'No one was clapping for us': Care, social justice and family carer wellbeing during the Covid-19 pandemic in Wales

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Introduction

The Covid-19 pandemic has threatened not only people's lives, but their capabilities to live 'well'. In this article, we argue through a novel theoretical framework that combines critical care ethics and the capabilities perspective that a focus on the concept of wellbeing draws out the social justice implications of the experiences of family carers during the covid-19 pandemic. The article draws on findings from a qualitative study of family carer wellbeing, conducted in Wales during the first coronavirus lockdown in the spring and summer of 2020. We suggest that addressing family carers, and the particular nature of their experiences during 2020, provides a distinctive, significant, and urgent discussion. It is urgent partly because the position of family carers is under-explored as a social justice issue in general (Williams 2018) and partly because their roles and contributions during the pandemic have been both vital and often obscured. Our motivating claim in this article is that the concept of wellbeing works as a demonstrator concept in this context. Thus as we aim to show, a focus on the wellbeing of family carers during the pandemic helps reinforce our central claim that unpaid care of older people is a critical issue for social justice.

The article continues as follows: In the next two sections, we address existing literature on wellbeing, in connection with family carers and relevant aspects of political philosophy. We then outline the methods and approach adopted in the qualitative study on which the discussion draws. Next, we present key findings of that study, before then drawing out what we regard as their salient implications. Those findings inform an emerging argument which can be summed up in four main claims. The first - the situation of family carers in the pandemic raises critical and pressing questions of social justice. The second is more specific - the withdrawal of support services has exacerbated poorer wellbeing outcomes experienced by family carers across all wellbeing domains. Third - in addressing those first two claims, we argue that there is substantial value in applying an extended concept of wellbeing – specifically, one that challenges the individualism characteristic of current liberal welfare applications and that incorporates and highlights the importance of extrinsic material factors. Those three steps lead us to the overall conclusion that, at the practical level as well as conceptually, we need suitably relational wellbeing measures that incorporate the extent to which (with the right kind of structural support) care can act as a contributor to positive wellbeing outcomes and furthermore must include consideration of care inequalities experienced at an individual level.

Wellbeing and family carers, before and during the pandemic

A steadily growing focus on wellbeing has become salient in recent decades across discussions of economic development (McGregor and Pouw, 2016; Sen, 1999; Stiglitz, 2009), theories of social justice (Sen, 1992; Nussbaum, 2006; Austin, 2018), and moral philosophy (Griffin, 1986; Fletcher, 2015, parts 2 and 5). The term features in legislation in the UK, Wales, New Zealand and elsewhere – often as a means by which to bridge domains hitherto treated as separate, or in formulating a more holistic and less reductive agenda. During the past five years and in particular in the UK, the term has been embedded into social care welfare support programmes (Bache 2016; Bache and Scott, 2018; McGregor and Pouw, 2016). The Welsh Government has made the concept a central plank of the rethinking of the scope of social welfare policy embodied in the Social Services and Well-Being (Wales) Act 2014. It is, unsurprisingly, a contested concept. It is also a multi-purpose one, being invoked both as an end in itself, and as part of the means of identifying who gets what in terms of social care support.

Meanwhile, the position of family carers is an increasingly prominent policy issue (Daly 2002, Daly and Lewis 2000, Moen and DePasquale 2017, Naonori 2017, Ward and Barnes 2016). Older family care is an integral part of government responses to population ageing and is a central pillar in most contemporary welfare reform programmes (Kodate and Timonen 2017, Saraceno and Keck 2010, Yeandle 2011) . In the UK, the older age population are predominately cared for by family carers (Vlachantoni 2019) in what has been called 'familialism by default' (Naonori, 2017). Notwithstanding the intention to promote the wellbeing of unpaid carers and care receivers, recent figures for the UK show that 55 per cent of older adults with (ADL) difficulty had unmet need (Vlachantoni 2019) and empirical evidence has consistently demonstrated the negative impact that caring can have on an individual's health and wellbeing across multiple areas including health, wealth, and social relations (Bauer and Sousa-poza 2015, Keating and Eales 2017, Pinquart and Sörensen 2003). Together with the growing demand for care and inconsistencies of coverage connected to the personalisation and marketisation of care (Needham et al 2018) the combined effects of these factors has helped reinforce a widespread discourse of a 'crisis of care' in Europe (Daly and Lewis 2000, Pickard 2015). Amid the coronavirus global health emergency, this crisis of care has taken on new dimensions. Care has been acknowledged as central to how we respond to and 'build back' after the pandemic (Daly 2020). Family carers, through their association to the person that they care for, are particularly vulnerable to the effects of the disease and we see more broadly that the devastating effects of coronavirus can be traced along socio-economic fault lines in society – hitting the disadvantaged harder, and reinforcing existing gaps between those better and worse off (Bambra et al 2020, JRF 2021).

