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Mapping Care: A Case Study of Dementia Service Provision in the North East of England

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Abstract

This paper reports on the first author's ongoing Arts and Humanities Research Council (AHRC) funded PhD research, exploring the potential for design disruption interventions within the context of informal health and social care.

The paper describes a specific project to map the experiences of people caring for dementia patients, exploring their interactions with governmental and charitable support organisations, their perception of the services available to them, and other informal methods they employed to cope with the caring role.

The findings offer a new way of visualising the complex interrelationships between these organisations, and highlight a number of important issues faced by informal carers. These include a pressing need for clearer, more accessible support pathways, clarification of the role and duties of some support organisations, and the value of intangible forms of assistance such as emotional support. These findings will form the basis for future disruptive design interventions in this area.

KEYWORDS: design disruption, mapping, health, social care, informal, intervention, carer, dementia, visualization, timeline, PhD, research, experience

Introduction

In the UK, almost 6 million people provide unpaid, informal care for a family member or friend who couldn't manage to live independently or whose health or wellbeing would deteriorate without their help. This role can include caring for a person (or for multiple people) who are ill, frail, disabled, or have mental health or substance misuse problems.

The vast majority of health and social care in the UK is provided by these unpaid informal carers. This saves the UK taxpayer over £119 billion per year (Carers UK and the University of Leeds, 2011). In England, around 3 million households contain an unpaid informal carer, which represents huge social care and NHS cost savings. The official figures from the 2011 Censuses show that there are 25,810 adult carers living in Newcastle upon Tyne, which is

almost 10% of the city's population. Although the role and experience of informal carers is unique to their situation, and caring can be a rich source of satisfaction, it is also known that they have a significantly increased risk of mental and physical health problems. Thus, it is very important that we identify informal carers so that we can provide much needed help and support such as the unique and innovative disruptive design workshops that will re-imagine social and health care through participative design events. This has the potential to achieve more than simply ploughing more money into social and health care would achieve on its own.

Anyone can become a carer; carers come from all walks of life, all cultures and can be of any age. Many feel they are doing what anyone else would in the same situation; looking after their mother, son, or best friend and 'just getting on with it'. Carers experience many difficulties in their caring situations. For example, a carer could be someone looking after a new baby with a disability or caring for an elderly family member with complex needs. In the UK, informal carers are the largest source of care and support. Of 4,935 carers surveyed nationwide, 56% stated that they provide unpaid care for 90 hours or more each week (Carers UK, 2015). However, the demands of the caring role can lead to a number of other related problems including:

- » Carers facing a life of poverty, isolation, frustration, ill health and depression.
- » Carers giving up a regular financial income, future employment prospects and pension rights.
- » Carers juggling several jobs with their caring responsibilities.
- » Carers struggling alone not knowing that help is available to them.
- » Carers lack access to information and financial support that are vital in managing the impact of caring on their own lives.
- » Carers with multiple caring roles - often referred to as "sandwich carers" – who are frequently older women who care for relatives (e.g. a mother with dementia and a daughter who misuses drugs).

This paper will describe an ongoing Arts and Humanities Research Council (AHRC) funded collaborative project with Newcastle Carers, an independent charity working in the areas of health and social care. They provide carers with expert, confidential, non-judgemental, and impartial assistance. This assistance takes the form of information and advice, guidance, emotional and practical support groups, activities, training, one-to-one counselling, and complementary therapy. They also work with local communities and professional services to raise awareness of the problems faced by carers. Newcastle Carers also conduct individual assessments of carers and the people they care for, and make referrals to appropriate organisations for specialist support services.

Aims and Objectives

The aim of the research is to develop disruptive design interventions (*e.g.* products, systems, services) for breaking the cycle of well-formed opinions, strategies, mindsets, and ways-of-doing, that tend to remain unchallenged in the caring of vulnerable individuals in the UK. Example interventions include "sticker" campaigns, "fortune cookie" services for restaurants, "lamppost data" prompts, and others (see <http://designdisruptiongroup.wordpress.com/> for more examples). Disruptive Design is an approach that the academic members in the HEI lead partner (Rodgers and Tennant, Northumbria University) have developed over several years. A disruptive design approach

encourages the development of richer, more varied solutions to everyday issues by emphasising fun (Bisson and Luckner, 1996), “safe failure”, and doing things in ways that participants wouldn’t normally do. It utilises “the cloak of creativity and apparent silliness” (Michlewski, 2015) to seek new insights that can lead to innovative ways of doing. In essence, the disruptive design techniques and approaches provide opportunities for users to experiment in a relaxed, stress-free environment with expert facilitators.

