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INTERDEPENDENCE, AND THE TRANSFORMATIVE POTENTIAL OF CARING RELATIONS

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Abstract: Since the early 1980s, critical literature on care has foregrounded the interdependent roles of emotion, moral reasoning, and care orientations, presenting alternative modes of reasoning to that of the rational self-interested individual. This paper synthesises findings of three studies undertaken carers in Cork, Ireland between 2008 and 2015. The synthesis reveals connections between family caring and existing familial relationships. It highlights the interdependent roles of emotion, moral reasoning, and orientation to care, as well as the central role they play in sustaining people and enhancing quality of life. The findings reveal the centrality of other-centeredness and relationality in people's decisions.

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Introduction

Historically and culturally in Ireland the idea that those needing long term care should be cared for by family members has held sway. Following this social care has primarily been provided by family members, often female family members, sometimes with assistance from means-tested welfare payments. Some assistance might also be sourced from voluntary sector services, where they exist, often run by charitable organisations. In practice, there is limited state support for care,

despite the stated policy aim of Government, since at least 1968, as detailed in the to promote care in person's own home in own community.

Furthermore, support, where it does exist is commonly constructed as charitable and is not rights based. Provision of home help has been identified as a key support service in enabling sustainable home care. However, while the service has come under criticism for its limited nature, different levels of provision across health areas, poor staff remuneration and training, and lack of transparency more generally (Barry and Conlon 2010; Walsh, Carney and Léime 2015). More recently provision seems to have become more limited. Home Care Packages which were introduced in 2006 can be viewed as a privatisation of home

help provision and have also come under criticism. An NESF Review of the Home Care Package Scheme in 2009 several shortcomings in their development. These included variations across local health offices, lack of clarity on financial and medical eligibility, on monitoring of packages, as well as delivery of packages by a range of different organisations. Such factors, alongside poor budgeting, communication and data collection combine to limit the effectiveness of home care packages and surrounds them with an element of confusion limiting their potential as core support services. These concerns were reiterated by the OECD (2011) and Harvey (2010) along with more general concerns regarding the range of austerity measures that served to contract social protection, welfare, health and public services since 2008. Furthermore, according to an analysis of Budget 2013 carried out by the Carers Association, they are increasingly 'concerned about the cumulative effect of the cuts to social welfare and health services coupled with the imposition of the new Local Property Tax' (Carers Association, 2013: 1). Later, in 2016 Age Action Ireland again drew attention to the poor level of home care support for older people, stating in reaction to Budget 2016 that '[t]he to do so [remain in their own homes] are not there and the Government must prioritise this area'. More recently still (O'Regan, 2016) the Minister for Health, Simon Harris, strongly criticized the HSE for the slow roll out of home care packages and their attempts to re-allocate funds that had been allocated to it. Drawing on research undertaken with family carers and latterly, care recipients, from 2006 – 2015, this paper locates their experiences of developing and sustaining care relations within the gaps that exist between this stated policy and the realities they face on an ongoing basis. In identifying challenges faced by carers and care recipients the reality of this policy / practice gap as experienced in people's everyday lives is made clear. Challenges faced and the orientation of caring relations on

interdependence and meeting the needs of the specific other, have the potential to illuminate structural inequalities and make visible the state undervaluation of care. These inequalities become more visible, not only as they manifest in the personal lives of people, but in society more broadly. Evidence from the combined research exercises indicate that as these structural inequalities are detected the transformative character of care is sometimes realised. It manifests in people's ongoing attempts to access services in order to maintain quality caring relation, in engagement in public discussion on the role and value of care in society as well as in a range of civic and political activities that challenge dominant orthodoxies.

Methodology

This paper synthesises and integrates the findings of three empirical studies that were undertaken with current and former family carers in Cork, Ireland between 2008 and 2015. They focused on i) supports and experiences of family carers in Cork (2008/2013); ii) experiences of former carers (2014/2015); and iii) caring relations in contexts of mental health issues (2015). The research included quantitative and qualitative analysis and the latter qualitative study included the perspectives of care recipients. All three studies prioritise people's lived experiences in the context of the environments in which they are living.

The synthesis of the three studies reveals the connections between family caring and existing familial relationships. It highlights the interdependent roles of emotion, moral reasoning, and orientation to care, as well as the central role such interdependencies play in sustaining people and enhancing quality of life. In challenging the ideal of the autonomous self-centred individual, the findings reveal the centrality of other-centeredness and relationality in people's decisions, and highlights the manner in which dominant

assumptions that devalue and marginalise human social relations are challenged.

