes…he loves it…absolutely loves it…*

JS: *So you go together…?*

D4 : *We always go together umm…and I haven't thought about bloody Parkinson's…*

JS: *Even though you might be with a group with Parkinson's…*

D4 *It doesn't matter…you're not thinking………………...*

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Findings
Emotional Support /Fusion

JS……[re: activity with the Parkinson's UK groups]… *when you say share the load, some of this helps share that, the load, would you say…?*

A1: *not the day to day load, it, it shares…what it does is it…it makes having this condition, living with this condition, far more bearable and has a far more positive, I can't say a positive side to it…but as you know Sam said once…there has to be some positives in this…you know, you're lumbered with this awful condition and thank God we've found some positives in it …..…well because we've been blessed in, erm, finding these wonderful support groups which have turned into wonderful friendships, people we can't wait to spend time with because there's so much happiness……….. and yes fun, lots and lots of laughs, lots, lots of touching, lots of hugs………...a whole new world's opened up to us…who would have thought all those years ago, Sam would have been going to a [dance] class…I mean its just………unthinkable…*

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Findings

Health and Social Care Networks: Positive and Negative Features

Effective information brokers/network spanners

[GP referral to a new low vision service]

A1: [to the GP re: eye clinic]…we *said we still hadn't heard from them,…. so I was discussing this with the GP one day and he said…look I have just come into contact with this centre, I even went down to it…*

Difficulties in navigating the network

[Carer talking about early contact]

H8: *it was..mind boggling..getting hold of the OT..the physio ..they changed offices in X...the girls gone back to Australia…the telephone number changes., that was an awful few months…*

Carer validation

[Carer talking to the neurologist and team]

B2: *and he had a group of students there when I spoke about myself and…they clapped because they admired the, the way I came out with different things…*

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Findings
Health and Social Care Networks: Shaping the Network

Carer Pro-actively Shaping the Network

B2: *I got a new Consultant…it's been the making of Bert…anyhow when I spoke with…… Doctor S…Professor S…I said to him what I was doing…and I said would you take us under your wing…and he agreed…*
I just did it…just transferred myself…so I said umm…if I can't have another Consultant I'll go to another hospital…I was that adamant…………..
Yeah…and we also changed GP's, I was under Clive Street…didn't like her…she never acknowledged me as being with Bert… No I found another GP…the one in Mill Street and they're very good…

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Evaluation, Dissemination and Future Work

- Utilising a social care model and the concept of social capital have offered theoretical perspectives to examine the social relations of carers and care recipients.

- Social network analysis is an effective means of examining how these social relations develop and interact

- The methods used were complementary, carer visualisation of their networks generated from name generator and diary entries offers an effective technique and enhanced exploration of the network at interview

- Dissemination is planned with Parkinson's UK, clinical commissioning groups and carer hubs

- Mapping social networks of carers, care recipients and local community-wide groups offers potential to identify how care networks operate in 'real time'

- Visualisation of these networks could aid co-production of evolving services, enabling targeted support to strengthen and develop the networks further

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Thank-you and Questions

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References

- Balducci, C., Mnich, E., McKee, K. J., Lamura, G., Beckmann, A., Krevers, B., et al. (2008) Negative impact and positive value in caregiving: validation of the COPE index in a six-country sample of carers. *Gerontologist,* 48(3), 276-286.
- Borgatti, S., Mehra, A., Brass, D., & Labianca, G. (2009). Network Analysis in the Social Sciences. *Science, 323*(5916), 892-895.
- Cantor, MH., (1991)Family and community: changing roles in an aging society. *Gerontologist*;31:337–46.
- *Care Act* 2014*, ch.23*. Available at: http://www.legislation.gov.uk/ukpga/2014/23/pdfs/ukpga_20140023_en.pdf.
- (Accessed: 24th August, 2015)
- Department of Health (2010a). *Recognised, Valued and Supported: Next steps for the carers strategy*. London: Department of Health.
- Department of Health (2010b) *Carers and Personalisation: Improving Outcomes*. London: Department of Health.
- Department of Health (2010c). *Equity and Excellence: Liberating the NHS*. London:
- Department of Health (2010d). *Practical Approaches to Co-production*. London: Department of Health.
- Department of Health (2010e). *Practical Approaches to Improving the Lives of Disabled and Older People through Building Stronger Communities*. London: Department of Health.
- Engster, D. (2007) *The Heart of Justice. Care, Ethics and Political Theory.* Oxford: Oxford University Press.
- Granovetter, M. (1973). The Strength of Weak Ties. *American Journal of Sociology, 78*(6), 1360-1380.
- HM Government (1995) *Carers (Recognition and Services) Act*, London: TSO.
- HM Government (1999). *Caring about Carers: A National Strategy for Carers*. London: TSO
- HM Government (2007). *Putting people first: A Shared Vision and Commitment to the Transformation of Adult Social Care*. London: TSO.
- HM Government (2008). *Carers at the Heart of 21st Century Families and Communities.' A Caring*
- *System on Your Side. A Life of Your Own'*. London: TSO
- HM Government (2012) *Caring for our Future: Reforming Care and Support*. London:TSO.
- Independent Commission on the Future of Health and Social Care in England (2014) *A New Settlement for Health and Social Care.* The King's Fund: London.
- National Audit office (2015) *What are third sector organisations and their benefits for commissioners?* Available at: **http://www.nao.org.uk/successful-commissioning/introduction/what-are-civil-society-organisations-and-their-benefits-for-commissioners/** (Accessed 24th August 2015).

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References

- NHS England (2014) *Commitment to Carers*. Available from http://www.england.nhs.uk/wp-content/uploads/2014/05/commitment-to-carers-may14.pdf (Accessed 24th August 2015).

- Office for National Statistics. (2013) 2011 Census Analysis: Unpaid Care in England and Wales, 2011 and comparison with 2001. Available from: http://www.ons.gov.uk/ons/dcp171766_300039.pdf (Accessed 24th August 2015).

- Office for Public Management (2009) *Social Capital, Co-production and the Delivery of PuttingPeople First: Scoping a Framework for Social Capital*. London.

- Pahl, R., and Spencer (2010) Family, Friends, and Personal Communities: Changing Models-in-the-Mind. *Journal of Family Theory & Review* 2: 197–210.

- Sevenhuijsen, S. (1998) *Citizenship and the ethics of care. Feminist considerations of justice, morality and politics.* London and New York, Routledge.

- Szreter, S. and Woolcock, M. (2004) Health by association? Social capital, social theory, and the political economy of public health. *International Journal of Epidemiology:* **33**:650–667

- Tronto, J. (1993) *Moral Boundaries. A political argument for an ethic of care*. London and New York: Routledge.

- Wanless, D. (2006). *Securing Good Care for Older People : Taking a Long-Term View*. London: King's Fund.

- Wellman, B. (2002) *Little boxes, glocalization, and networked individualism*. In Makoto Tanabe, Peter van den Besselaar and Toru Ishida (eds.), Digital Cities II. Berlin: Springer. p. 10-25.