This is in sharp contrast to existing strategies of public service design, characterised by “disjointed incrementalism...where services are altered and adapted by changing political drivers, professional fashions, shifting institutional norms and boundaries, and the biased lessons of past experience” (Design Commission, 2014).

Most of the research in public health seeks to evaluate intervention effectiveness and value for money. By contrast, design disruption embraces experimentation, and consequent failures, as an integral part of dynamic systemic change, embracing the mantra of *Worstward ho* – “Ever tried. Ever failed. No matter. Try again. Fail again. Fail better.” (Beckett, 1983) – as a path towards unexpected, radical change. Design disruption focuses on “trial and error, hunches and experiments that only in retrospect look rational and planned” (Mulgan *et al*, 2007).

We propose to develop and test a series of disruptive design interventions and assess how they might improve carers’ lives in the North East of England. This research builds upon the established relationship between Newcastle Carers and Northumbria University, in which disruptive design workshops have helped carer support workers create a “charter of care” to help them explore and articulate the values underpinning the service (Rodgers, Tennant, and Dodd, 2014). Given the extremely challenging nature of the informal caring situation in the UK, the main aims of the collaborative research are to:

- » Help change society’s perceptions of caring in the UK through a series of disruptive design interventions (*i.e.* products, systems, services).
- » Create a series of designed interventions that will help carers access support before they hit “crisis point” when their health is sometimes irreparably damaged.
- » Help identify the major day-to-day consequences of caring for people through the use of disruptive design techniques and approaches.
- » Consider how prevention and early intervention (*e.g.* designed products, systems, services) could enable carers to have greater choice and control.
- » “Formally invite” carers to participate/collaborate in the creation of the designed interventions.

Research Questions

- » How can disruptive design interventions help ensure that all carers will receive greater choice and control in their lives?
- » What role can disruptive design interventions (*i.e.* designed products, systems, services) play in improving the physical, mental health and wellbeing of carers?
- » Can disruptive design interventions support informal carers to have a life of their own outside of their caring role, including a social life, in work and education and training?
- » Can disruptive design interventions contribute to ensure that carers do not suffer financially as a result of their caring role?
- » Can disruptive design interventions help ensure that carers are treated as expert partners in care?

Mapping Care: A Case Study

The methodology proposed here adopted an iterative mixed-methods approach, useful in the capture of both quantitative and qualitative information, which has advantages over other research approaches particularly relating to the development of reliable explanations (Cresswell, 2003). Utilising research approaches and tools such as participatory design, ethnography, interviews, and cultural probes (Gaver et al., 2004), the research focused exclusively on people caring for family members diagnosed with dementia in its various forms, including Alzheimer’s Disease, Vascular Dementia, and Lewy Bodies.

Individual carers were interviewed by the first author (Designer) in early 2015. The carers were encouraged to speak openly and honestly about their experiences as carers, from when they first noticed a (typically very minor) deterioration in the patient’s cognition, until the present day. Particular care was taken to establish which statutory and charitable organisations the carer interacted with during this period. The carer was also asked to explain whether they felt these interactions were positive, negative, or neutral.

During these interviews, the Designer created colour-coded “maps” to show the interactions between the carer, the patient, and the various organisations involved. These maps helped to visualise not just the carers’ individual experiences, but also the relationships between the organisations, providing “rich descriptions of processes in identifiable local contexts” (Miles and Huberman, 1994).

Historical Context

These maps of “emotional experience” take inspiration from artists including Adolf Wölfl, who created richly detailed artworks of his own imaginary life story through the prism of his mental illness, “imposing his own sense of order on it” (Harmon, 2004). Similarly, Guy Debord stated that the Situationists’ forays into psychogeography were an attempt to examine the “specific effects of the geographical environment...on the emotions and behaviour of individuals” (O’Rourke, 2013) – subjective, fragmented, and a direct challenge to “the rational city” (Sadler, 1999) imposed upon the citizens of Paris (Figure 1 - right). Likewise, Lars Arrhenius’ urban maps (Figure 1 – left) are created to reveal “those spaces that conventional cartography would ignore” (Arrhenius, Ryman, and Wilson, 2003).

