

The imperative of professional dementia care

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Abstract

Despite negative effects on their health and social lives, many informal carers of people living with dementia claim to be acting in accordance with a *moral obligation*. Indeed, feelings of failure and shame are commonly reported by those who later give up their caring responsibilities, suggesting a widespread belief that *professional dementia care*, whether delivered in the person's own home or in an institutional setting, ought always to be a last resort. In this paper, however, I suggest that this common intuition gets things the wrong way around. Adopting a relational egalitarian framework, I argue that the most serious injustices engendered by present-day dementia care services are contingent on broader societal structures—they can thus be ameliorated relatively easily (if resource intensively) by changing those structures. Informal dementia care, on the other hand, carries similar risks of injustice and is much more resistant to structural reform. While there may be moral obligations to provide informal dementia care in present-day societies, then, they arise because of the deficiencies of professional care, not the virtues of its informal counterpart. Though we may be far from achieving just care arrangements in most of our societies, we must never lose sight of the fact that, when we engage in morally permitted informal dementia care, we are exercising our last resort.

KEYWORDS

dementia, equality

1 | INTRODUCTION

Estimates by Alzheimer's Disease International suggest that 84% of those living with dementia globally do so at home, supported by *informal care* from friends and relatives.¹ Despite negative effects on their health and social lives, many informal carers claim to be acting in accordance with a *moral obligation*. Indeed, feelings of failure and shame are commonly reported by those who later give up their caring responsibilities, suggesting a widespread belief that *professional*

dementia care, whether delivered in the person's own home or in an institutional setting, ought always to be a last resort.²

Adopting a relational egalitarian framework, according to which justice requires the eradication of paradigm inegalitarian relationships

¹Alzheimer's Disease International. (2018). *Global estimates of informal care*. <https://www.alzint.org/u/global-estimates-of-informal-care.pdf>.

²See Carlsen, B., & Lundberg, K. (2017). "If it weren't for me...": Perspectives of family carers of older people receiving professional care. *Scandinavian Journal of Caring Sciences*, 32(1), 213–221. Brank, E., & Wylie, L. (2008). Assuming elder care responsibility: Am I a caregiver? *SSRN Electronic Journal*(4), 899–924.; Jacobson, J., Gomersall, J. S., Campbell, J., & Hughes, M. (2015). Carers' experiences when the person for whom they have been caring enters a residential aged care facility permanently: A systematic review. *JBI Database of Systematic Reviews and Implementation Reports*, 13(7), 241–317; Nolan, M., & Dellasega, C. (2000). "I really feel I've let him down": Supporting family carers during long-term care placement for elders. *Journal of Advanced Nursing*, 31(4), 759–767.

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like domination, oppression and stigma from our societies,³ in this paper, I argue that this commonly shared intuition gets things the wrong way around: it is informal care, not professional care, that should always be the last resort for people living with dementia (if not for all persons in need of care).⁴ This is so, I argue, because the deficiencies of professional dementia care services in our contemporary societies can be relatively easily (if resource intensively) ameliorated through structural reforms. As informal dementia care is resistant to the kind of oversight that I argue is necessary to prevent care relationships from perpetuating injustices, the just society for people living with dementia would be one in which it was discouraged in favour of well-regulated, well-funded professional care provided by well-trained, professionally accountable carers. There may be a moral duty to provide informal dementia care in our actually existing societies, then, but if there is, it is because of the inadequacies of our professional dementia care infrastructure, not the virtues of its informal counterpart.

The argument proceeds as follows: first, in Section 2, I set out three features common across the different forms of dementia that lead to risks of injustice within care relationships: dependency, decline and parallel subjectivity. Then, in Section 3, I use the U.K.'s social care system as a case study to highlight the kind of structural barriers to just dementia care that exist in our contemporary societies and the relative ease with which they can be removed. In Section 4, I contrast this with informal dementia care, noting that the risks are still present but that this form of care is resistant to the kind of oversight necessary to liberate people living with dementia from injustice in their care relationships. I also consider and reject a purported benefit of informal care: that it is inherently more loving and individualised, arguing instead that this is itself a pressing moral problem not present in professionalised care services. Having set out this conceptual terrain, I conclude in Section 5 with an analysis of the duties of loved ones of people living with dementia in ideal and nonideal circumstances: namely, that loved ones may be morally permitted to provide informal care where professional care services are not good enough, but that the just society, in which such services were properly funded and regulated, would likely prohibit them from being the *primary* carers of people living with dementia.

2 | THE VULNERABILITY OF PEOPLE LIVING WITH DEMENTIA TO INJUSTICES IN CARE RELATIONSHIPS

Though it is commonly conflated with Alzheimer's Disease,⁵ dementia is a condition with numerous underlying causes, including aggregates of protein known as Lewy bodies, damage to the frontal and temporal

lobes, problems in blood supply to the brain, Parkinson's disease, multiple sclerosis, Creutzfeldt-Jacobs disease and syphilis.⁶ This heterogeneity of origin is matched by a diverse range of symptoms. Early Alzheimer's disease, for instance, is more associated with memory and spatial orientation problems.⁷ Parkinson's and Lewy-Body dementia, on the other hand, are more associated with visual disturbances and hallucinations.⁸

Nevertheless, while significant, the extent of this differentiation should not be overstated. All types of dementia draw on a common pool of symptoms; the key differences are their severity and frequency in the differing patterns of progression.⁹ Thus, despite their diversity, all people living with dementia share three characteristics that render them more vulnerable to abuses of power than the average member of the population.

First, they have impaired cognitive functioning, which makes them more likely to be *dependent* on others to meet their basic needs. This manifests as a vulnerability to abuses of power through refusal to meet needs or the meeting of needs in harmful or disrespectful ways. For example, by rationing incontinence products, a care home in Edmonton Canada in 2020 met the personal hygiene needs of those under its care, but only infrequently and in a way that threatened their dignity.¹⁰

Second, dementia is a progressive condition, which means that the capabilities of those who live with it are *declining*. Thus, they are vulnerable to abuses of power in ways related to their increased dependency over time. For instance, rehoming of people living with dementia has a well-established deleterious effect on health and well-being.¹¹ Consequently, they are exposed to the power of others when decisions are made about facilitating and providing care. If the decision-makers choose not to diligently research services to ensure that they can continue meeting a person's needs *throughout* the progression of the condition, they expose them to risks of neglect.

