Inequality and the social care ‘crisis’ in England: older people and self-funded care

Thematic Panel 21: Inequalities and care needs in old age

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Older people: care and self-funding experiences – context and background

There have been significant changes in the way that statutory social care In the UK has organized over the last few decades. Unlike health care via the NHS, social care provided through local authorities has always been means tested. The social care system in the UK is complex and fragmented as some health-related needs may be paid for via NHS. For example, continuing care and 6-week intermediate care following hospital discharge. Publicly funded social care – via a needs assessment through adult social care and a separate financial assessment – typically only those with high needs and limited finances are eligible but the boundaries of what this have narrowed with austerity cuts.

Transformations since the 1980s onwards mean that local authorities do not directly provide services but contract them out to the private and voluntary sectors. This shift towards non- state service providers through market principles has been underpinned by a rhetoric of choice and independence, promoted through the concept of ‘personalisation’. This purports to give those who use services greater control so that services can be tailored to meet individual needs and with it the prioritization of individual rather than collective solutions in welfare services and practices. This includes ‘cash for care’ payments where the service user has control and management over their own personal budget to ‘buy’ services they require. The claim, by proponents, is that produces more responsive services. This isa clear example of the embedding of market philosophy within in the design, provision and delivery of welfare services and an erosion of shared understanding of the political, democratic and ethical significance of care as a collective responsibility – that the welfare settlement embodied.

Alongside these shifts what we have also seen the response to the banking crisis in the form of ‘austerity politics’ in the UK. A recent report by Conservative politician and former Secretary of State for Work and Pensions, Damian Green argued that there has been a 20% reduction in productivity in social care and this is framed as a failure of local authority’s to manage their budgets. The crisis in care resulting from austerity actually means that Adult Social Care departments have had to make over £3.5 billion in cuts, leaving approximately 1.4 million older people without access to the care they need (CQC 2018).

What does this mean for older people who need care?

What this has meant for older people is a reduction in support as they are not receiving statutory assessments of their care needs from social workers – even though everyone has a legal right to an assessment regardless of income and who will be paying for the care. It is now commonplace that people either don’t receive an assessment from a qualified social worker or wait for a long time before getting one.

The eligibility criteria to receive state funded care has become much tighter – so not just that your income needs to be below a financial threshold your care needs have to be judged as high enough to reach a specific criteria which is much greater than previously. This also means no state supported care for ‘prevention’ – low level support to keep people going thus avoid more ‘acute’ situations.

So not surprisingly there are increased numbers of older people paying for their own care – the assumption being that they will ‘choose’ and consume the care that they need via the market (some of which is completely unregulated). Navigating the system is very challenging – the added complexity – health care via NHS remains ‘free’ – and particular issues arise for people being discharged from hospital into the community when the transition involves making decisions about care in a situation of ill health, under pressure due because of bed shortages in NHS, with a lot of uncertainty and unknowable factors about their care needs. We know from existing research that older people invariably need care at the very time when they are facing: multiple losses, such as of abilities, activities, identity and self-worth; fears about the future and concerns about dependency; and conflicting feelings about recognising the need for help but not wanting to be a burden on others.

Our Project

Our project is funded by the Wellcome Trust and is taking place in three sites in England: Brighton and Hove, Lincolnshire and Solihull. This provides us with a view of experiences in a coastal town, an urban area and a rural area. In each site we have an academic team working alongside co-researchers from the local community.

We are seeking to keep older people at the centre of our research and are carrying out a series of one to one interviews with older people receiving care, aiming to interview each person three times over an 18 month period. We are also interviewing people who have helped to arrange care, or have cared for, an older relative or friend as well as conducting focus groups with informal carers.   In addition to this we are interviewing relevant stakeholders such as Adult Social Care Commissioners, care providers, care workers etc.

Our work is underpinned by care ethics. This is a distinctive approach to ethics grounded in the relationality of what it is to be human. From this perspective moral reasoning needs to be based in the recognition of the connectedness between people. And care needs to be recognised as central to human life. We need to care to survive and flourish when we are babies and infants, and throughout our lives care is fundamental to our well-being, and it becomes even more important in old age when our dependency on others becomes more obvious.

Care ethics then offers a radically different starting point to thinking about responsibility for care. The ways in which care is organised in a society – how it is recognised and valued, the conditions under which it is carried out become profoundly moral and political questions.

Care ethics doesn't romanticise or simplify the challenges of care, it names and addresses issues of power within care relationships. It seeks to unsettle the negative connotations of 'dependency' and the powerful impact these have on shaping our capacity to recognise our own needs for care and how we perceive those who are constructed as 'needy' or a 'burden'.

We are working with care ethics in several ways in this project. Conceptually it frames the co-production and the ways in which we work together and understand research practice. A central point is that the knowledge and experience of receiving care is vital to understanding the process of care. This highlights not only the value of experiential knowledge, but also the situated knowledge of care receivers – which is often missing from policy, practice and research – so in the production of knowledge about care. Care ethics works very well with a participatory research approach where power and knowledge are problematized and questions of what counts as knowledge and whose knowledge counts are key concerns. Care ethics also requires dialogue through which new knowledge and understanding can be produced through relationships that recognise the value of insights from different perspectives. By working with older co-researchers and making their involvement central to the development of the research we are actively seeking to place their experience and knowledge at the heart of the project. But we are taking our co-production further by working with groups of key stakeholders in knowledge exchange groups. These create spaces to discuss ideas and data from the research and bring older people's perspectives into dialogue with health and social care practitioners and commissioners and care providers. Both these areas of co-production require careful attention to the process to ensure that people can take part in ways that make sense to them and in which their contributions are valued and heard.