Caring Relations and the Centrality of Human Interdependence

Since the early 1980s, critical literature on care has progressively foregrounded and highlighted hierarchies of power embedded in constructions of care, caring, carers and care recipients (Tronto 1993; Hartsock 1996; Kittay et al 2002; Held 2006). It has progressively drawn our attention to the centrality of care in sustaining human life, making the point that the care is a normal and necessary part of every person’s life. This literature argues that care is both a practice, grounded in specific contexts, and a disposition and that it takes place in several settings, from the household to bureaucratic institutions, although it not often acknowledged or recognised. Not acknowledging the ubiquitous of care, as the normalised reaction to it in society generally, gives the false illusion of the autonomous human being, environment and social world, where care is considered as an anomaly, applicable only to specific groups. In turn, they these groups are conceptualised in terms of their vulnerability. (Tronto 1990,1993, 2013). A more empowering approach would be to see care as a fundamental part of life and then to explore what conditions and reasoning help sustain it for the wellbeing of society. Indeed, Tronto (1990) suggested four phases of care: caring about, caring for, caregiving and care receiving. Later, (2013) she added a fifth dimension, that of caring. She argues that of these dimensions require full consideration in understanding the role and nature of care in our lives.

It is pointed out that the moral claims of those needing care are compelling and inextricably connected with the development of care relations that enable human development and promote personal and societal wellbeing (Tronto 1993, 2013; Held 2006; Lawson 2007). Held (2006:10 argues that ‘[t]he ethics of care recognizes that human beings are dependent

for many years of their lives, that the moral claim of those dependent on us for the care they need is pressing, and that there are highly important moral aspects in developing the relations or caring that enable human beings to live and progress’. Thus, our attention is drawn to the centrality of human interdependence in general (Tronto 1993; Kittay et al 2002; Held 2006).

Furthermore, this literature has highlighted the interdependent roles of emotion, moral reasoning, and care orientations (c.f. Kittay et al 2002; Lynch et al 2009) and presented alternative modes of reasoning to that of the rational self-interested individual as valorised by dominant neoliberal discourse (Gilligan 1982). Value is given to an orientation to particular others and the role of reflexive emotion in interpreting and understanding specific contexts in the development and sustenance of human relations. Held suggests that ‘[p]ersons in caring relations are acting for self and other together (Held 2006: 12) and care involves attention to the well-being of the caring relationship, to oneself and to the particular other.

It is argued that understandings of social relations gleaned from these particular care contexts, while grounded in their specificities, can inform broader social relations and societal structures (Lawson 2007; Robinson 2011). From this foundation, market relations which are increasingly permeating all areas of social, while they simultaneously marginalise care and care work, life can be viewed critically. Such relations are reliant on arguments that are often based on narrow economic models of production. Through such processes we see the increasing acceptance of competitive efficiency and responsibility for social services being transferred from public to the private sectors.

A core foundation of a feminist ethic of care – that which values human relationality – automatically challenges perspectives which view the person as an autonomous self-

centred individual and urges us to consider personhood from this relational perspective in understanding our social and human positions (Kittay 2001). She argues for a reconceptualization of personhood, moving away from the notion of an autonomous self-interested individual, to thinking about personhood in terms of our relational capacity.

It is argued that experiences of caring relations can be transformative for those involved (Lynch et al 2009), as the experience itself can expose the power relationships embedded in the privatisation of care. This is not to imply that power is not also embedded in caring relations. It is acknowledged that such relations are imbued with power hierarchies. What is suggested is that identifying and addressing avenues where power can be abused, can support the development of sustainable caring relations.

Carers Lives Experiences – Priorities identified in the research

As stated the synthesis of the three studies undertaken reveals the connections between family caring and existing familial relationships. It highlights the interdependent roles of emotion, moral reasoning, and orientation to care, as well as the central role such interdependencies play in sustaining people and enhancing quality of life.

All three research exercises sought to understand the position and experiences of people caring for family members and the most recent included the perspectives of care recipients. The synthesis of these offers us insights into who is doing informal caring, what it looks like and how it interacts with family and personal relationships. We are alerted to the motivating factors that influence people to take on and sustain caring roles, the challenges faced and changes that take place in people's lives. We see and how the practice and process of caring has the potential to lead to deeper levels of societal reflexivity, community activism and advocacy.

Family caring and existing familial relationships

Family/informal caring is carried out by family members in the context of the everyday lives and patterns of families/ households/ relationships, and is viewed in the context of the needs and obligations of those personal and familial relationships. It has no time boundaries and becomes incorporated into all aspects of one's life. It can mean anything from being constantly contactable to just needing to physically being there for someone. It can be physically and mentally demanding, involving lifting, changing and becoming knowledgeable about physical and mental conditions. The focus is on the needs of 'the particular other' (Tronto 1993, Held 2006) and changes the orientation of the person away from their own needs and towards the needs of the other. The rationality involved is not an individualist, it can be time consuming, is largely invisible and, as is pointed out in the literature is both a practice and a disposition.