Third, hallucinations, persistent misconceptions and erroneous interpretations become increasingly prevalent across this decline,¹² which means that, to varying degrees, people living with dementia

⁵Alzheimer's Society. (2018, August 2). What is the difference between dementia and Alzheimer's disease? *Alzheimer's Society Blog*. Retrieved September 20, 2018, from <https://blog.alzheimers.org.uk/dementia-insight/dementia-alzheimers-difference/>

⁶Alzheimer's Society. (2022, August 3) *Types of dementia*. Retrieved October 6, 2022 from <https://www.alzheimers.org.uk/about-dementia/types-dementia>

⁷Smits, L. L., van Harten, A. C., Pijnenburg, Y. A., Koedam, E. L., Bouwman, F. H., Sijm, A. M., Reuling, I. E., Prins, N. D., Lemstra, A. W., Scheltens, P., & van der Flier, W. M. (2014). Trajectories of cognitive decline in different types of dementia. *Psychological Medicine*, 45(5), 1051–1059.

⁸Mosimann, U. P., Rowan, E. N., Partington, C. E., Collerton, D., Littlewood, E., O'Brien, J. T., Burn, D. J., & McKeith, I. G. (2006). Characteristics of visual hallucinations in Parkinson disease dementia and dementia with lewy bodies. *The American Journal of Geriatric Psychiatry*, 14(2), 153–160.

⁹Cerejeira, J., Lagarto, L., & Mukaetova-Ladinska, E. B. (2012). Behavioral and psychological symptoms of dementia. *Frontiers in Neurology*, 3, 73.

¹⁰Johnson, E. (2020, February 21). Nursing home rationed diapers while residents suffered rashes, infections. *CBC*. <https://www.cbc.ca/news/canada/edmonton/nursing-home-rations-senior-diapers-1.5470130>

¹¹Coleman, E. A., Barbaccia, J. C., & Croughan-Minihane, M. S. (1990). Hospitalization rates in nursing home residents with dementia. *Journal of the American Geriatrics Society*, 38(2), 108–112.

¹²Social Care Institute for Excellence (SCIE). (2015). *A different reality*. <https://www.scie.org.uk/dementia/living-with-dementia/difficult-situations/different-reality.asp>

³Nath, R. (2020). Relational egalitarianism. *Philosophy Compass*, 15(7), e12686.

⁴An argument about the optimally just care arrangements for all persons in need of care, given the diversity of conditions such an account would have to encompass, would be far beyond the scope of this paper. While it is possible that some of what I say here may also hold for other conditions, then, I remain agnostic about the wisdom of such an expansion.

experience life through, what I have described in earlier work as *parallel subjectivities*. Where this occurs, the person's internal experience of the world is subjectively consistent but differs significantly from what others perceive as the objective world.¹³ Once this stage of decline is reached, powerful others can determine the connection between their subjective experience of the world and objective reality.

To illustrate this phenomenon, consider the following anecdote from Australian dementia self-advocate Christine Bryden. When visiting a dementia care facility as part of her outreach work, she struck up a conversation with a woman living with dementia who was seeing mice running along the wall. Bryden, who was at an early stage of progression, reports that she was able to assuage this woman's anxiety by taking her on a walk to find a cat to chase them away.¹⁴ Had Bryden ignored this woman, persistently corrected her or dismissed her experience, she might well have missed the need being expressed. Thus, as this example illustrates, people experiencing parallel subjectivities are exposed to the power of others to interpret *what their needs are*.

People living with dementia, then, are severely exposed to the power of others when they enter care relationships. When this power is abused, as has become an all-too-common phenomenon,¹⁵ most of us would believe that they have experienced an injustice. In previous work, I have argued that some of these injustices can be captured by the concept of domination, in the sense used by neo-republicans and (most) relational egalitarians, because they stand as incidences of unrestrained, arbitrary expressions of power.¹⁶ In other work, I have highlighted the ways in which usage of this power can reinforce stigmatising, oppressive attitudes about the lives of people living with dementia.¹⁷ Whether I am right in either of these arguments, however, is largely orthogonal to the point: given the extent to which the dependency, declining capacities and tendencies towards living life in parallel subjectivities increase carer power, all should be able to agree that care relationships carry inherent risks of injustice for people living with dementia. If we are to create a just society for them, it follows that we need this power to be restrained and regulated, rather than ignored or, worse, amplified.

¹³Reference to author's own work redacted.

¹⁴Bryden, C. (2005). *Dancing with dementia: My story of living positively with dementia* (p. 148). Jessica Kingsley Publishers.

¹⁵See Grunau, A. (2018, December 28). *Nursing home abuse in Germany: "I can't let my mother die of thirst"*. Deutsche Welle. <https://www.dw.com/en/nursing-home-abuse-in-germany-i-cant-let-my-mother-die-of-thirst/a-46890600>; BBC News. (2018, November 13). *Nurse abused care home residents*. BBC News. <https://www.bbc.co.uk/news/uk-scotland-edinburgh-east-fife-46201827>; Clemenson, M. (2020, March 5). *Hornchurch care home closed after health inspectors find evidence of 'financial abuse' of dementia sufferers*. *The Romford Recorder*. <https://www.romfordrecorder.co.uk/news/health/hornchurch-care-home-alton-house-to-close-over-abuse-fears-1-6546143>; Ravani, S. (2020, July 3). *Contra Costa DA alleges elder abuse, sexual assault at troubled Orinda nursing home*. *San Francisco Chronicle*; Lintern, S. (2019, December 24). *Care home criticised after staff recorded abusing elderly resident with dementia*. *The Independent*. <https://www.independent.co.uk/news/health/care-home-abuse-neglect-elderly-dementia-ombudsman-a9259566.html>

¹⁶Reference to author's own work redacted.

¹⁷Reference to author's own work redacted.

3 | REMOVING BARRIERS TO JUST CARE: THE UNITED KINGDOM AS A CASE STUDY

In this section, I use the state of dementia care services in the United Kingdom as a case study, highlighting two key problems that allow or even encourage carers to exert their power in unjust ways: insufficient training and inadequate staffing levels. I then set out a series of potential reforms that could be sufficient to ameliorate these risks. As I go on to emphasise, these are not radically different from those already under consideration by relevant stakeholders. Although the feasibility of such reforms has no direct bearing on the duties of policymakers to implement them, the relative ease with which they could be implemented does helpfully highlight the *contingent* nature of the injustices committed by care services in the United Kingdom and, by implication, other jurisdictions.

Of course, because each individual jurisdiction has its own hurdles to overcome, the suggestions that I make here may not be appropriate in every case. However, this discussion is intended to be illustrative, not definitive. Rather than offering firm public policy prescriptions, my goal is to demonstrate that many problems with dementia care services have very little to do with them being *professional*. In fact, as I will go on to argue, this quality may be an *asset* to the goal of achieving a just set of care arrangements for people living with dementia.