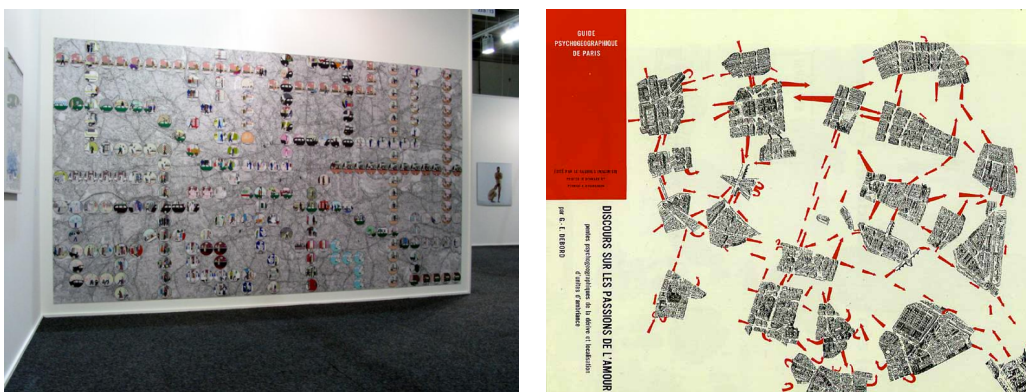


Figure 1. Lars Arrhenius, A-Z (2002)ⁱ (left) and Guy Debord, Psychogeographic Guide to Paris (1955?)ⁱⁱ (right)

Lars Arrhenius' *A-Z* is a map charting overlapping events in the lives of 18 protagonists operating within the same landscape. "Arrhenius' stories of everyday life interest both meaningfully and apparently randomly to relay everyday emotions...all of which play out on a directly experimental, if wordless, level, and which the reader fills in as another rewriting" (Arrhenius, Ryman, and Wilson, 2003). Arrhenius' map proposes questions and makes observations, but offers no specific answers.

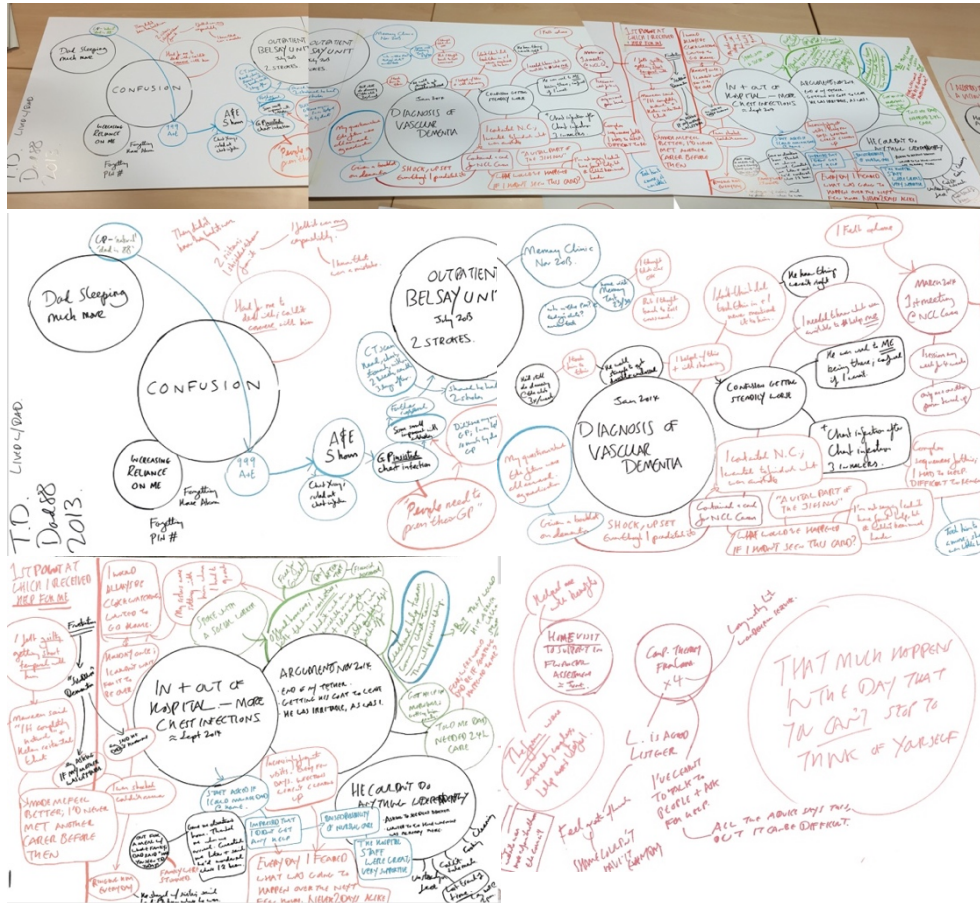


Figure 2. Samples of colour-coded "carers experience maps" created by the First Author during interviews with informal, unpaid carers. 11 maps were created, detailing the experiences of 11 individuals caring for family members suffering from dementia.

In decoding the recorded data, the Designer experimented with a number of different visualisation styles (Figure 2). The following examples (Figures 3 to 8) show different interpretations of a single carer's map across the period 2012 – 2015.