Family carers occupy a vulnerable, but often partly hidden position in this landscape. We know that care is stratified according to socioeconomic status and in the richest economies, the poor are disproportionately likely to be carers and that carers are disproportionately likely to be poor. We know also that disadvantage is amplified in both directions: that carers experience extra stresses and hardships when in poverty, and that those in poverty experience extra stresses and hardships when carers. Thus; 'Poverty is overwhelmingly associated with dependency and care.' (Engster 2015: 204). COVID-19 has been an amplifier of these already existing inequalities. Studies in the summer of 2020 found that people in the most deprived areas of England and Wales were twice as likely to die after contracting the virus – and that while 'general mortality rates are normally higher in more

deprived areas… COVID-19 appears to be increasing this effect' (O'Dowd. 2020). In sum, evidence suggests that with a series of intersecting factors having already placed family carers in a disadvantageous position their wellbeing has been particularly vulnerable to negative impacts during the pandemic period – and that these effects have been exacerbated by the various impacts of the virus.

Yet while we can see in a general, panoramic way that the wellbeing of family carers is a matter of particular concern, there is still a dearth of evidence regarding how the pandemic has been going for them – and how these wider features and trends have played out at a more granular, everyday level.

Wellbeing, Covid-19 and social justice

In this study, we used a model of wellbeing offered by McGregor and Pouw (2016) who broadly define wellbeing as human-centric, multidimensional and relational and with three distinctive dimensions: material, relational and subjective (OECD, 2011; McGregor and Pouw, 2016). In policy terms, measures of wellbeing are customarily individualistic. When applied to carers, this has the effect of privatising and individualising the way wellbeing is understood and assessed (Barnes 2011). That is to say: it will tend to treat the wellbeing of carers as being something experienced on a personal level, according to indicators the scope of which are isolated to the immediate circumstances of their individual experiences.   This restricts the scope of our understanding of wellbeing and neglects wider structural factors. This applies in two senses. Firstly, 'objective' measures of wellbeing (such as indicators of physical health, living standards, access to resources and so on) will be calibrated in individualised rather than more structural terms. This means that the extent to which individuals are doing well in relation to – for example – their class position, or their social networks, slip inevitably out of focus. And on the other hand, the same applies to 'subjective' measures of wellbeing, such as preference satisfaction, self-esteem, or a sense of happiness with one's lot. Because preferences may be in the light of disadvantage or oppression (Elster, 1985; Khader, 2011; Nussbaum, 2001a, 2001b) and expectations lowered, subjective measures of wellbeing will be limited insofar as they lack any mechanism for factoring in the relationship between social stratification and reported wellbeing. More generally, we can say that simpler individualistic understandings of wellbeing have a kind of relationality deficit. Unless we place individuals in relation to structural inequalities, we will not appreciate the extent to which their experience of wellbeing is filtered through their own structurally inflected version of 'having enough time for the important things in life', or 'feeling valued'. And we may also miss factors connected to affiliation and belonging which – as we will argue – form a vital part of what it takes for life as a carer to go well.

