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Title	Multiple stakeholders' perspectives on respite service access for people with dementia and their carers
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Publication date	2019-07-12
Original Citation	O'Shea, E., Timmons, S., O'Shea, E. and Irving, K. (2019) 'Multiple stakeholders' perspectives on respite service access for people with dementia and their carers', The Gerontologist, 59(5), pp. e490-e500. doi: 10.1093/geront/gnz095
Type of publication	Article (peer-reviewed)
Link to publisher's version	10.1093/geront/gnz095
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Download date	2026-11-02 05:14:37
Item downloaded from	https://hdl.handle.net/10468/9257

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Multiple Stakeholders' Perspectives on Respite Service Access for People with Dementia and their Carers

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Funding: This research was funded by the Health Research Board SPHeRE/2013/1.

Ethical approval: Obtained from Dublin City University Research Ethics Committee (DCUREC/2017/018).

Authors' contributions: EmOS collected the data, transcribed and analysed the data, and drafted the manuscript. EmOS, KI, EaOS and ST conceived of the study and supported the data analysis process. All authors reviewed and gave input on the final manuscript.

Declaration of Conflicting Interests: The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Abstract

Introduction: People with dementia and carers do not always access respite services in a timely manner, or in some cases, at all. While carers' perspectives on respite access have been explored, other stakeholder perspectives, especially providers and people with dementia, are under-represented in the existing literature. The aim of this study was to synthesise multiple stakeholders' perspectives, including people with dementia, on accessing respite services in the context of dementia.

Methods: Purposive maximum variation sampling was employed. Semi-structured interviews were conducted with 35 key stakeholders, including people with dementia (n=6), carers (n=9), respite front-line staff (n= 4), respite managers (n=8), primary care professionals (n=3) and policy-makers/academics (n=5). The process of consent is outlined. Data were interpreted inductively using thematic analysis. Reflexivity was considered throughout the research process.

Results: Three themes ('Service Acceptability'; 'Navigational Knowledge and Skills'; 'Constructing and Adjudicating Respite Need') were identified that relate to how access to respite services is negotiated between service providers and dyads.

Discussion: A number of the findings support previous research; however novel findings discussed relating to the access negotiation process include 1) the ambiguous legitimacy of respite needs, in a system configured to deliver a biomedical model of care and which considers non-medical care as a family responsibility, and 2) the constraining effects of disparate conceptualisations of 'respite' between carers and providers. Future research should interrogate the appropriate boundaries of public responsibility in relation to respite service planning/delivery for dementia, with particular reference to client preferences for community and in-home provision.

Introduction

Dementia affects approximately 50 million people worldwide and this is set to increase to 132 million by 2050 (WHO, 2017). Currently there is an over-reliance on informal carers to support people with dementia in the community, as health and social care systems struggle to meet increasing demands for care. In Ireland, family care accounts for almost half (48%) of the overall resource burden, while the estimated cost of informal care, using an opportunity cost approach is estimated to be €807 million per annum (Cahill, O'Shea, & Pierce, 2012). This is unsurprising given that just 9% of the total costs of dementia care can be attributed to the provision of community-based (i.e. non-residential/long-stay care) health and social care services.