Visualisation Iteration 1



Sample of a map created during an interview with a carer, spanning the period 2012 - early 2015

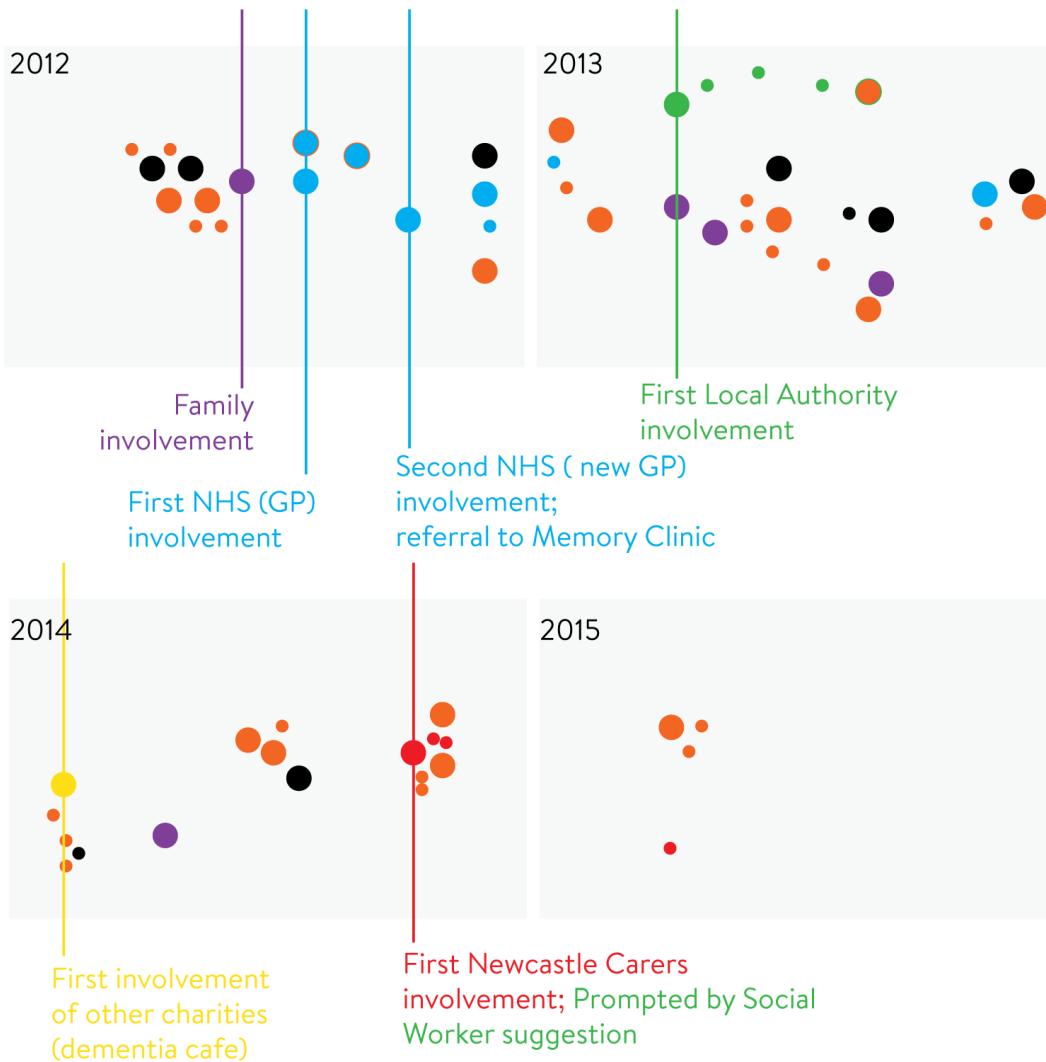


Figure 3. Initial Attempt to Decode Map Data

The various services accessed by the carer are distinguished by colour. Placement of the circles correspond to their position on the hand-made maps created during each interview. This interpretation removes almost all text from the original data, which limits their usefulness, although it does highlight that Newcastle Carers did not become involved until over 2 years after the carer first sought assistance from their GP.

Visualisation Iteration 2

This second attempt to decode the map data focussed on separating the individual services into distinct timelines (Figure 4). Arrows point up to indicate a positive interaction, and down to indicate a negative one. Circles indicate a “neutral event”, i.e. one which is objectively neither positive nor neutral. Explanatory text next to each event gives further information about the specific issues encountered by the carer. However, separating the information into distinct timelines makes it more difficult to recognise connections between the actions of different groups and organisations.