This point has been made forcefully by Joan Tronto, in connection with care. The terms on which family carers care for others will have a heavy bearing on their sense of wellbeing. But those terms are themselves stratified. Responsibilities for care are not evenly distributed, and neither are the burdens or rewards which caring may bring (Tronto, 2015). There are well established negative wellbeing outcomes in connection with health (M. Pinquart & Sörensen, 2004; Martin Pinquart & Sörensen, 2011; Martin Pinquart & Sörensen,

2003; Rubin & White-Means, 2009); income and wealth, (N. C. Keating, Fast, Lero, Lucas, & Eales, 2014)), social networks (N. Keating & Eales, 2017) and in the case of working carers (Bauer & Sousa-poza, 2015; DePasquale, Polenick, Davis, Berkman, & Cabot, 2018). And the reasons for this cannot be understood without due attention to the 'background' workings of structural factors, and the implications of – for example – the workings of the market on how care is shared and experienced. On these terms, one essential factor in the tendency for the poorer carer – and the caring poor – to be disproportionately worse off in terms of wellbeing indicators is that having less money means a lack of freedom to choose the terms on which the carer role plays out. Similarly, the economic costs of unpaid care work are part of what makes it detrimental to wellbeing (OECD, 2011).

All of this clearly points to a field of social justice issues in loose terms, reflecting the position of family carers. We can unpack those issues in terms of distributive justice: the terms by which resources, benefits and assets are distributed among individuals. Those distribuenda are themselves diverse and plural – extending, we would argue, to what Brighouse and Swift (2014) call 'familial relationship goods', and including the distribution of these in the remit of what social and public policy should address. If, as they put it, 'familial relationships are, for many, among the most important elements of human well-being', then we have justice-related reasons to ask: 'In what ways does our society influence the distribution of opportunities for healthy, loving familial relationships? What can be done to make that distribution fairer?' (Brighouse and Swift, 2014: 40).   Brighouse and Swift focus on childrearing. We would suggest that these same points can be translated just as to the context of caring for an older relative. This is a relational good, the distribution of which is on these terms a matter of social justice. But just as with the parent-child relationship, it is not (of course) simply conducive to wellbeing. It will involve stresses and burdens. And as we have seen, the distribution of those burdens – just like the distribution of the benefits of caring relationships – is neither even nor fair.[1] Crucially, this reflects structural dynamics: aspects of the experience of being a family member which are inexorably shaped and conditioned by wider socio-economic and political factors over which individuals have little direct control. Under Covid-19, those factors have intensified, and served to exacerbate unfairnesses in the distribution of familial relationship goods – specifically, in our case, for family carers.

This analytic frame does not itself provide a *metric* of justice: a specification of the type of good which is subject to redistribution. Rather than familiar metrics such as 'welfare' or 'resources', we regard the capabilities approach as providing the firmest critical purchase in this regard. From this point of view, what matters is not the distribution of bundles of goods, but of human capabilities. To put it a different way, our attention should be directed not just to the resources people have, or their levels of happiness, but to *functionings*: health, standard of living, education, mobility, and other aspects of their state of being, and what they are able to do – 'the actual living that people manage to achieve' (Sen, 1999: 74). Comparing different people's levels of wellbeing requires a measure which covers this everyday achievement of living – but crucially, incorporates people's relationship to their functionings. Sen describes *capabilities* as the real opportunity or freedom to achieve a range of functionings. Capabilities are what people are realistically able to do or be. They

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[1] The contours of this unfairness as it plays out in the context of family care – particularly, on gendered lines – will be the focus of a forthcoming article.

are capabilities to choose a life one has reason to value (Sen, 1999: 73; Nussbaum, 2006; 2011).

Four points about how we view the applicability of the capabilities approach to family care and wellbeing are worth stressing at this stage. The first is foundational: one key functioning is what Martha Nussbaum identifies as *affiliation* and Kimberley Brownlee as *belonging*. Nussbaum articulates affiliation in terms of 'being able to live with and toward others, to recognize and show concern for other human beings,' and 'having the social bases of self-respect and non-humiliation'. Protecting this means 'protecting institutions that constitute and nourish such affiliation' (Nussbaum 2011: 34ff). Unpacking this capability in terms of the need to belong, Brownlee argues that it involves more than our *ability* to 'live with and toward other people' in conditions of mutual care. It includes 'our positive exercise of those abilities' (Brownlee 2020: 14). Brownlee appeals here to Wolff and De-Shalit's account of secure functionings: that it is important not just that we are able to exercise our capabilities, but to achieve a certain level of functioning over time (Wolff & De-Shalit 2007). Secondly: we regard unpaid care given by family members as a means by which this functioning is achieved – and one which will loom especially large in the lives of those concerned. Thirdly: the capability to choose the terms on which one achieves this functioning is of clear value to family carers – partly because this contributes to the security of belonging. And fourthly: that capability will be shaped and conditioned by a range of wider and structural factors, including the distribution of work and resources, the ways in which the position and contributions of family carers are perceived and valued, and the conditions under which they make their everyday and longer-term choices about their caring relationships. Caring responsibilities, of course, are not typically chosen in any simple way. They may stem from an imposed *requirement* to respond to others. Yet this reinforces the point that the terms on which we do this – and the autonomy afforded to the carer – are vital, precisely insofar as we have a fundamental interest in exercising what Brownlee calls our interactional freedom – 'control over *how* we interact with the people with whom we do interact' (2020: 115). The need for this control, we suggest, is enhanced rather than diminished by the fact that often, the responsibilities at stake are bestowed rather than chosen. Thus, while the ultimate focus of the capabilities approach is the wellbeing of the individual, the context in which any such analysis is set – or the wellbeing itself achieved – is inevitably social. While it is normatively individualist, it is, of necessity, methodologically sensitive to the complex effects of social structures and the interplay between these and individual agency.