While caregiving can be a positive experience associated with a greater sense of purpose, satisfaction with life, higher quality of life, and higher self-effiacy (Lloyd, Patterson, & Muers, 2016; Quinn & Toms, 2018), it is also associated with poorer physical and mental health outcomes, including carer strain (Bom, Bakx, Schut, & van Doorslaer, 2018; Etters, Goodall, & Harrison, 2008). One of the most common interventions for tackling carer strain is providing access to respite services, which are typically defined as 'a service or group of services, intended to provide a temporary break in caregiving for the carer', either outside or inside the home (Maayan, Soares-Weiser, & Lee, 2014). One of the priority actions in the Irish National Dementia Strategy (2014) is to understand "how best to configure resources currently invested in respite care so as to facilitate people with dementia to continue living in their own homes and communities for as long as possible and to improve the supports available for carers" (p15). Respite service models are heterogeneous across and even within countries, and can differ in terms of the setting, provider, scheduling, duration, geographical availability, approach to care and cost (Maayan, Soares-Weiser, & Lee, 2014). While we don't have national data on the precise characteristics of the range of respite service models in Ireland, the most commonly available respite services are residential respite (in a care home or community hospital), day services (in the community or a care home), and in-home models (typically privately purchased) (Cahill et al., 2012). Informal carers in Ireland are entitled to an annual state-funded 'carer support' grant of €1700 (as of June 2018) if they meet certain criteria, as well as up to 30 nights of free care in a residential respite facility annually, often taken in two, two-week blocks. Access to respite services is usually facilitated by primary care providers, i.e. general practitioners (GPs) and/or public health nurses (PHNs; community-based generalists providing core nursing care to whole populations, including people with dementia). However, it is clear from the literature that accessing formal supports, including respite, can be particularly challenging for community-dwelling people with dementia and their carers (Donnelly, Humphries, Hickey, & Doyle, 2017; Macleod, Tatangelo, McCabe, & You, 2017; O' Shea, Timmons, O' Shea, Fox, & Irving, 2017a; Oliveira, Zarit, & Orrell, 2019; Phillipson, Jones, & Magee, 2014; Stephan et al., 2018). Furthermore, the timeliness of service provision can be problematic. This is important given that the point in time when dyads access support can have implications for the sustainability of the carer role (Stephan et al., 2018).

Some of the barriers to accessing formal supports and services, such as respite, include inadequate carer knowledge about the availability of supports and an inability to navigate the healthcare system (Phillipson et al., 2014; Stephan et al., 2018), inadequate primary care professionals' knowledge and signposting abilities (Hochgraeber, von Kutzleben, Bartholomeyczik, & Holle, 2015; Stephan et al., 2018), lack of services (Mansfield, Noble, Sanson-Fisher, Mazza, & Bryant, 2018; Stephan et al., 2018), the costs associated with service use (Stephan et al., 2018), carer perceptions regarding their own need for help (Leocadie, Roy, & Rothan-Tondeur, 2018; Stephan et al., 2018), carer guilt around 'abandoning' the person/their duties (Leocadie et al., 2018; Macleod et al., 2017), resistance and

service refusal by the person with dementia (Macleod et al., 2017; Stephan et al., 2018), concerns about care quality (Leocadie et al., 2018; Macleod et al., 2017), and a carer belief that respite use indicates failure in relation to their own ability to provide care (Macleod et al., 2017; Stephan et al., 2018). Facilitators of service access include having a central point of contact (Leocadie et al., 2018; Stephan et al., 2018), transport to and from services (Hochgraeber et al., 2015), a belief on the part of carers that breaks will help them to care for longer (Macleod et al., 2017), and a perception that service use is not just for the carer i.e. that the person with dementia will have unmet needs addressed also (Leocadie et al., 2018).

However, it must be noted that the majority of the existing literature to date on accessing formal services, and especially research focused on respite services, has been from carers' perspectives (Stephan et al., 2018). The voices of people with dementia are especially absent in this literature, while service providers and policy-makers are under-represented. Including other stakeholder perspectives is necessary to give us a deeper understanding of the access process as regards respite services for dementia. Therefore, this study aims to understand and synthesize multiple key stakeholder perspectives on accessing respite services for dementia, in the Irish context. By integrating multiple stakeholder views on respite care, it should be possible to get a more holistic and integrated perspective on patterns of access.

Research Design and Methods

Qualitative semi-structured interviews were conducted in the Republic of Ireland between July 2017 and March 2018. This study is presented according to the Consolidated Criteria for Reporting Qualitative Research (COREQ) (Tong, Sainsbury, & Craig, 2007). The research presented in this paper was conducted as part of a wider qualitative semi-structured interview study conducted in the Republic of Ireland between July 2017 and March 2018, which focused on key stakeholders' perspectives on respite services and their development more broadly.