3.1 | Training

In the United Kingdom, there are at least three training-related issues with professional services that stand as barriers to achieving just care, some of which may be replicated in other jurisdictions. These are of concern, both because they make it more likely that carers will pursue harmful interventions and because they lead to a lack of effective oversight to deter them from doing so. On a relational egalitarian analysis, these stand as archetypal relationships of domination, in the sense that carers are able to interfere with their charges without being forced to track their interests.¹⁸ As I suggest here, however, these problems could be easily remedied through reforms.

The first problem is that recruitment standards across the sector are low and, consequently, staff are usually not required to have undertaken training before they are employed.¹⁹ Of course, there are other workers such as nurses and physiotherapists who are required to work while they are being trained, but there are usually clear distinctions between the role of a trainee and that of a fully qualified member of staff. By contrast, many professional carers spend some time working as full members of staff, before receiving any formal training,²⁰ and, according to a report by the trade union UNISON, it

¹⁸Nath, op. cit. note 3.

¹⁹Groot Kormelinck, C. M., Janus, S. I. M., Smalbrugge, M., Gerritsen, D. L., & Zuidema, S. U. (2020). Systematic review on barriers and facilitators of complex interventions for residents with dementia in long-term care. *International Psychogeriatrics*, 33(9), 13–16.

²⁰All-Party Parliamentary Group on Social Care. (2019). *Elevation, registration & standardisation: The professionalisation of social care workers* (pp. 27–28). <https://img1.wsimg.com/>

was found in 2015 that 27% of carers working with people living with dementia had received no training on the condition at all.²¹

In the United Kingdom, professional healthcare roles like 'registered nurse' and 'physiotherapist' are protected titles, which means that they can only be used by people who are fully qualified and maintain registration with the relevant professional body.²² Despite some recent moves in that direction, including the introduction of the 'Care Certificate', no equivalent set of standards exist for dementia care.²³ This leads to a lack of accountability, which means that staff who are not competent, or have a track record of acting in ways that harm their charges, are able to apply for jobs across the sector, even if they are fired from their particular service. In my experience of working in care, it was common to hear that staff who had been fired for gross misconduct had been hired by another service. Although it is difficult to find data on how common this experience is, the fact that it is possible at all means that freedom from such harmful interventions cannot be robustly guaranteed. To ameliorate these risks, then, this kind of professional registration ought to be mandatory.

Promisingly, there is already progress in this direction. For instance, the All-Party Parliamentary Group on Social Care has recommended a registration body for social care in England, alongside statutory enforcement of the Care Certificate.²⁴ Now, none of these regimes are *dementia-specific*, which could allow nonspecialist carers to work with people living with dementia without the requisite specialised training. Nevertheless, a registration scheme that recognised the specific requirements of a dementia carer would not require much change to those that are active or proposed today. Indeed, there is already a similar distinction in the process of registering as a mental health nurse, as opposed to a general nurse.²⁵

The second problem is that, while the Care Quality Commission (CQC) has recently increased the number of mandatory training programmes that must be refreshed on a yearly basis,²⁶ there remains no statutory obligation for care providers to deliver specific ongoing training on dementia. Tom Kitwood, whose theory of person-centred care undergirds many training programmes, argues that without ongoing training, staff would not complete their learning cycle and would be unlikely to improve their practice. To this end, he proposed monthly training sessions centred around the current practice within each facility.²⁷ Yet, UNISON found that, of those who

had received some training, less than half of carers working with people living with dementia had received anything on an ongoing basis.²⁸

Care services in the United Kingdom, then, are able to present staff who have not received training for a significant amount of time as dementia-trained. Consequently, family and friends who are tasked with choosing a care service for their loved ones are unable to reliably distinguish between carers who have received ongoing training and those who have only received initial training. Moreover, given the idiosyncrasies of particular people and their particular experience with dementia, a lack of ongoing training makes it less likely that carers will be able to identify appropriate interventions, leading to risks of the undignified 'warehouse' model of care, in which people living with dementia are treated as interchangeable units who can be treated identically, bemoaned by Kitwood.²⁹

Yet again, appropriate solutions are evident. Bodies such as the forementioned APPG³⁰ and the Nuffield Council on Bioethics³¹ have long called for changes to the frequency of dementia care training. Now, neither specifically recommends mandatory training for carers centred around the *specific people they care for*, which is key to countering the effects of the warehouse model.³² However, this is a very minor addition to these recommendations, which ought to be easy for relevant stakeholders to embrace.

Finally, there is a problem with the quality and content of training. While there are some exceptions, such as the University of Bradford's postgraduate Dementia Studies degree,³³ a 2019 audit of training programmes for carers found that the majority were unassessed and relatively superficial: both because of insufficient content and duration.³⁴ This means many staff can present themselves as trained despite having no proof that they fully engaged with their training and a lack of depth in what was presented to them. Any care system with this little rigour in training, evidently, cannot robustly guarantee that its service users will be free from interventions that fail to track their interests.

The need for greater training is likely to be as common-sensical a recommendation as the others I have made here. For instance, few would disagree that dementia carers need to be trained on the symptoms of the various types of dementia, which would make it easier for carers to assess and discover wider interests. Nor would there be widespread objections to improving training on recognising abuse, which would help carers to play an effective role in the kind of

[blobby/go/c6219939-c33a-4460-a71e-4df262903498/downloads/SC%20Inquiry%20Final%20%20.pdf?ver=1567432735387%2C%2A0](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/446047/SC20Inquiry%20Final%20%20.pdf?ver=1567432735387%2C%2A0)

²¹UNISON. (2015a). *Homecare training survey report*. <https://www.unison.org.uk/content/uploads/2015/04/TowebUNISONs-Homecare-Training-Survey-Report.pdf>

²²The Chartered Society of Physiotherapy. (2016, November 3). *Regulation of physiotherapy*. <https://www.csp.org.uk/professional-clinical/professional-guidance/regulation-physiotherapy>; The Nursing & Midwifery Council. (2020, March). *Our order and rules*. <https://www.nmc.org.uk/about-us/governance/our-legal-framework/our-order-and-rules/>

²³UNISON. (2015b). *Introducing the care certificate*.

²⁴All-Party Parliamentary Group on Social Care, op. cit. note 20, pp. 25–26.