Daniel Engster, stressing the commonalities between the capabilities approach and care ethics, treats both as suitable starting points for developing a theory of disability justice (Engster, 2015: 176).[2] We seek to extend this idea to a theory of justice for family carers of older people. In particular, we would argue that supplementing the capabilities approach

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[2] Engster also treats elements of Nussbaum's capabilities approach, in particular, as being less congruent with care ethics to the extent that her preference for invoking a list of ten central human capabilities installs a 'species norm' (Nussbaum, 2006: 179) which, as a threshold for capability development, will serve to stigmatise those who fall below that account of what it means to be a fully-fledged human being. We share that concern, and also Engster's contention that care ethics avoids these objections (2015: 174-180). Sen's more elastic and locally contingent sense of which capabilities count is arguably better placed to accommodate the particular position of family carers and those they care for.

with key elements of care ethics allows for a fine-grained framing of social justice issues arising for family carers in the wake of Covid-19. To show why, it is helpful to focus on the plurality of ways in which care happens, and matters – and to unpack the implications of care ethics in its political dimensions. Fischer and Tronto (1990) define care as a 'species activity' and supply four key principles attributed to care: 1) 'caring about', which requires attentiveness; 2) 'taking care of' and responsibility for care; 3) 'care giving' the tasks of care requiring competence; and 4) care-receiving (Fisher and Tronto 1990). In part in response to the 'crisis of care' Tronto has since added a fifth element to the phases of care, defined as 'caring with' Tronto (2013). Tronto explores care in close relationship with ideas of citizenship, democracy, and equality and in the fifth phase of care 'caring with' as a fundamental for a 'caring democracy' (Tronto 2013). In *Who Cares* (2015) she outlines how we might operationalise this fifth phase of 'caring with'. As she says 'Any given act of care is unequal. But across generations, and across any given person's lifetime, we can set a democratic goal to even out these inequalities', so that there is an 'ongoing pattern of care', consisting in the reciprocal ways in which, over time, care is given and received between citizens.' (Tronto, 2015: 14).

It is against this theoretical background that we here discuss the position of family carers in the pandemic. Rather than being summative (FitzGerald 2020: 249) our analysis considers primary evidence gathered on carer wellbeing in a way which assumes both that a combination of care ethics and the capabilities approach is fertile ground for such work and also that this stands in need of further development and elaboration as a normative political theory (Kim 2021). In a pandemic, where lives are both placed under threat and lived under drastically altered circumstances, moral binaries have been further entrenched and pronounced: freedom vs safety, health vs wellbeing, deserving (of care) and un-deserving. The ethics of care, in combination with a focus on capabilities as the metric of justice, preserves a critical eye for ambivalence, contradiction and attention to the normative value base on which policy is developed.