Recruitment/Sampling

Purposive maximum variation sampling was employed across stakeholder groups including people with dementia, informal/family carers, respite service providers (front-line staff and management), primary care providers (PHNs and GPs) and academics/policymakers. This was with a view to capturing a spread of characteristics across stakeholder types (e.g. male/female; rural urban; respite model; management/frontline; dementia type; spousal/child carer, as applicable). Regarding service providers, the researcher approached management in two residential respite services (one rural, one urban), four day services (3 urban, 1 rural) and three private domiciliary care services (serving urban and rural areas) for permission to interview management and staff within those services; all agreed except one day service. PHNs, GPs, academics and policy-makers from across the country were contacted directly by email/phone; all of those contacted agreed to participate. People with dementia and carers were recruited through participating day/residential services, as well as through a PHN. The nurse managers in participating respite services were key research gatekeepers for granting us access to people with dementia and carers for inclusion in this study. It is not clear how many service users were approached by these gatekeepers, or how many people refused them. The researcher was contacted by gatekeepers only when service users expressed interest in the study; all who expressed interest ultimately participated. Regarding people with dementia and carers, a recorded formal diagnosis of dementia was required for inclusion and participants had to be community-dwelling respite service users. One person with early onset dementia in this study was not a current user of respite services; however she was previously a service user in her capacity as a carer for her mother

who had dementia. For the other stakeholder groups, they had to be currently working with/caring for people with dementia, organising/managing care, and/or involved in dementia policy-making. Some stakeholders occupied multiple roles e.g. respite service provider *and* carer. Participants occupying multiple stakeholder roles were asked what they would like their primary designation to be, and are reported accordingly.

Data Collection

Cross-sectional semi-structured interview data were collected in-person for all participants. Providers, academics and policy-makers interviews ranged from 60-180 minutes. Interviews with carers and people with dementia ranged from 20-65 minutes. All participants were interviewed alone, with the exception of one person with dementia, who wanted their daughter present. The researcher spoke to the informal carer prior to the interview to understand key aspects of the person's biographical history, as well as information about their life now, to facilitate communication and interpretation throughout the interviews, and to help build familiarity and rapport with the person. Following piloting, a semi-structured interview schedule was finalised. Key topic areas were access, availability, acceptability/fit, equity issues, health systems factor, provider factors, and client/dyad factors. This schedule was used flexibly across stakeholder groups and the focus of the questions was tailored so that they made sense to each participant given their circumstances and cognitive ability.

While participants were given an option, all ultimately agreed to have their interviews digitally recorded using an OlympusVN-750 audio-recording device. This device does not have a password-protection function, so the data was immediately transferred to a hard drive for secure storage and deleted from the device.

Data Management & Analysis

To uphold confidentiality, the audio and written data files were assigned anonymised codes and saved to an encrypted, password-protected hard-drive. Data was also backed-up online using 'Google Drive' and the university server, which is backed-up daily. Personally identifiable information was removed from all data by EmOS, the only team member who had access to the codes; other team members only had access to completely anonymised transcription data.

Inductive thematic analysis was employed, as described by Braun and Clarke (2006). The data were transcribed verbatim by EmOS. The transcripts were read closely before the coding process began and initial memos were made. NVivo 11 was used to support coding and data management. Initially, a subsection (7/35 [20%]) of the transcripts were coded using an inductive, bottom-up approach. Labels were applied to meaningful segments of the data, to develop a set of codes to apply to all subsequent transcripts. As the codes were applied to the remaining transcripts, several iterations of coding were necessary, where codes were added or revised to reflect new learning and more nuanced understanding of the data, as it relates to the research question. Examples of coding, including initial codes, and the final codes used to inform category development, are outlined in table 1.