²⁵Nursing and Midwifery Council. (2010). *Standards for competence for registered nurses*. <https://www.nmc.org.uk/globalassets/site/documents/standards/nmc-standards-for-competence-for-registered-nurses.pdf>

²⁶Skills for Care. (2022, June 27). *Core and mandatory training*. Retrieved October 6, 2022, from <https://www.skillsforcare.org.uk/Learning-development/Guide-to-developing-your-staff/Core-and-mandatory-training.aspx>

²⁷Kitwood, T. (2019a). The caring organisation. In D. Brooker (Ed.), *Dementia reconsidered, revisited: The person still comes first* (p. 130). Open University Press.

²⁸UNISON (2015a), op. cit. note 21.

²⁹Kitwood, T. (2019b). Improving care: The next step forward. In D. Brooker (Ed.), *Dementia reconsidered, revisited: The person still comes first* (p. 104). Open University Press.

³⁰All-Party Parliamentary Group on Social Care, op. cit. note 20, p. 42.

³¹Nuffield Council on Bioethics. (2009). *Dementia: Ethical issues* (pp. 42–57).

³²Kitwood (2019a), op. cit. note 27, p. 130.

³³University of Bradford. (2022, January 18). *Advanced dementia studies*. Retrieved October 6, 2022, from <https://www.bradford.ac.uk/courses/pg/advanced-dementia-studies/>

³⁴Smith, S. J., Parveen, S., Sass, C., Drury, M., Oyebo, J. R., & Surr, C. A. (2019). An audit of dementia education and training in UK health and social care: A comparison with national benchmark standards. *BMC Health Services Research*, 19(1), 1–9.

oversight necessary to prevent care relationship from becoming dominating.

However, policymakers might require more convincing to, for example, establish training in the kind of therapeutic questioning skills that counsellors and psychotherapists possess. Yet, much recent work on dementia suggests that they may be necessary to counteract avoidable harms. After all, as Bryden argues, many people living with dementia only appear violent or threatening because their expressions of needs are not being heard.³⁵ Unsurprisingly, then, a 2019 study found that restraint was being overused on people living with dementia in hospital wards, in part because of inadequate training.³⁶

Nevertheless, given that many health and social care workers, such as paramedics, nurses and physiotherapists, are now educated to undergraduate degree level in the United Kingdom, it does not seem unreasonable to argue that similar standards are required in the initial training of dementia carers. Thus, although the level of training required to pursue dementia care justly may be far beyond current policy, there are several precedents for it. If policymakers can be convinced of the value of these advanced skills in providing such care, then, it should not be impossible to establish the kind of training necessary to support them.

3.2 | Staffing levels

In addition to being poorly trained, many carers are allowed or even encouraged to perform badly, because they operate within services that are understaffed. In the United Kingdom, the Care Quality Commission requires care providers to have an adequate level of staff to meet the needs of its users but does not recommend a specific ratio.³⁷ Of course, as service users have different needs that require differing numbers of staff, what might be adequate staffing for one service may be over- or understaffing for another, so perhaps it is wise to avoid being too numerically stipulative. Nevertheless, it is striking that a 2018 study found neglect present in 99% of care homes, with staff shortages among the most common contributing factors.³⁸

Evidently, where carers face staffing pressures, they will face difficulties in caring effectively. Ascertaining the interests of a person living with dementia and acting accordingly takes time. The indirect-first approach to dementia care, which I have defended in previous work as the best model for ensuring that care does not become dominating, requires carers, where possible, to make thoughtful,

interpretive interventions into the *environment* of the person they are caring for to put them in a position in which they can meet their own needs.³⁹ Carers are unlikely to be able to engage in such a practice if they are only allocated 15 min to fulfil their duties.

Consequently, service users may be woken up at times that do not suit them, rushed through washing routines in emotionally distressing ways or, most strikingly, prevented from exercising their own capabilities because it is faster for the carer to meet their needs for them. Indeed, to this last point, a 2013 study found that the overall level of resident activity in care homes remains low, despite a renewed emphasis on meaningful activity in government policy.⁴⁰

I would be hard pressed to find an expert on this topic who did not agree that care services tend to be understaffed. It might be more difficult, however, to convince relevant stakeholders of the *degree* of that understaffing. If treating a person living with dementia justly requires working at their pace and giving them time to exercise their capabilities with support, as I have argued in previous work,⁴¹ then it is likely that staffing needs to be increased far beyond that which exists today. Nevertheless, because there is a broad consensus that staffing levels need to be improved, it is not impossible to imagine the CQC tightening its recommendations and sanctioning those services that do not deploy sufficient staff.

No doubt, there are resource challenges in particular jurisdictions and structural problems that I have not considered. What I have sought to illustrate here, however, is that a significant number of present-day problems with *professional* dementia care can be resolved through effective public policy. This is so, because the relational injustices of present-day care services, including the lack of restraint on carer power, are *structural* problems: attributable to a regulatory framework that fails to robustly ensure that services are well-staffed with well-trained, knowledgeable carers, who are subject to effective oversight to ensure that they do not violate the interests of their charges in their interventions. While my suggestions may not get there on their own, the general point ought to be clear: professional care is not inherently unjust for people living with dementia, because the injustices that they perpetrate can straightforwardly be remedied through structural reform.

4 | THE CASE AGAINST INFORMAL DEMENTIA CARE

Public policymakers, if the arguments above are generalisable, can and should reform private dementia care services to prevent them from instantiating inegalitarian, unjust relationships over their service users. Even so, there may be some who would still view them as a last resort. After all, that such services need not be actively unjust does

³⁵Bryden, C. (2015). *Nothing about us, without us: 20 years of dementia advocacy* (p. 196). Jessica Kingsley Publishers.

³⁶Gunawardena, R., & Smithard, D. G. (2019). The attitudes towards the use of restraint and restrictive intervention amongst healthcare staff on acute medical and frailty wards—A brief literature review. *Geriatrics*, 4(3), 50.

³⁷Care Quality Commission (CQC). (2019, July 18). *Regulation 18: Staffing*. <https://www.cqc.org.uk/guidance-providers/regulations-enforcement/regulation-18-staffing>

³⁸Cooper, C., Marston, L., Barber, J., Livingston, D., Rapaport, P., Higgs, P., & Livingston, G. (2018). Do care homes deliver person-centred care? A cross-sectional survey of staff-reported abusive and positive behaviours towards residents from the MARQUE (Managing Agitation and Raising Quality of Life) English national care home survey. *PLOS ONE*, 13(3), e0193399.

³⁹Reference to author's own work redacted.