Theoretical approach and methods

This study is theoretically informed by a care ethics perspective (Barnes, Brannelly and Ward, 2015; Fine and Tronto, 2020; Sevenhuijsen, 1998; Tronto, 1993; Tronto, 2013; Tronto, 2015; Tronto, 2017). In addition, we used a model of wellbeing offered by McGregor and Pouw (2016) who broadly define wellbeing as human-centric, multidimensional and relational and with three distinctive dimensions: material, relational and subjective (OECD, 2011; McGregor and Pouw, 2016). Through qualitative semi structured interviewing we aimed to conduct theoretically informed data collection to understand the reality or 'the hidden truths' (Fine and Tronto 2020) of caring during the pandemic for family carers in Wales. The research was conducted in two stages, beginning with a critical review of the literature relating to wellbeing and care, this type of review is particularly suitable for the purpose of conceptual development and aims to move beyond mere description of identified articles and includes a degree of analysis and conceptual innovation (Grant and Booth 2009). The research question and theoretical framing of care and wellbeing informed the search strategy and analysis, with synonyms of wellbeing used and to ensure a focus on family

carers of older people, the adjacent 3 function in the search engines, that is, the word family and its variants was within three words of the word carer. Post hoc inclusion and exclusion criteria were applied.

Results from the critical review identified 45 studies on wellbeing and care. Findings show that to date, the literature is limited in scope and lacks theoretical framing: most studies report on subjective wellbeing measures and operationalise wellbeing on the basis of burden and stress theory. Cunningham and Cunningham (2018) note in their systematic scoping review of 19 studies that none of the studies identified discuss the relationship between intrinsic and extrinsic aspect of carer wellbeing. (Cunningham et al 2018). We contend that this makes three highly problematic assumptions about family carer wellbeing: 1) that carer wellbeing is individualised and private; 2) that care is negative and associated with decline, disease and degeneration; and 3) that dependency is negative. This can be understood to compound the difficulties experienced by many unpaid carers during the pandemic, due in part, to the ongoing impacts of discourses problematising older age care (Barnes, 2011). We have highlighted how this may result in further oppression for carers of older people.

Findings from the literature review informed the development of an interview schedule that divided lines of broad questioning based on the three major domains: material, subjective and relational. The study received full institutional ethical approval for this stage (two) of the study where primary data was gathered through a series of qualitative standardised open-ended questioning with carers where the features of carer wellbeing during Covid-19 were explored. Interviews were audio recorded (with permissions) and transcribed. A total of 30 family (unpaid) carers of people aged 50 and over took part in the research. Participants were drawn from a convenience sample of carers caring for an older person in Wales and were recruited through the researchers close links with local and national carers organisations and using existing channels such as newsletters and online bulletins and recruitment adverts were circulated widely across Wales. Participant demographics are shown below in table 1.

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Findings and discussion
The following section provides an overview of the research findings in response to the primary aims of this study. Thematic analysis, informed by an ethics of care perspective was applied to the 30 interview transcripts and the following themes were identified: wellbeing losses, poorer wellbeing outcomes, 'caring solidarity', and wellbeing-related challenges to the discourse on care. The findings suggest, corroborating with recent empirical evidence (Cohen et al 2020, Savla et al 2020), that staying at home caring for dependent older family members had a negative impact on their wellbeing across all domains (subjective, material and relational). Accompanying the main findings in this section, we provide a critical narrative to explore the implications of the findings on family carers during the pandemic and argue that overwhelmingly, the evidence presented here suggests a profound and

systemic lack of care for family carers, in ways which echo and reinforce the issues and concerns we have already outlined.

Subjective wellbeing – isolation loss and conflict

In the wake of the pandemic in Wales (as elsewhere across Europe) blanket restrictions were applied by government and home was deemed the safest place to be. In the following section we consider the impact of the restrictions on personal freedoms on carers wellbeing. Respondents described staying indoors complying with government directives and the impact on their wellbeing. The majority of carers interviewed in this study were co-resident with the person cared for (n=19).   The qualitative descriptions provided by participants evidence levels of increased depression and general low mood thus negative impact on levels of subjective wellbeing; one respondent described staying in every day with the care recipient; "I know now this afternoon it's going to be down, it's going to be you walk in you can hear the telly, you know what you're going in to…there's very little joy in sitting there with my mother & I think that's what affects you mentally." (P27, female). In addition, carers described anxiety and worry regarding the virus and the potential of it coming into the home; "So I stay in, I don't go out. It would have to be an emergency for me to go out". (P16, male).