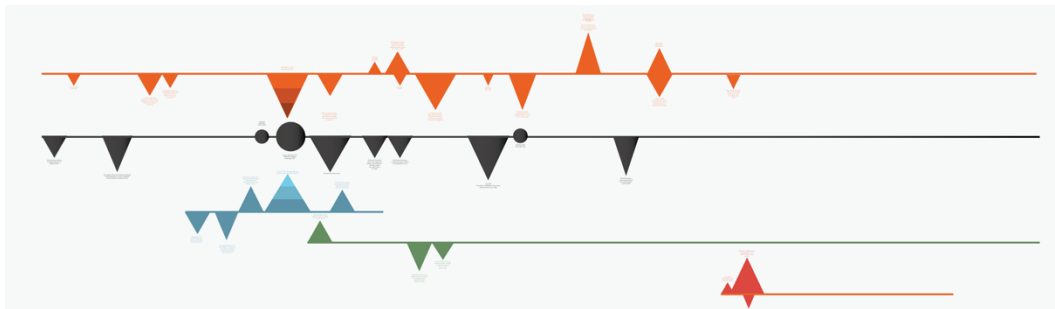


Figure 4. Second Attempt to Decode Map Data

Visualisation Iteration 3 (final iteration)



Figure 5. Key developed for the final iteration of the map data

Figure 5 details the Key developed for the final iteration of the map data. Each colour corresponds to a different organisation, group, or service involved in the carer’s experience.

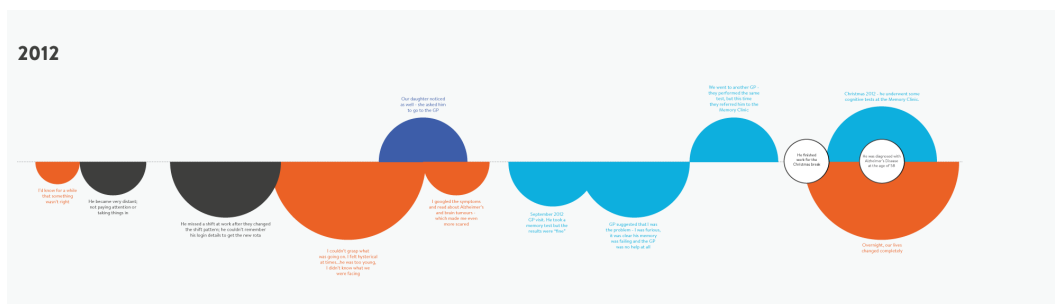


Figure 6. Carer’s Journey, 2012 (Final Iteration)

Each map is divided by a horizontal line in the centre of the page (Figure 6). All information above the line corresponds to a “positive” interaction; all information below the line indicates a “negative” interaction. Explanatory text offers further context to each of these interactions. This map shows a gradual build-up of negative experiences, interspersed by some positive assistance from friends and family, as well as the NHS.

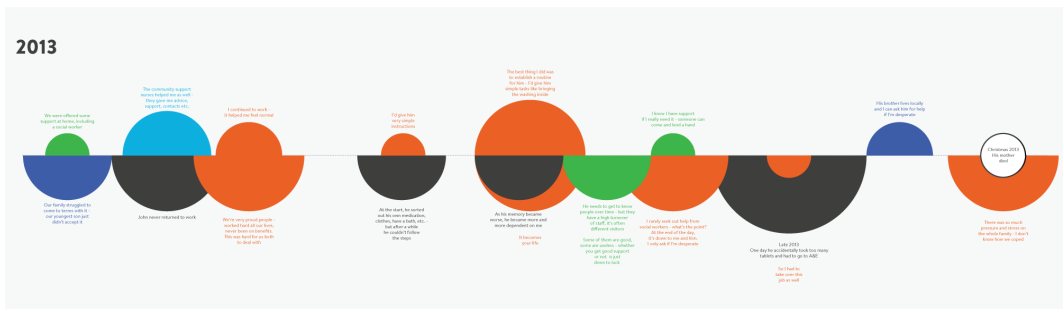


Figure 7. Carer's Journey, 2013 (Final Iteration)

The following year (2013), this carer continued to experience significant difficulties, with only occasional positive experiences (Figure 7).

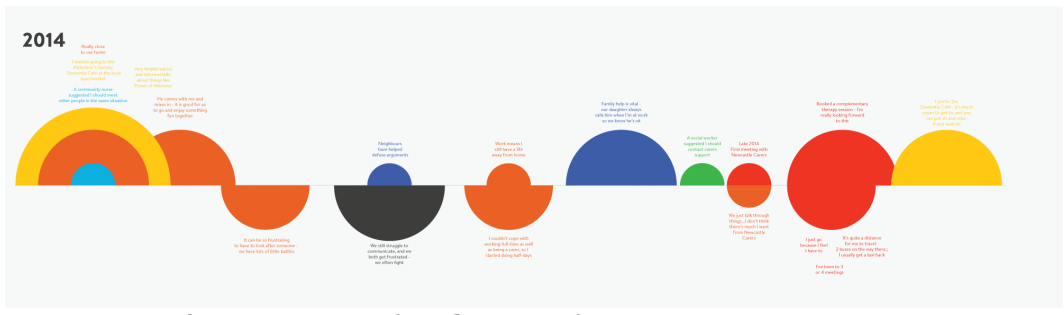


Figure 8. Carer's Journey, 2014 (Final Iteration)