⁴⁰Wenborn, J., Challis, D., Head, J., Miranda-Castillo, C., Popham, C., Thakur, R., Illes, J., & Orrell, M. (2013). Providing activity for people with dementia in care homes: A cluster randomised controlled trial. *International Journal of Geriatric Psychiatry*, 28(12), 1296–1304.

⁴¹Reference to author's own work redacted.

not automatically entail that they are optimally good or just for their users. Indeed, some may feel that informal care *maximises* a person's interests or welfare, rather than merely being free from harm and indignity, so anyone who can provide it, ought to.

In this section, I reject this view. First, I consider informal care in light of the previous section, demonstrating that the same problems will inevitably be present, but that they cannot be so easily resolved through structural reform. Second, I demonstrate that an oft purported advantage of informal care—its intimate, personal and loving nature—actually risks further injustices that are also difficult to resolve through public policy. Thus, I conclude that informal dementia care, taken in isolation, carries greater risks of injustice, than its professional counterpart.

4.1 | The difficulty of regulating informal care

Informal carers, by definition, are not employees. In that sense, the issues of poor training and understaffing, which I identified as root causes of unjust dementia care in the United Kingdom, are not directly translatable to them. However, albeit in a different form, problems of this kind are still present in nonprofessional dementia care contexts.

To understand this, consider how people come to take on the role. Though it would be odd to refer to them as 'recruitment standards', the requirements for adopting this role are fairly loose, by definition. After all, were a friend or family member required to maintain official registration, attend a rigorous job interview or demonstrate extensive prior experience, we would no longer be talking about informal care.

Rather, informal carers come to occupy their roles because of the relationships that they already have with the person being cared for, not the skills or demonstrated competence they have. Accordingly, due to the nature of the role, informal carers are not guaranteed to be adequately trained, not guaranteed to receive ongoing training and need not necessarily meet any particular standards before taking on their duties. All three training-related issues that are present in the U.K.'s professional care services, then, are present in informal care relationships.

Moreover, because family and friendship group numbers are limited, informal carers may not always have enough people to provide adequate care to their loved ones. No doubt, informal carers often operate on a 1-1 ratio with the person being cared for, which is better than many care homes can offer. Problems in staffing may still occur, however, if the person living with dementia needs access to care throughout the day. After all, professional care services can split days into shifts so that the person in receipt of care has access to a carer who is awake and alert *at any time of day*. In a limited group of informal carers, however, this may be impossible without subjecting them to an intolerable strain on their time and energy. The risks of understaffing that are present in today's professional care services are therefore likely to be present in many informal care relationships.

These are not merely theoretical concerns. Informal caregiver distress, of the kind that a lack of training in dementia care may engender, seems to be associated with a worsening of outcomes for people living with dementia.⁴² Likewise, increases in caregiver burden, of the kind that could be engendered by overworking, seem to be associated with an increase in abuse.⁴³ It is alarming, therefore, that a recent study of informal caregivers in the United Kingdom found that over 20% were at high risk for depression,⁴⁴ while another found that over a third of informal carers in the United Kingdom report working over 100 h a week providing care for their loved ones.⁴⁵ There are, thus, a significant number of informal carers of people living with dementia today who are, even if it is by no fault of their own, putting their charges at risk of abuse and neglect.

To be clear, this is not to say that all informal carers are incompetent, nor that families and friendship groups do not engage in serious deliberation over who among them should provide care. The point, rather, is that, without specified standards of experience and training, competence cannot be *robustly guaranteed* for all people living with dementia who receive care informally. If adequate sanctions or restraints on their carers cannot be levied, no informal care relationship can be free of domination. This remains true even if many informal care relationships are in fact enabling and caring—relationships of domination, in the sense used by relational egalitarians, are characterised by the capacity to exercise arbitrary power, even if its wielder never does so.⁴⁶

Perhaps, similar to proposals that have been made about parenting,⁴⁷ governments could issue dementia care licenses on the receipt of training, which could be removed in instances of abuse. Provided there is adequate financial and social support to enable informal carers to receive these licenses, this might go some way towards ameliorating these risks. Nevertheless, there are a number of problems with invigilating informal care, which might make such a regime difficult to uphold.

Consider, first, the lack of institutional support inherent to informal care. While a professional care service can make use of supervisions, spot-checks and peer evaluation to moderate standards and tackle issues, none of these is fully compatible with the provision of informal care. Thus, because carers do not have superiors to report to or formal channels through which they can ask for assistance or be disciplined, they may treat their charges unjustly without anybody knowing.

⁴²Stall, N. M., Kim, S. J., Hardacre, K. A., Shah, P. S., Straus, S. E., Bronskill, S. E., Lix, L. M., Bell, C. M., & Rochon, P. A. (2018). Association of informal caregiver distress with health outcomes of community-dwelling dementia care recipients: A systematic review. *Journal of the American Geriatrics Society*, 67(3), 609–617.

⁴³Gimeno, I., Val, S., & Cardoso Moreno, M. J. (2021). Relation among caregivers' burden, abuse and behavioural disorder in people with dementia. *International Journal of Environmental Research and Public Health*, 18(3), 1263.

⁴⁴Borsje, P., Hems, M. A., Lucassen, P. L., Bor, H., Koopmans, R. T., Pot, A. M. (2016). Psychological distress in informal caregivers of patients with dementia in primary care: Course and determinants. *Family Practice*, 33(4), 374–384.

⁴⁵Dementia Statistics Hub. (2018, August 14). *Impact on carers*. <https://www.dementiastatistics.org/statistics/impact-on-carers/>

⁴⁶Nath, op. cit. note 3.

⁴⁷LaFollete, H. (2010). Licensing parents revisited. *Journal of Applied Philosophy*, 27(4), 327–343.

Of course, egregious abuse may be apparent to other family or friends, but whistle-blowing cannot be robustly guaranteed in every case. After all, different families and friendship groups involve different social dynamics, are of different sizes and are spread out over differently sized geographical areas. Thus, the ability to invigilate one another's work may vary depending on each group's particular situation.

Likewise, though well-funded social workers may be able to invigilate the provision of informal care to some degree, their ability to discover and sanction abuse may be limited. After all, while a professional care service can increase staff numbers, replace carers who are not performing well or remove those struggling from particular service users until they are better trained, social workers can do little of this without professionalising the role of the informal carer. Thus, if its informal nature is to be maintained, social workers may only be able to react to problems by mandating professional care or threatening to do so—something they may be reluctant to do outside of cases of egregious abuse.