Of the respondents who were not co-residing with the person cared for, a related theme emerged around 'connections lost'. Carers described a sense of disconnect with the person that they cared for negatively impacting on relationships. In the following example, the cared-for was living in a care home and the carer describes her loss in terms of not being able to express and connect with her as she usually would through the clothes she wore when visiting; "I had a very good relationship with [cared for] & she loved anything that was bling or leopard skin or anything like that, sparkle, so I'd always go dressed up in something like that – these are my earrings I wear…she'd say I love your earrings because they're sparkly and we'd chat." (P23, female). Some participants referred to strained relationships because of social distancing; "I'd always give my dad a kiss on his head every time I left him I'd always give him a kiss but obviously I haven't done that since March. I'm the apple of his eye so just little things like that have been quite difficult as well really. Just to give him a kiss top of his head & he's happy then for the day." (P09, female).

Furthermore, interviewees pointed to feelings of turmoil and internal conflict in navigating the 'correct course of action', describing disorientation and confusion regarding how to respond to the threat of the virus, with the need to care for their family members further compounding reports of anxiety and distress: "Do I insist the carers wear PPE? Do I not?…Do I have to tell my family they can't see their own Mam?" (P01, female). Relatedly, several respondents described intensified family conflicts and a heightened sense of anxiety caused by the lockdown experience.

> "One of my brothers at the moment is really struggling…he's quite frantic with his wife – his wife went out for lunch recently with her daughter as is allowed, & he went berserk on her when she came in telling her that she was trying to kill his mother." (P27, female).

The responses offered here suggest that staying at home (because of the lockdown) and caring for family members negatively impacted carers' subjective wellbeing. Wellbeing (as identified in the previous discussion) in the context of care is typified by individualism. The accounts presented here show how this individualistic conception of care obscures the relational ontology that care ethicists argue is at the centre of defining care and our ambition for 'good care'. Our expanded conceptualisation of wellbeing (informed by the capabilities approach and care ethics) recognises and allows room for relationality and avoids viewing individuals as unconnected. This in turn, enables us to be alert to when our need to care and connect through care, is threatened and under the Covid-19 restrictions the subsequent harms that can result.

Material wellbeing - The withdrawal of support services

Interview questions were asked regarding material wellbeing and specifically in relation to support services such as care packages and day centre provision. Participants referred to these services as 'a lifeline' but in the context of the pandemic, they were reported as either closed or limited. In most cases the shrinking or withdrawal of support resulted in an intensification of care tasks and negative wellbeing outcomes. The majority of respondents in this study reported cancelling care packages and reflected upoon the impact on their wellbeing of the withdrawal of support; "I think it makes me, I think I'm on edge, I am never sort of relaxed, there is always a kind of frustration I suppose and not being able to cope, that's what I feel, and overwhelmed." (P21, female). One respondent described how cutting out support was not sustainable given the negative impact on her wellbeing: "So I cut all the carers out because I thought that was a risk I could minimise so therefore I did it all myself. Then I did suffer for that and I won't be doing it again going forward, no not whatsoever" (P11, female).

Not only did carers report cancelling social care packages because of the perceived risk of contracting the virus, but several reported cancelled community medical visits, thereby leaving the carer and the cared for at significant risk:

> "I do feel isolated sometimes because when I was putting the support stockings on, it was ripping off the scabs & then the scabs would bleed & then the infection would come & no nurses would come out to visit, due to the pandemic, I find that's a huge responsibility on somebody who cares for somebody, because I'm not a nurse. With this pandemic I've kept very isolated yes then because I have no support from professionals." (P14, female)

This study findings reinforce other recent empirical reports (Bennett et al 2020, Giebel et al 2020) that evidence how carers were left to 'go it alone', resulting in considerable stress and anxiety, factors consistently shown to contribute to negative wellbeing states. Furthermore, a critical ethical perspective of the impact on carers in the context of the pandemic brings to the fore important questions regarding the responsibility of governments to vulnerable groups such as carers and puts in question the extent to which carers can reasonably be expected to 'go it alone', given the well-established body of evidence that documents negative wellbeing outcomes?