At the start of 2014, this carer accessed a “Dementia Café” support group run by the Alzheimer’s Society (far left). This led to a number of positive emotions and interactions (Figure 8). The carer began to access Newcastle Carers’ service towards the end of 2014 (far right), which prompted a mixed response as she considered the Dementia Café to be more useful. The negative experiences continue, although they are significantly mitigated after the carer accessed support for her own needs.

Notation System

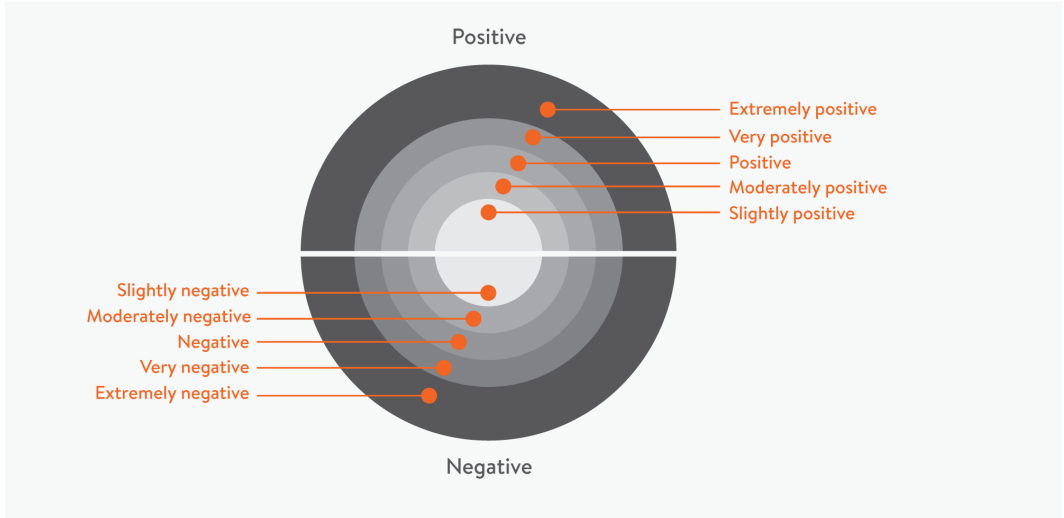


Figure 9. Data Map Notation System

The notation system employs a Likert scale (Likert, 1932) to measure the significance of the issues raised by each carer. The larger the size of each semicircle, the more significant the

carer considered this interaction to be (Figure 9). Carers were invited to a second interview to decide the size of each section, to ensure it accurately reflected their views. The key advantage of this notation system is that allowed the first author to make clear connections between organisations and incidents which might otherwise be unclear. The notation system also allowed the Designer to highlight simultaneous positive and negative outcomes – for example, in situations where the carer experienced a problem but found an effective solution (Figure 10).

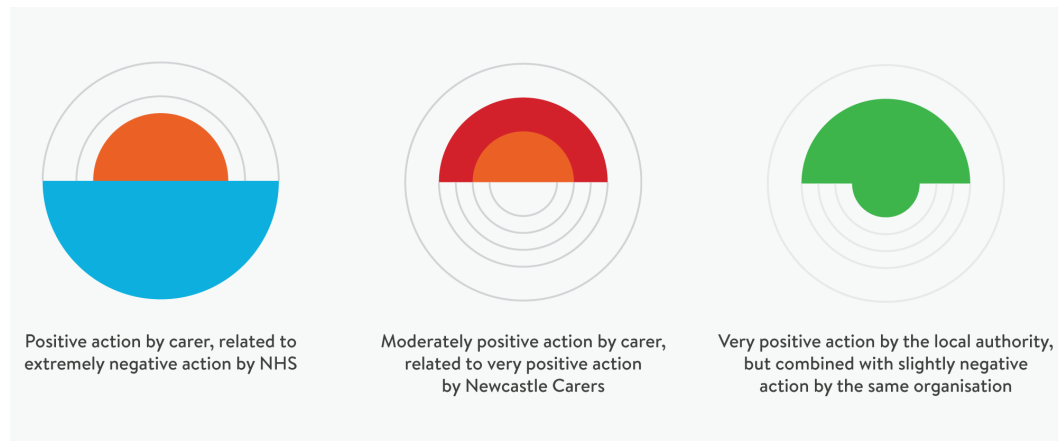


Figure 10. Notation System highlighting relationships between different forms of health and social care support

Figure 10 demonstrates how this notation system can highlight and explore relationships between different forms of health and social care support.