The areas we are interested in:

Self-funders 'under the radar'

People who:

- have not met the current eligibility criteria for services
- are not eligible (or become ineligible) for financial support for services
- do not approach social services at all
- top up on a funding (e.g. in a care home)
- purchase additional services which are not provided by social services or to supplement those services provided by social services
- 'lost to the system' (Henwood and Hudson, 2008)

The assumption that being a self-funder means you are an autonomous individual exercising your choices about what care you want, and your ability to find and manage that care is not questioned.

We want to understand how risks, responsibilities and relationships have changed/ now play out in the current context of the demise of collective responsibility and shift towards individual responsibility with marketisation of care:

- What has changed in relation to responsibilities of adult social care and the responsibilities of service users

- What new risks are there for commissioners and what strategies have they developed as a result.
- What are the risks for older people who now have to source and manage their own care? What happens if something goes wrong and how are responsibilities for safeguarding and risk managed in the new landscape given the variety of mechanisms for delivering care
- What impact is the development of an unregulated care market having on contracted providers e.g. more competition, service users expectations, less security /business / unpredictability of demand in market place
- What about responsibilities of local authority commissioners for 'market shaping' and 'market failure' and how might these impact on quality of care?
- What risks does self-funded care generate for different stakeholders (older people, carers, service commissioners and providers) and how are these managed?
- What insights can an *ethics of care* contribute both to understanding care relationships in a self-funding context, and to informing commissioning and service provision?

Inequalities in self-funding: emergent findings?

Fragmentation and complexity:

- Unequal outcomes
- Unequal access to information, advice and support
- Inequalities in the oversight of care
- Inequalities in the safety of care
- Inequalities in the interest taken about care
- Inequalities in the responsibilities – from statutory bodies

Financial resources:

- Payment not related to quality or choice in care
- 'Sufficient' money needed to try out different care options rather than just trying get basics met

We are still collecting data so these are emergent themes – here we are highlighting issues that will need further analysis -

Our main argument in this paper at this stage is that our work is highlighting areas of inequalities that go beyond existing ways of thinking about inequality (eg structural inequalities related to class, gender, 'race', disabilities – and the forms of marginalisation that most usually are captured within mainstream equality frameworks). The contexts of our participants show a very complex, fragmented picture. A system of organising care around market principles will generate inequalities

– the inevitable winners and losers – that is what markets do. But it is much more difficult to say who these will be because of the complexity of being old and in need of care – the vulnerability that this can produce crosses ‘traditional’ structural boundaries. The starting point of our project has been to focus on older people’s voices as these were clearly missing in the evidence base – both policy and practice have tended to focus on managerial concerns of the provision and allocation of resources rather than the actual experience of receiving care. We are also centrally concerned about risks and responsibilities that marketised care is producing (or reallocating). Marketised care creates all kinds of complexities – these will not be experienced evenly or equally by all.

Discussion

- The myth of individual consumer power
- inequalities in ‘risk’ created by market
- the risk of market failure,
- the risk of the uncertainty about your care and how to pay for it.
- Towards a new framework based in care ethics

In the UK (and England where this study is taking place) our participant’s accounts need to be understood in the context of the impacts of austerity. The ‘undoing’ of collective responsibility for care and the assumption that ‘self-funders’ are wealthy. The reality is that people only need to be slightly over the financial threshold not to be eligible for state help– not necessarily wealthy. This has implications that are beyond the financial ones that involve paying for care. It also means having no professional support from a social worker to assess your care needs and related a lack of support and oversight if anything goes wrong with the care package or your needs change. Basically you are out there in the market on your own.

Markets create ‘winners’ and ‘losers’. To be a ‘winner’ in the care market requires not only having sufficient money to ‘buy’ or choose – but also having the capacity and the emotional, psychological and practical resources and support to negotiate your way through the market, to negotiate the financial relationships involved. Inequalities in social support available from family or friends and social networks are not linked necessarily to financial resources.

These kinds of inequalities go beyond common frameworks of understanding inequality and not simply related to ‘age’ and being old – although that is not to deny the operation and deep rootedness of ageism understood as a structural inequality. It some respects ageism as a structural inequality might suggest that old age can act as a kind of ‘leveller’. But this is not straightforward and common (maybe universal) aspects of ageing may obscure other (not related to age) aspects of marginalisation that an intersectional approach would address. What may be considered as a ‘leveller’ is needing care in a context of vulnerability and losing autonomy. This suggests an intersectional analysis of inequality in old age needs to incorporate questions of care needs and vulnerability.

It is possible that we need to develop a different framework for understanding inequality in old age and that using a care ethics lens might provide a useful tool here. Understanding the differences that ‘matter’ in relation to care in old age and how might they be different from other contexts might also help think through the assigning of responsibilities for care. Conceptually care ethics offers a challenge to individual autonomy as the principle on which to base care – it exposes the falsehood of the principles on which the market claims to be based - Needing care and not being an equal player in the market – challenges assumptions about equal exchange and the market being the mechanism.