And it is not nine-to-five job. It is a twenty-four hour care, Monday to Monday. There is no time off'

'I have to have my phone switched on basically nearly twenty-four hours ...'

'You have to look after her all of the time ... So you kind of have to be there for her all the time for her, do you know what I mean. Or if I am not there you, kind of, need somebody that will be around her'

How can you make people understand what it is to care – 24 hours a day? ... that inability to make people realise what it demands of you, morning, noon and night and the constant thinking of the other person...

As increasing care needs intersect with people's understanding of what it means to be a wife, husband, mother, father, sister, brother it also alters what this means. The care element that is embedded in the relationship takes priority and the response to this claim (Tronto 1993; Held 2006; Lawson 2007) for care alters the relationship. For instance, as in

the cases below being a mother now became something more intense and full-time than before. Carers commonly reduced their participation in employment and their social lives became much more limited than before. The following quotes from participants illustrate this well.

‘...my life changed from being a mum to being a mum and a full time carer for my daughter. The emotional impact affected all of us, each one of the family’

‘As a mother I will do this as long as it takes’

Assumptions made by health professionals in their interactions with family members reinforce and even *enforce family care* responsibility. Expectations that family members are automatically available and are obliged to become involved in caring are common. Yet, research has repeatedly found that those who take on caring roles often do so with minimal support from other family members. (REF) Such assumptions play into a reductionist view of care that does not recognise its role in sustaining wellbeing and which do not speak to the five phases of care identified by Tronto (1993; 2013).

‘the expectation [by health professionals] is that the family will kick in. You are told that if you have other siblings or whatever that they should do their bit first’

‘people are being challenged, if you are in hospital and you are taking out someone you are being told you have x amount of family members’

Thus, carers often experience considerable levels of stress that is often related to unrealistic expectations and high levels of what is termed care burden. While the term has been critiqued for its concentration on negative elements of care, carers are cognisant of the fact that their work is not optional. Furthermore, this burden does not lift and there is no expectation that supports will materialise as the carer ages.

At times no, [don’t feel able, to continue caring] but that’s not an option’

‘I’m 78 years old and I hope to continue as long as I can’

‘At times it seems too much. It is the continuous need to give every day’

‘It’s getting harder as I’m 68 years old’

In looking for support carers refer to the need to keep their strength and also sometimes look for solace/support from within their own past relationships and positive experiences of them. Here we are alerted to the interdependent roles of emotion, moral reasoning and care orientations, as identified, for instance, by Kittay (2002)and Lynch et al (2009).

‘When I feel really down I visit my father’s grave and I feel some comfort in this’

Evidence from our research indicates (O’Riordan and O’hAdhmaill 2013) that state responsibility for social care provided as of right, is limited. The level of support offered is often minimal, can be very difficult to access, and decisions of availability is subjective, making it difficult to sustain home care and leaving carers with a feeling that they are engaged in a constant ‘battle’. The disconnect between state policy that promotes home care and their realities are quite evident to them.

‘Accessing services is so full of red tape. It takes so long to get anything that sometimes you just forget about it’

‘I found it degrading to have to beg for this service [home help] but I needed to give my other children a chance to see me as a normal mother and spending time with them’

‘As one gets older it gets more difficult. If more aids were provided and the house was wheelchair friendly it would be easier’

‘the policy, on what they [state services] claim, to keep people at home is certainly not their policy because they seem to do everything they can to obstruct it’

Furthermore, we found that support which exists, has been retracting in more recent years.

'We did have two weeks cut in respite in 2010 but we went to war there and got another ... but you have to do all that sort of thing which is time consuming and emotionally draining, Being a carer was always emotionally draining but it is far worse now'

'but they did stop the disposable sheets'. 'Mine were stopped twice' 'And mine were stopped'

'this new thing, you know, reducing the respite and then paying for the other respite'

'people are being reviewed now and I believe ... the review has only one objective and that is to cut people off'

As mentioned above Lawson (2007) suggests that understanding gained from specific contexts can translate into greater understanding of social relations and societal structures. Carers see themselves at the butt end of increased bureaucracy and reduced resourcing. Meeting the frequent challenges they face in attempting to access support services, people became aware of the clear disconnect between stated policy and the reality of resourcing for community care. Reduction in resourcing was evident to them in their attempts to surmount increased bureaucracy and they then questioned the objectives of reviews and rhetoric.

Family/informal caring is not confined to those who live in the same household; it continues if and when someone is in hospital, in a respite centre and in cases where a family member is living in a nursing home. All research exercises found that research participants began caring, and continued caring in their homes, and when family members spent time in respite centres, or transferred into nursing homes, long term and acute hospital care.