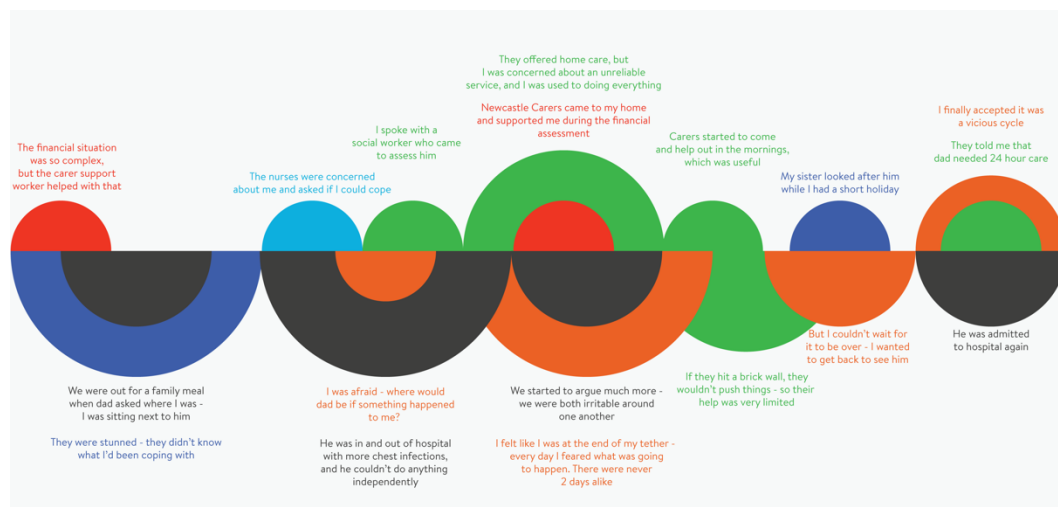


Figure 11. Carer's experience map illustrating the complex interactions between groups and organisations involved in care provision

Finally, Figure 11 shows a detail of one carer's final experience map. It visualises the complex interactions between the numerous groups and organisations involved in supporting the carer and patient.

Data Interpretation

11 carers were interviewed for this project. The complete maps can be viewed at <http://www.cargocollective.com/danielcarey>. Each map is manifestly different from the next; some span over ten years, whilst others are comparatively brief. Each map is an artefact offering crucial insights into the experiences of the individual carer. In common with Arrhenius and Debord, these artefacts offer no specific answers; instead, they raise questions

about how carers engage with existing health and social care services, and prompt consideration of whether these services could or should be disrupted.

Observations

Information Sharing

Carers expressed frustration at having to provide a full account of their problems each time they accessed a new service. This is particularly burdensome during a crisis, when the carer may be experiencing significant physical or emotional pressures. Carers further explained that when services did share information, vital details were often not passed on (Figure 12). Some carers expressed a wish that all services could access and add to the same information – providing each service with a complete and accurate account of the carer’s circumstances – rather than placing this burden on the carers themselves.



Figure 12. Completed timelines on display at Institute of Design Innovation, Glasgow School of Art

Clearer Pathways

In all accounts, carers’ first contact with dementia services came via a meeting with a General Practitioner (GP) doctor service: either their own GP or that of the cared-for person. Carers explained that they knew to make this contact because of a previously established relationship with the GP, and an understanding that the GP would be able to assist them in some way. In most cases, the cared-for person was referred by the GP for further tests and assistance from specialist dementia services in the region. In other cases, this referral did not take place, or the specialist dementia services did not provide any information to the carer. As a result, the carer was left unaware of the support services available to them, and instead left to cope alone. This typically resulted in the carer struggling to cope with the demands of their role, resulting in crises where the health of the cared-for person deteriorated to the extent that lengthy hospital admission or respite care was required.

This lack of support also had a significant impact on the carer – interviewees complained of social isolation, depression, guilt, feelings of marginalisation and anxiety, and dependence on government benefits after being forced to give up paid employment in order to care full-time. Carers Support Allowance, the government benefit paid to eligible carers on a weekly basis, stops when the carer becomes eligible for the UK state pension. As a result, carers who come to rely on this benefit whilst in employment find that they are no longer eligible to receive it once they retireⁱⁱⁱ. These complaints are typical of the “malignant social psychology” (Kitwood, 1990) encountered by dementia sufferers themselves. The complexity of existing systems of support “remain difficult to understand and navigate – leaving many carers missing out as a result” (Bucker and Yeandle, 2011).