(INSERT TABLE 1 HERE)

Codes were subsequently grouped into potential categories and interrogated for meaning to arrive at cohesive themes. Particular attention was paid to identifying positive and negative cases regarding

each theme, within and across stakeholder groups. The goal was to move beyond identifying simple semantic themes, where engagement with the data occurs only on a surface, descriptive level. We have tried to derive latent themes. By this we mean that we have made an attempt to interpret the patterns we observed in our data, and to consider them in light of their potential significance, broader meaning and implications. This was achieved by discussing patterns in the data with other team members to understand what the underlying assumptions and ideas might be, in order to make sense of them in a way that facilitated cohesive collation. To encourage reflexivity, thoughts and experiences in relation to data collection and analysis were recorded and brought to meetings with senior members of the research team throughout the research process. The purpose of these meetings was to challenge the assumptions being made by the primary researcher, to support her in becoming aware of the values/beliefs underlying her interpretations.

Ethical approval was obtained from Dublin City University Research Ethics Committee (DCUREC/2017/018). Informed consent was obtained for participants with the ability to give it. For people with dementia who could not give informed consent, proxy consent was obtained from informal carers. In addition, the process consent method (Dewing, 2007) was employed throughout these interviews.

Results

Participant characteristics in relation to sex and respite service use/provision/planning are outlined for all stakeholder groups in Table 2.

(INSERT TABLE 2 HERE)

Some further demographic information of note on informal carers: Of the nine carers, three were adult children (two daughters, one son; age range: 38-52), five were spousal carers (three wives, two husbands; age range: 62-89), and one was a family friend (age 76). Table 3 outlines further demographic information about the people with dementia, including sex, age, diagnosis, age at diagnosis, severity, marital status, living arrangements, and ethnicity.

(INSERT TABLE 3 HERE)

This analysis has highlighted three salient themes, relating to how respite access is negotiated between healthcare providers, informal carers and people with dementia. These are ‘Service Acceptability’, ‘Navigational Knowledge and Skills’ and ‘Constructing and Adjudicating Respite Need’. They will be outlined in turn below.

Service Acceptability

Poor acceptability, either perceived or experienced, was a considerable barrier for some people with dementia, and consequently their informal carers, in relation to respite service access. While service providers often tended to characterise service refusal as stubbornness, or a fear-based phase that could be overcome with exposure, in fact, when asked, the people with dementia that were reluctant to use respite services usually had sensible reasons for refusing care. While day services outside the home were acceptable to some (largely because of the social and activity elements, the food, transport

and/or the value for money), residential respite generated a poor response across the board from people with dementia. Even the mention of residential respite created tension, both in the actual interviewing process and with their informal carers. Some people with dementia spoke of the clinical nature of residential respite environments, with one person outlining the "coldness of it", and another lamenting the lack of engagement.

"It was unbelievable there… I had nothing to do all day only walk around in a circle…I will not be having that again"

One woman with early onset dementia, who is not currently using any form of respite, indicates that she intends never to use respite services because she feels that she would be "*out of place*" in terms of demographics and interests, but also that staff "*wouldn't know what to do with me*" in relation to engagement. She was also concerned, as were some informal carers that using the same services as more advanced people with dementia would cause her excessive anxiety about her future:

"It would make me feel terrible about what is happening to me, and would give me a vision of what might be to come for me in years to come…"

In the dyadic interview, the topic of attempting to access a second day of day services, and of trying to access residential respite for the first time caused conflict mid-interview, with the person with dementia clearly delineating, in line with some of the other people with dementia, and many informal carers, that he would prefer to be supported in his own home.

"I can't see why I have to… 'you must go to day centre '… I don't want to… and when there's so much to do at home… I don't want that respite… I don't want to go and stay anywhere… I need to have my own thing here [indicating at home]*"*

Informal carers found reluctance and refusal on the part of people with dementia to access out of home respite care difficult to manage and overcome, sometimes leading to intense feelings of guilt for having raised the issue. Service providers and policy-makers also noted that service refusal can be a substantial relational barrier to informal carers seeking timely access, but refusal was usually perceived by these stakeholder groups as an attachment-related issue, rather than as a service acceptability problem, as the people with dementia frame it. While a number of informal carers interpreted reluctance as a somewhat natural part of a transition process and indicated that they could work through it, others did not feel that it was worth the conflict and the guilt, especially regarding residential respite, and indicated that they would not pursue access at that point.