The central role of equality in an ethics of care perspective is useful to highlight here, as Sevenhuijsen, (1998) writes; "We can do justice to the idea that people are differently situated and that this is exactly what makes public dialogue and collective support necessary." If we attach a care ethics/capabilities-centred perspective to wellbeing in the context of family care, we are able to appreciate the unequal and disadvantaged starting points that empirical evidence has consistently shown some family carers experience and thereby identify family carers as a group that require support and help, never more so than in times of crisis. The sense of abandonment expressed by family carers in this study puts into context what is at stake, with carers describing difficult and sometimes dangerous circumstances which can be seen as directly undermining their capabilities to achieve functionings connected to the basics of their everyday lives. In this regard, the pandemic can be understood as an opportunity to critically assess care through a social justice perspective and understand the deeply problematic implications of viewing care as a private and exclusively 'familial' responsibility.

Relational wellbeing - 'Caring Solidarity'?
In this section, we describe results based on interview responses concerning the 'Clap for Carers' movement, focused around weekly public demonstrations of thanks for key workers mobilised to deal with the pandemic. Participants in this study articulated a range of views. Overwhelmingly, however, they felt invisible and excluded from the wave of public affirmation:

> No I didn't feel part of that at all to be honest & I didn't join in it either. I must admit it just frustrated me. Perhaps I'm being a bit unfair but I think we all have our jobs to do & I felt it was very much focused on NHS staff & we certainly weren't getting to jump the supermarket queue or to get a discount or a free meal or anything else. I just felt the whole thing was a bit divisive really." (P11, female).

The imperative for public recognition and value for care is a well-established argument amongst political care theory (Engster 2015, Held 2006, Kittay 2011). However, as evidenced by our study, participants perceived a lack of recognition of those providing care outside the domain of the labour market and this stood in stark contrast to the valorisation of National Health Service workers. Exploring this sense of invisibility, we turn to the fifth element that Tronto describes as essential for a caring democracy the role of 'caring with' – where plurality, communication, trust, respect and solidarity are moral qualities that 'caring with' requires (Tronto 2015). In the initial stages of the pandemic, government communication pointed to values of unity and solidarity; 'we are all in this together' resulted in the basic message to stay at home to 'protect the NHS'. The sense of unity was not evident amongst our participants; "What about all the people that work long hours, what about the pharmacists & the family carers & people like myself, it's a whole collective thing it's not necessarily just the NHS" (P23, female). Through the 'Clap for Carers' movement, the focus on professionals particularly in the NHS and the public (and political) appreciation of care work, in stark contrast however, was the lack of recognition of care and carers wherever they happen to reside was. In the case of older dependents adults in the UK, this is in the home and community (Vlachantoni 2019). We can therefore argue an unintended consequence of the initial 'Clap for Carers' movement and based on the study

findings, is a sense of division and injustice expressed by carers whose role was itself in pivotal in responding to the public health emergency.

Returning to the conceptualisation of wellbeing in the context of care can help to make sense of this. As previously discussed, wellbeing is theorised and applied in the context of care predominately as an individual notion offering individual rights to those who are dependent and those who care. This narrative directs attention away from a conceptualisation of care that recognises the inevitability of human connection through dependency and vulnerability (Engster 2019).   Through the ethics of care lens we are able to challenge wellbeing conceptualisations offered and measured by subjective reports and therefore as an individual private notion we are able to see why family carers were not included and their wellbeing was not attended to in the initial response to the pandemic. From the capabilities angle, we can see too how this sense of lack of recognition would increase the sense of a lack of 'real freedom' to choose the terms on which unpaid care is carried out. And we can see potential of the concept of wellbeing to bring care out of the shadows into the political sphere. Carers we interviewed spoke of positive wellbeing outcomes, despite the immense pressure and struggles – and placed a clear value on their care work as a functioning. This offers a fertile ground on which to place the fundamental principle of care as vital to democracy and citizenship and which we turn to in the final discussion below.

Challenging the discourse on care

The final contribution that an examination of wellbeing in the context of the carers of older people in the pandemic offers us relates to the discourse on care. As previously discussed, family carer wellbeing literature is situated predominately within a burden and stress discourse and focused almost exclusively on the outcomes of care relating to subjective wellbeing domains.[3] Carers we interviewed for this study, spoke of deep personal struggles and sacrifices and for many the pandemic has deepened and intensified negative wellbeing outcomes. Despite this however, we find positive reports. Only four out of the 30 respondents said there was nothing positive to say about care and the remaining provided statements relating to feelings of self-worth, gratification, duty and doing good. Respondents pointed to these ideas as increasing positive emotional wellbeing states and, in some instances, contributing to positive intra-family relationships.