This consistent GP engagement stands in sharp contrast to the seemingly random nature of referrals to carer support services, including Newcastle Carers. No two interviewees came to Newcastle Carers through the same referral process. In some cases, these referrals were made by community nurses or hospital staff; in other cases, carers received contact details via other charities, flyer campaigns, or community outreach work by Newcastle Carers staff. Since Newcastle Carers estimate that they currently assist fewer than 10% of the total number of carers in their catchment area, this suggests that a more consistent referral process could help ensure that a larger number of carers are given information about the services available to them. For example, GPs could be enlisted to identify and refer family carers whenever they encounter a new patient suffering from dementia.

Role of the Local Authority

The carers’ experience of local authority intervention (primarily in the form of social worker involvement) is largely negative. Carers spoke of an initial lack of clarity surrounding the role of the social workers, why they become involved in some cases and not others, and in what way they can assist the carer and cared-for person. This lack of clarity leads to carers and their families perceiving social workers in a negative light. Paid carers (employed by the local authority) are criticised for a frequent turnover in staff, which may prevent them from building a rapport with the carer and cared-for person. The uncertainty surrounding the role of social workers may itself exacerbate existing crises. “People may...delay taking action fearful of having their suspicions confirmed and believing there is nothing that can be done to help in dementia” (Keady and Nolan, 2003). This is unfortunate, as some carers accessed extremely useful support from social workers and paid carers. It appears that there is a great deal of effective assistance available from the local authority in the correct circumstances, but this is undermined by an occasionally dysfunctional or unclear relationship between social workers and carers.

Not Always Firefighting

The maps show distinct periods of ‘crisis’, during which carers encounter a number of emotional and social problems, and require a high level of assistance from one or more health and social care organisations. Perhaps unexpectedly, the maps also show periods during which there are no particular crises to deal with. During these times, the carer may be coping well, even as the cared-for person shows signs of a gradual decline in cognitive and physical ability. In some cases, these ‘quiet periods’ last for over a year. These may offer an opportunity to assist the carer without focusing on solving immediate problems. For example, they may be used to prepare the carer to properly deal with or negate possible future crises, to improve their own health and wellbeing, or to focus on education and career advancement.

The Value of Intangibles

During each interview, the first author (Designer) asked the carers what they felt was most important about the support offered by Newcastle Carers. In each case, the carers stated that intangible support – such as the opportunity to “be heard”, share experiences with other people in similar situations, and honestly express their feelings in a non-judgemental environment – was more important than practical assistance. This insight offers an opportunity for other organisations to establish relationships with carers which extend beyond practical support. The support offered by each service could be made directly meaningful and valuable to the individuals concerned.

Conclusions and Future Work

These maps are the first major outcomes in this AHRC collaborative project with Newcastle Carers. The observations set out above provide the framework for discussion, collaboration, and further exploration between Newcastle Carers, the researchers, and other health and social care services in Newcastle upon Tyne and beyond. The maps themselves propose an alternative visual syntax for understanding the strengths and weaknesses of, and interrelationships between, the numerous agencies involved in health and social care.



Figure 13. Maps presented at Dementia Strategy Meeting, Newcastle upon Tyne, July 2015

These maps have been presented to dementia strategy planning groups in North East England, with overwhelmingly positive feedback (Figure 13). They disrupt the widely-held assumption that all carers receive similar forms of assistance. They demonstrate that the carers experience is not a distinct, repeatable, linear pathway, but a largely decentralised experience closer to the multilinear, rhizomatic model (Deleuze and Guattari, 1998). The maps will be used as the basis for future workshops with local health and social care services, including Newcastle Carers, GPs, the Local Authority, and carers themselves. The aim of

these workshops will be to consider the observations made in this research, and design disruptive interventions to address the issues raised. If innovation is “a system of overlapping spaces rather than a sequence of orderly steps” (Brown, 2009), the results of these workshops may inform the role of, and potential uses for, these maps in future interventions.

As each map illustrates a manifestly different experience, they help support the assertion that there is no specific ‘pathway’ for dementia carers. Rather than a strict hierarchy of support in the mould of the *scala naturae*, there is an interconnected and often chaotic network of support which can be accessed through a wide variety of different paths. In this research, a key disruptive insight is the indication that all participants in this network – including GPs, carers, social workers, and third sector support – have the opportunity to act upon this interconnectivity, and collaborate rather than pursuing entirely separate agendas – with the eventual goal of the “transformation of existing conditions into preferred ones” (Simon, 1996). These maps highlight the symbiotic relationship between health and social care services that initially appear quite distinct, and suggest that “when everything is connected to everything else, for better or worse, everything matters” (Mau, 2005).

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