All this is to say that, though it is often romanticised, informal dementia care is fraught with the same problems as its professional counterpart. Moreover, because its practitioners are not employees, regulating and applying sanctions to their activities may be much more difficult. The upshot of these reflections, then, is that a preference for informal care cannot be defended on the grounds that it is *optimally just* in comparison with professional care. On the contrary, it carries the same risks of harmful and disrespectful treatment alongside a greater difficulty in restraining carer power.

4.2 | The problem with 'the Personal Touch'

Alongside those risks of unjust treatment shared with professional care, there are distinctive issues that arise from one of informal care's purported goods. It is common to hear people expressing concerns about professional care as *impersonal* or *transactional*, such that it strips away important emotional components of the care relationship. No doubt, overpopulated care homes with tiny, clinical bedrooms and dreary lounges with dozens of armchairs packed tightly together are terribly undignified and oppressive. So too are brusque, impersonal community carers, who can only attend to each of their long list of clients for 15 min before rushing on to the next home.

Where services of this kind are all that are available, the aversion of many towards professional care is perfectly understandable. Due to their personal relationship, an informal carer may be kinder, more knowledgeable and more loving towards the person receiving care than an employee of an unjust professional care organisation. A lack of professional distance, such as that which exists between informal carers and their charges, however, may also carry risks of marginalisation—risks that are more difficult to mitigate through policy than their professional counterparts.

Consider first the embeddedness of informal carers within particular family or friendship systems. The fact that these carers have close relationships with other loved ones of the person they are

caring for might lead to a number of issues with the ability to invigilate their care. Harmful or undignified interventions may be tolerated, for instance, because the person living with dementia fears the withdrawal of familial affection or because there is no effective conflict resolution practice within the group that they are embedded in.

Even where an incompetent or malicious informal carer is relieved of duties, moreover, they may not be totally removed from the social or familial circle. Thus, unlike in properly regulated professional care settings, a victim of abuse or neglect may be required to continue sharing social space with the perpetrator, in the sense that they may be cared for by or socialise with people who maintain contact with them. In this sense, the lack of professional distance both makes sanctioning bad behaviour more emotionally taxing and makes it harder to fully remove threats.

Key to understanding these difficulties is recognising that informal care is provided over *transformed* relationships, rather than new ones. People living with dementia are the elderly relatives, spouses or friends of their informal carers. These are either relationships in which they could have sought social recognition by providing care themselves or peer relationships in which they could share in a common life on equal terms. However, as care relationships are unavoidably asymmetric in power, informal care transforms these ties such that the person becomes dependent on and vulnerable to those they are close to.

For many, this transformation may be accompanied by a risk to their sense of dignity. Indeed, as noted by Maria Stuifbergen and Johannes Delden, many people are uncomfortable with the idea of being cared for by their children, spouses or friends, because it involves activities, such as being assisted to wash or eat by them, that they consider inappropriate for the relationship.⁴⁸ Even for those who can tolerate it, however, this transformation may carry an oppressive, marginalising character, because it erodes their ability to gain recognition as a useful participant in the most intimate circle of their social lives.

Note that it is not the mere fact of their dependency that causes this marginalisation; as Iris Marion Young notes, dependency need not be oppressive.⁴⁹ Rather, it is that the barrier between their social circle and the people on whom they directly depend to meet their vital needs has broken down. Thus, the asymmetry of the care relationship risks overshadowing their intimate, familial and social relationships in a way that disrupts their ability to be an equal participant in their social life.

By way of illustration, consider an informal care relationship between two friends. Sam, who lives with dementia, used to think of herself as an equal participant in her friendship with Nina. They would help each other with personal problems, provide assistance when one of them was in need and take part in leisure activities that they both enjoyed together. As Nina now cares for her, however,

⁴⁸Stuifbergen, M. C., & Van Delden, J. J. (2010). Filial obligations to elderly parents: A duty to care? *Medicine, Health Care and Philosophy*, 14(1), 68.

⁴⁹Young, I. M. (1990). *Justice and the politics of difference* (p. 55). Princeton University Press.

Sam is now dependent on her friend's assistance in a way she knows she can never repay. She also has little privacy in their interactions, while Nina has an entire life outside of this care relationship. Worse, when she is upset with Nina or feels like she is making a mistake, Sam cannot be frank and honest with her the way she used to for fear of losing support. Where Sam once enjoyed social recognition from a peer then, she now experiences a marginalising, asymmetrical dependency, of the kind Young herself highlights, in which she has no private life, little individual choice and lacks the social standing necessary to demand respectful treatment.⁵⁰

Of course, exceptional carers will do their best not to highlight this asymmetry, instead seeking to enable their charges to take part in social life with people outside of the circle who are not involved in their care. While these practices may reduce the severity of this risk of marginalisation, however, they cannot remove it from *their relationship with the charge*. After all, no matter how professionally a son seeks to care for his father, there is a history of intimacy between them that cannot be easily discarded. Thus, even exceptional informal carers remain a part of their charge's social circle, such that the capacity for social recognition and equal participation between them is eroded.

Some may doubt that a barrier between one's carers and one's social circle is necessary to avoid marginalisation. Indeed, many care ethicists might think that the solution to marginalisation through asymmetric dependency is to *normalise* our interdependence, such that we are all conscious and appreciative of the way we care for *each other*.⁵¹ As noted by Tom Shakespeare, however, this approach ignores the extent to which disabled people are *socially* constructed as dependent, such that they needlessly have less control over their own lives and fewer opportunities for social recognition than others. Without minimising the areas in which disabled people are dependent through social support schemes and professional care, he argues, they will be further marginalised by a social structure that does not take their needs for social recognition and independence seriously. Maintaining the barrier between one's personal care and one's social circle is then, in Shakespeare's terms, a necessary component of the 'level-playing field' upon which the social order that recognises our interdependence must be built.⁵²

Far from being a benefit for people living with dementia, then, the personal nature of informal care carries many risks of injustice. This example serves to illustrate the threats to dignity and social standing inherent to delivering dementia care through extant, intimate relationships. Accordingly, just as a preference for informal dementia care cannot be justified on the grounds that it is less prone to unjust treatment, it also cannot be justified on the grounds that it is more personal than its professional counterpart, due to the risks of marginalisation.

That care laid over extant intimate relationships may be unjust, it should be noted, ought not to be conflated with the more radical claim that personal knowledge, reliability and availability (qualities of the ideal relationships that we share with loved ones) are of no value or have no place in justice considerations. To engage in the kind of nondominating, nonmarginalising care justice demands, professional carers may need to acquire intimate knowledge of their charges. Moreover, it seems highly plausible that, for at least some persons, just care arrangements would involve a professional carer facilitating deep, meaningful interactions with loved ones. All that has been established in this section is that such meaningful social interactions cannot take place without risks of marginalisation, unless the person living with dementia's dependency needs are met by someone outside of their social circle.