Navigational Knowledge and Skills

For a minority of informal carers, the timing and ease of access to the range of respite services was satisfactory, and they felt they had a central point of contact (i.e. GP, PHN) they could turn to for information about services. However, for many informal carers, access was far more protracted and frustrating. Carers indicated, and many providers corroborated, that the complex and fragmented healthcare system is almost unnavigable for carers, who are not aware of the GP/PHN pathway to respite service referral. Furthermore, many carers felt that making contact with the PHN was problematic; PHNs were experienced by some as unresponsive service gatekeepers that unnecessarily complicated, rather than facilitated access. Carers noted that direct (e.g. online) access to information about supports would be preferable in this context.

"They just have all the information and we can't get at it until we can get to talk to them… it was very hard to get through to the lady on the phone… I actually rang the number given to me about 30 times and left voice messages but no one bothered to get back to me… I think if they had all the information online then it would be better… I wouldn't need to waste all that time finding someone to give it to me…"

Some informal carers also describe later learning that the range of available respite services and supports conveyed to them by the GP and/or PHN was not exhaustive. Some acceptable and appropriate services from informal carers' perspectives were overlooked, indicating that signposting is not always tailored or comprehensive. Service providers corroborated this perspective, explaining that primary care providers are not always aware of the range of available dementia supports, because of the generalist nature and wide remit of their work.

In the absence of a special interest in dementia, primary care professionals are not always embedded enough in the dementia care landscape to effectively signpost respite alternatives. For one GP, the extreme of this scenario can culminate in 'emergency respite', crisis ED admissions with a view to accessing community supports, or even care home placement.

"We struggle to know where services are… I have a network of people around me that I can ring for that information…but that wouldn't necessarily be typical of GPs… I know colleagues who don't have access to a community hospital and who don't have links with the Alzheimer Society… I have no doubt that us in primary care, not knowing where all of these services are, contributes to that situation of patients ending up in hospitals EDs, so that they will be discharged with supports, or to a nursing home…"

Constructing and Adjudicating Respite Need

Another vital issue regarding timely access relates to how respite 'need' is conceptualised and adjudicated differently by informal carers and service providers. PHNs and policy-makers signified how the health system has been configured to be responsive to physical needs primarily; this is demonstrated by how PHNs typically only encounter dementia dyads when a nursing need arises. Indeed, even when contact is made, psychosocial and relational issues which might necessitate formal supports are sometimes purposefully not probed by PHNs, particularly when they have limited supports to offer. Carers indicate that sometimes they felt they even had to plead with healthcare professionals to establish respite candidature.

"I was so stressed when the doctor rang me and said that physically there's nothing wrong with him so we're thinking of discharging him… I really went off at him and I was nearly begging him saying "oh my god you don't realise what it's like, I can't keep doing this"… He rang me back an hour later and said, "actually, you're putting up with a lot at home, leave it with me and we'll get something in place"

Not surprisingly, perhaps, the difficulties in negotiating access to public services have forced some of the informal carers interviewed here, who are able to afford to pay out of pocket, to purchase private home and day care for the purpose of respite.

While some respite service providers criticise primary care professionals for not detecting and responding to respite needs early enough, many other service providers, and policy-makers locate fault at the systems-level as regards under-provision.