> So I am pleased I can do it, we have got a very close relationship which I love. I have got her close to me which I love & I feel – I'm not sure proud is the right word – but quite satisfied that I have done my best & am doing my best for her so there's something quite warm about that. (P02, female)

Theorising wellbeing in relation to burden may be understood as a reflection of how care is framed within a broader context of 'crisis' (Daly and Lewis 2000) and care for older people in

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[3] An important exception to this is a recent study by Funk et al (2019), investigating how family carers navigate formal support services and applying the analytical concept of 'structural burden' to identify the process of accessing and receiving resources. They found that family carers can experience the process of service navigation as an additional form of burden located at the structural, rather than agential, level (Funk, Dansereau, and Novek, 2019).

particular, has had long standing connections to what is often termed 'dirty work' considered to be physically, morally and socially less attractive (Clarke and Ravenswood 2019). These factors play a key role in understanding both why there is little identification of positive wellbeing aspects in relation to family carers, and how in the context of Covid-19 family care remained, in the eyes of carers, under-recognised and under-valued. We would argue that seeing care as a functioning – a key and essential element of everyday lived experience which may carry positive or negative implications for wellbeing offers a more nuanced and critical basis on which to assess the relationship between care and wellbeing. We can conclude too that the capability for real decision-making, a genuine chance to shape the terms on which care is offered – can enable positive accounts of wellbeing for carers, as well as that of those for whom they care.

This points to the necessity of a concerted political agenda. For Tronto, the achievement of a caring democracy requires not only that we change the discourse about care as a matter of daily personal concern, but also political and social institutions. Through our interrogation of wellbeing in the context of care and identifying positives despite the immense pressure and hardships that the pandemic brings for many, we see encouraging arguments of how a 'caring democracy' can begin to be operationalised.

Conclusion

We have argued here that a focus on wellbeing, through the combined critical lens of care ethics and capabilities, allows us to draw out the social justice implications of the experience of family carers – particularly in a period of a public health emergency. Our finding that participants report deprivations of wellbeing cross material, relational and subjective domains points not just to matters of concern, but matters of injustice. Inequalities have been exacerbated because of the withdrawal of support services, leaving carers alone and without support in many instances putting themselves and the cared-for at increased risk of negative wellbeing states, and as described previously, these risks and burdens trace well-established gendered and socio-economic lines. Thus, carers who have the least opportunity for enhancing their capabilities to experience and provide 'good care' are most at risk of negative wellbeing outcomes. In this regard, these is a clear and urgent need as Daly suggests, for further collection of evidence regarding the costs to unpaid carers of non-recognition, and lack of support (Daly 2020).

As a concept 'wellbeing' is well-established in care-related policy, in its mobilisation it is also often unspecific, and arguably incomplete. We have presented an analytical framework of wellbeing in the context of family care that is rooted in a relational conception of the self and that extends measures of wellbeing to encompass structural inequalities with a bearing on all three domains of wellbeing. We believe this analysis is valuable in that it offers a fuller, more accurate perspective on wellbeing and the factors which affect it, and importantly, enables a focus on aspects of structural disadvantage and oppression that shape the wellbeing outcomes of those least likely to be able to achieve functionings related to care. This analysis therefore emphasises the importance of and scope for more effective political interventions. It will also help in the specific and immediate work of counting, and accounting for, the costs of care during the pandemic.

Finally and relatedly, there is a danger that a heightened awareness of the role of care as 'key work' has been problematically depoliticised and divorced from hard questions about the social distribution of risks, burdens and rewards. It may serve to reinforce neoliberal notions of care as a commodity, and a deficit model of care. Participants in our study, reflect and articulate positive aspects of caring, in a way which point to the burdens to wellbeing arising not from the nature of care itself, so much as the wider and drastically uneven distribution of capabilities to function. If the pandemic has reinforced the needs for a 'caring revolution' (Littler et al, 2020), then this kind of analysis can, we believe, help furnish the critical tools with which to take such forward steps.

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