Before moving on, it should also be noted that, while it may carry a risk of injustice, some may object that a personal, intimate care relationship is likely to be *good* for a person living with dementia, given the inherent value that we place on love and care in existing relationships. If this is right, then there may be a conflict between what is good and what is just for a person living with dementia, which some may be inclined to resolve in favour of the good.

A meditation on the relationship between the good and the just is, naturally, beyond the scope of this paper. I raise this point, however, as a prompt to restate the background assumptions of this paper. I began explicitly from the view that persons living with dementia are owed justice, and that that should take the form of liberating them from paradigm inequalitarian relationships. Any objection to the arguments I make here that begins from the premise that we ought to do what we think is good for a member of this group, even if it conflicts with what is just, must demonstrate that such treatment is compatible with the demand that we relate to them as equals. As many of us would object to others treating us unjustly because they think it will maximise our good, such a view may be highly counterintuitive.

5 | CHOOSING DEMENTIA CARE FOR A LOVED ONE

As I have suggested here, informal care carries the same risks of relational injustice as its professional counterpart, while carrying unique risks of marginalisation. However many formal carers are benevolent in their wielding of dominating power, or are educated on dementia, freedom from these relational injustices cannot be guaranteed because the model is inherently resistant to oversight. It stands to reason, then, that an ideally just society would not *rely* on family and friends of people living with dementia in the provision of care. Instead, well-regulated, trained and staffed professional care services would be accessible to all those who needed them.

That family and friends in such a society would not have an *obligation* to provide informal care, however, does not settle the *permissibility* of doing so. Nor does it clarify the duties of the loved ones of people living with dementia in our present-day, nonideal

⁵⁰Ibid: 54.

⁵¹Held, V. (2006). *The ethics of care: Personal, political, and global* (pp. 11–14). Oxford University Press on Demand.

⁵²Shakespeare, T. (2000). The social relations of care. In G. Lewis, S. Gewirtz, & J. Clarke (Eds.), *Rethinking social policy* (pp. 59–63). SAGE.

circumstances. In this final section, then, I address these two issues in turn, concluding by inverting the common intuition that I began by considering that informal, not professional care, should always be considered a *last resort* for people living with dementia.

5.1 | Informal care in ideal circumstances

In ideal circumstances, public policy initiatives would be used to restrain the power of professional dementia care workers, using training, regulation and staffing to deter them from harmful, undignified interventions. In other words, in ideal circumstances, professional care services would not be *actively unjust*, because the threats of domination would be removed. It is for this reason that, in such a society, informal care would not be relied upon.

As I indicated in the previous section, some restraint on the power of informal dementia carers could be exercised through such initiatives. Yet, even if legislation were able to prevent the risks of harm and indignity in informal care entirely, the risks of marginalisation inherent in the transformation of intimate social bonds into asymmetric dependency relationships may not be resolvable. Consequently, anyone choosing to provide informal dementia care, in ideal circumstances, would appear to be committing a grave harm, by exposing their loved ones to unnecessary risks of injustice.

This, however, may be too quick for some. After all, such an argument implies that a just society ought to *prohibit* the provision of informal care, which would strike many as a demeaning intrusion into family life. Moreover, there may be some people living with dementia who consistently communicate that they *want* to be cared for by their close family and friends, such that a preference for informal dementia care forms a core part of their value-set.

The former objection, though perhaps emotionally compelling, does not carry much weight. There is nothing demeaning or insulting about making policy that applies to *all* carers, highlighting the risks *inherent in the relationship*. Of course, there might be bad versions of a prohibition on informal care, involving injustices such as disproportionate sanctions or overmonitoring of minority groups. None of these, however, is *inherently* risked by such a prohibition.

The latter, however, might appear thornier; the prevention of people living with dementia from receiving the type of care that they want could be construed as disempowering or harmful in itself. Nevertheless, banning *exclusively informal* dementia care, in which those who receive it are *only* cared for by nonprofessional loved ones, need not have this character. After all, there are many ways in which people can contribute to the care of their loved ones without *becoming their carers*, such as engaging in meaningful activities with them, helping professional carers to shape their environments or providing them with emotional support. Given that the risks of marginalisation that I specified in the previous section emerge, primarily, through the designation of carers and dependents in intimate social circles, such an arrangement would be less concerning.

Understood this way, there is nothing objectionable about friends and family members *helping* people living with dementia,

which may occur throughout the progression of the condition. An ideally just society, however, would likely *prohibit* loved ones from taking on *the role of carer in an asymmetric dependency relationship*, given that just professional dementia care would be widely available. Thus, though a loved one might prepare some of a person living with dementia's meals, wash their clothes, manage their diary or make suggestions to a professional carer, an ideally just society would prohibit them from bearing the *primary* responsibility for meeting the charge's needs.

Note that this need not require anyone with a diagnosis of dementia to move to a care home or be cared for by a permanent, live-in carer. In the early stages of the condition, it may be sufficient to have an advisor who helps to support the person so that they may live at home independently. In later stages, they may need to be visited several times a day by a carer but, if there are no immediate dangers that require constant monitoring, they may be helped by their loved ones, without risks of injustice in between visits. When continuous access to care is needed, however, justice demands that this is provided by a well-trained, properly regulated professional service: either in the person's own home or in an institutional setting.

5.2 | Avoiding informal care in nonideal circumstances

Absent such a just society, however, many would likely default to the position of viewing professional care services as a last resort. On one version of this view, even though informal dementia care carries greater risks of injustice, the known injustices of professional services are too severe to countenance subjecting their loved ones to them. In this sense, many believe that they have a *duty* to care for their older relatives and friends living with dementia.

Many versions of this view rest on the idea of reciprocity.⁵³ So understood, children who have been cared for by older adults who then, themselves, require care have incurred a debt that ought to be repaid. Yet, while there is something poetically pleasing about such a view, it is highly problematic. Not only does it exclude persons who have not cared for children (either because they do not have them or were not able to) from its scope, it also suggests that such duties vary in strength depending on the kind of relationship that a person has with their parent. This is particularly concerning, as those who are likely to have received extensive care, perhaps due to disability, may experience the duty to care for their carers as much more challenging. Any duty to care for our loved ones, thus, cannot be based on what Simon Keller calls a 'debt theory' of filial obligation.⁵⁴

Another version of this view rests on *hypothetical reciprocity*. So understood, the relationship between the informal carer and the person living with dementia rests on mutual acknowledgement that

⁵³Bliezner, R., & Hamon, R. R. (1992). Filial responsibility: Attitudes, motivators, and behaviors. In J. W. Dwyer & R. Coward (Eds.), *Gender, families, and elder care* (pp. 105–119). SAGE Publications.