Given this context it is not surprising that people experienced loss and guilt when using respite services, even though it is well established that the provision of suitable and

regular respite services are central to supporting and maintaining home care.

... can feel really guilty about respite care but as one settles in for the long haul...

One major alternative is long term institutional care, often in a nursing home, if that is available. The latter is not guaranteed, can be very expensive and access to the state's *Fair Deal* scheme which was developed to support nursing care costs can be difficult. However, feelings of guilt were further exacerbated if a decision was made to use nursing home facilities on a more long term basis. The quotes below illustrate the depth of feeling associated in the process of and aftermath of partner and mother moving into a nursing home, as their care needs had become too great for home care supported only by limited social services.

'So, its a type of divorce, plus the original bereavement, so [sobs]...really I can't explain it well enough, but I just will always remember it as the worst day of my life, always.'

'Basically, she [mother] is there [in nursing home] since May and she is getting on all right there. I'm finding is incredibly difficult, I'm finding it incredibly hard to deal with'

Facing challenges in trying to meet needs

From these experiences and challenges we can see that people are making decisions based on the needs of others and in the context of sustaining personal relationships. The centrality of the other-centeredness of these decisions is made clear as is the relational priority that is given to enabling others to live well. Care as an embodied and emotional practice and process is evident and is grounded in the tasks that people undertake, rather than being abstracted from them. Social, personal and financial costs were borne by them. They drew on what resources they could to sustain themselves and over time. Their marginalization and levels of invisibility showed up the flaws of a superficial

understanding of care, based on numbers rather than on dignity.

In some cases, the relationality crossed from the personal to community and societal concerns. Participants in the research exercises spoke about joining groups to take action, and of becoming advocate. This was, often initially related to their own caring contexts/in raising awareness of the particular medical conditions their family members suffered from but also crossed over to a keen interest and activism in several other areas. In becoming increasingly reflective of their own situations the links between their private concerns and social inequalities became more evident to them, highlighting to us the potential transformative nature of care.

Bibliography

- Age Action Ireland (2015), *Budget 2016 – Age Action reaction*. Available: <https://www.ageaction.ie/news/2015/10/13/budget-2016-age-action-reaction>
- Barry, Ursula and Ciara Conlon. (2010). ‘Elderly Care in Ireland – provisions and providers’, *UCD School of Social Justice Working Papers*, 10(1):1-34. University College Dublin. School of Social Justice.
- Government of Ireland (1968). *The Care of the Aged: Report of an Inter-Departmental Committee on the Care of the Aged, 1968*. Dublin: Government Publications.
- Hartsock, Nancy C.M. (1996) ‘Community, Sexuality, Gender: Rethinking Power’. In N. Hirschman and C. Di Stefano (eds), pp.27-49, *Revisioning the Political: Feminist Reconstructions of Traditional Concepts in Western Political Theory*. Westview Press: Boulder.
- Kittay, Eva-Feder (2001). When Caring Is Just and Justice Is Caring: Justice and Mental Retardation, *Public Culture* 13(3): 557–579.
- Kittay, Eva Feder and Ellen K. Feder (eds) (2002). *The Subject of Care: Feminist Perspectives on Dependency*, Rowman and Littlefield: Lanham.
- Held, Virginia (2006). *The Ethics of Care: Personal, Political, and Global*. Oxford University Press: Oxford.
- Lawson, Virginia (2007). Geographies of Care and Responsibility, *Annals of the Association of American Geographers*, 97(1):1-11.
- Lynch, Kathleen, John Baker and Maureen Lyons (eds). (2009). *Affective Equality: Love Care and Injustice*. Basingstoke: Palgrave Macmillan
- NESF (2009). *Implementation of the Home Care Package Scheme*, Report No. 38, NESF: Dublin.
- OECD (2011). *Help Wanted? Providing and Paying for Long-Term Care*, OECD: Paris.
- Robinson, Fiona (2011). *Globalising Care: Ethics, Feminist Theory, and International Relations*. Westview: Boulder.
- Tronto, Joan (1993). *Moral Boundaries: A Political Argument for an Ethic of Care*, Routledge: New York.
- _____ (2013). *Caring Democracy: Markets, Equality, and Justice*. New York University Press: New York.
- The Carers Association (2013). *Analysis of Budget 2013 from a Family Carer Perspective*, available: <http://www.corkfamilycarersforum.ie/files/Budget-Analysis.pdf>
- Walsh, Carney and Léime, (eds). (2015). *Ageing Through Austerity: Critical Perspectives from Ireland*, Polity Press: Bristol and Chicago.
- O’Regan, 2016, ‘HSE’s home-care package ‘not working’- Harris’, *Irish Independent, News; Health*.