⁵⁴Keller, S. (2006). Four theories of filial duty. *The Philosophical Quarterly*, 56(223), 256–257.

informal care would be provided were the roles reversed.⁵⁵ This duty may be plausible for many caring acts, but it is less clear that it can cover highly specialised dementia care. Such a duty, after all, must surely be limited by what it is *possible* for a person to do, and in particular limited by what *costs it is reasonable to demand they bear*.

By analogy, a friend who lives next door to me may have a care duty, grounded on hypothetical reciprocity, to bring me a bowl of soup or some paracetamol when I am struck with influenza. It would be unreasonable, however, for me to demand the same of a friend living on another continent. Indeed, it would still be unreasonable even if both of us mistakenly thought that we *would* be able to bring one another soup when the other is ill. Given the level of skill and knowledge necessary to avoid dominating persons living with dementia in care relationships, there can, similarly, be no reasonable duty derived from hypothetical reciprocity to provide it: at least not in all circumstances.

That this is an uncomfortable conclusion for many likely rests on the fact that, in our present-day societies, injustices that arise in professional care settings are much more familiar. In a sense, this ought to be unsurprising, as professional dementia care services, in many jurisdictions, are inadequate. That some may feel they have a duty to provide informal care in such circumstances, *despite its costs*, does seem to suggest that there is some duty of care they are drawing on.

This duty, however, is not best characterised as a duty to provide care. On the contrary, as argued by Maria C. Stuifbergen and Johannes J. Van Delden, what is being invoked here is more plausibly described as a duty to care *about* our loved ones.⁵⁶ Naturally, this duty requires us to care about our loved one's vital needs and to do what we can to ensure that they are met, but it also requires us to care about their social status and their claims to just treatment. Where care services are ideally just, as I have argued above, this duty requires the loved ones of a person living with dementia in need of care to ensure that those needs are met by professionals. Where professional care services are imperfect but are likely to bear fewer risks than informal care, this duty also points towards them. After all, *how* a person's needs are met is just as important as whether or not they are met at all.

Note, however, that where professional care services cannot meet a person's needs at all (or can only do so in a demeaning, disempowering way), the duty to care about our love ones could require their loves ones to provide informal care. In many of our societies, professional care services are of this nature, which might account for our common, intuitive aversion to professional carers and, in particular, care homes. It should be understood, nevertheless, that the validity of this intuition is *contingent*: the duty to care about our loved ones, given all that I have said above, could only require informal care where professional care services are *inadequate*.

Moreover, it ought to be noted that, if the inadequate professional care can be made good enough by informal

supplementation,⁵⁷ the duty to care *about* our loved ones with dementia may be best served that way, given the particular risks of marginalisation that arise from the private nature of informal care. For example, if a care home is generally pleasant and caring, but too understaffed to attend to all residents who need assistance with eating, their loved ones could supplement that care by visiting daily to sit with them at mealtimes. Likewise, if community care services are adequately staffed, such that they can help their clients out of bed at times of their choosing, but are only able to offer 15-min appointments, loved ones could supplement that care by laying out fresh clothes, preparing the bathroom or offering to help with the final stages of getting them dressed—for example, putting on their socks or tying their shoes.

All this is to say that there exists no general duty for a person to provide informal dementia care to their relatives as such. No doubt, there are many circumstances in which a person has no choice but to provide such care and it seems plausible that there is a special obligation to do so (though the obligation may be unenforceable). No doubt, there are many others in which the duty to care about their loved ones requires them to supplement the professional care that is available. In all such cases, however, this obligation exists because of the inadequacy of professional care, not because of the superiority of informal care. Thus, it is informal, not professional care, that should be considered a last resort.

6 | CONCLUSION

In this paper, I have argued that the inherent risks of relational injustice present in dementia care relationships can be ameliorated through regulation when it is professional, but are always present when it is informal. I have also argued that there exists no general moral duty to provide dementia care within close, personal relationships, though there may be when professional services are inadequate.⁵⁸ There are, thus, two pressing moral upshots of this analysis. First, there is an imperative for policymakers to improve professional care services so that people living with dementia can be free from injustice. Second, decision-makers ought to view informal dementia care as a *last resort*: only to be considered if their loved

⁵⁷This is a practice which some contemporary informal carers engage in, see Bowers, B. J. (1988). Family perceptions of care in a nursing home. *The Gerontologist*, 28(3), 361–368.

⁵⁸This argument bears a family resemblance to Adam Swift's work on school choice (see: Swift, A. (2004). The morality of school choice. *Theory and Research in Education*, 2(1), 7–21), though it differs in important aspects. For Swift, parents act unjustly by sending their children to private schools, in ideal circumstances, because it makes *everyone else* worse off. As I have argued here, loved ones act unjustly by providing informal care, in ideal circumstances, because it makes the person in *receipt* of that care worse off. Thus, while both arguments use institutional inadequacy as a justification for doing something that would, in ideal circumstances, not be morally permissible, the consequences of doing so differ greatly. On Swift's view, a child sent to a private school when state schools are inadequate would not be exposed to an injustice: in fact, they would be better off than they would have been had they attended a state school in ideal circumstances. A person living with dementia, on my view, would be exposed to a number of injustices if provided with informal care and would be much worse off than they would have been if they had received professional care in ideal circumstances.

⁵⁵Bliezner & Hamon, op. cit. note 53.

⁵⁶Stuifbergen & Van Delden, op. cit. note 48, pp. 69–71.

one's needs cannot be met in a way compatible with the demands of justice through the professional care system.

As the kind of structural reforms necessary to ensure non-dominating, egalitarian professional care are likely to be highly resource-intensive, we may be far away from achieving just care services. In many if not all jurisdictions, then, loved ones are likely to be justified in providing informal care as an alternative, and this justification may stand for the foreseeable future. It would be a grave error, nevertheless, to lose sight of the fact that professional care relationships *can* be made robustly egalitarian, where their informal counterparts cannot. This, then, is the key contribution of this paper: when setting a direction of travel for public policy around dementia care, policymakers should proceed with the aim of improving professional care, so that the loved ones of people living with dementia do not have to exercise their last resorts.

CONFLICT OF INTEREST

The author declares no conflict of interest.

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