"When you've come into contact with the PHN, things are probably getting a bit ropey for you… but for their own very good reasons PHNs are very well defended and it's because they have so little to offer in terms of support for those kinds of more psychosocial needs… What can they do about that? When asked about services they say things like 'all I can offer is' and 'this is all I have', because it's true…"

In some cases, respite 'need' could be seen as almost inconsequential to service provision. This is demonstrated by widespread inequitable access to such services on at least two levels, from the perspectives of service providers and policy-makers, in terms of how people with medical cards (which creates certain entitlements to free healthcare services) tend to be prioritised over those without, even when their 'needs' are similar, and how there is marked under-provision of respite services in rural areas compared to urban areas. This is further evidenced by, according to service providers and policy-makers, how even within the range of existing provision, under–resourcing and staffing, allied to inadequate training, can result in some respite providers refusing dementia referrals because they don't have the necessary capacity to care for people with dementia.

"Sometimes when I ring the day centre I am told that it wouldn't be an appropriate referral…but our big bug bear with respite is we have two potential respite facilities available to us in this area but one of them won't take a dementia patient if they are mobile… definitely not if they have challenging behaviour…"

The way that informal carers conceptualise 'respite', and their own need for it, also influences the access process. Some carers, wives in particular, admit that they were initially reluctant to acknowledge and/or attend to their own respite need, until they were really struggling, because they felt it was their duty to care. Respite providers corroborate this, indicating that many informal carers wait until either the person has substantial physical needs, and/or they are near burnout themselves, to seek access, which providers feel is often "*too late for them to get benefit*". This indicates that carers internalise the cultural attitude, also held by the state that the primary responsibility for care should fall on the family, unless there are substantial physical needs or there is a crisis situation necessitating professional intervention. In this way, respite use can signify failure to fulfil this perceived duty of care.

This reluctance to seek help is also intricately tied up in, and complicated by, carers' understandings of the term 'respite', and how their perception differs from health professionals'. For informal carers, 'respite' is typically seen as an outcome, a mental and physical break, which can be achieved through service use, but *only* when they trust that the care is person-centred and of high quality (*"it's only good to me when I know that he's looked after"*). However, some providers still tend to frame respite as a break from the "*burden"* of caring for the person, essentially problematizing the person with dementia. This burden-based conceptualisation offered by staff in healthcare encounters jars with informal carers' perspectives. This makes it exceptionally challenging for carers to legitimise help-seeking for a respite need, because it positions it as a carer-centred venture, and not necessarily one premised on mutual benefit.

"They can't buy into using respite and those kinds of services unless there is a benefit for the person because it's just all guilt if they don't believe there's something in it for the person…there has been too much emphasis up to this point that the benefit of respite is for the family, for their 'burden', and that is not helping"

In sum, these findings indicate that negotiating timely access to respite services is a complex interplay between clients and health services, influenced by; 1) anticipated/actual service acceptability, 2) poor primary care knowledge/signposting practices, and 3) how the concepts of 'need' and 'respite' are constructed and adjudicated differentially by informal carers and health care professionals.

Discussion

This study provides insights into a range of key stakeholder perspectives on how respite access is negotiated between dementia dyads and services. While most of the research in this area focuses on the perspectives of informal carers, this study adds the perspectives of people with dementia, respite and primary care providers and policy-makers, and marries these perspectives to arrive at some novel insights. A number of findings here corroborate the findings of previous research on access barriers, as outlined in the introduction, e.g. under-provision and poor availability, poor carer knowledge, poor primary care signposting, low acceptability, client reluctance and refusal, carer guilt and refusal to acknowledge their own need for a break, client care quality concerns, and carers' beliefs that respite use equates to failure. In terms of facilitators, having a central point of contact was perceived to support timely access.

As a result of including a range of key stakeholders, we have also discovered some unique insights relating to how respite access is negotiated, with particular reference to the construction and adjudication of respite need. It is clear from these perspectives that timely access to respite services is hindered in an overarching way by how the health and social care system is configured to provide a biomedical model of care. This model dictates that staff are primarily educated about, and responsive to physical, functional or emergency health needs. Therefore, 'respite' is not always considered a valid need in and of itself, or one for which the state should have to assume responsibility; some informal carers internalise this attitude which impedes help-seeking. Despite the biopsychosocial model, first outlined by Engel (1977), being widely accepted as the optimal approach to care, it remains hugely challenging to adopt this more holistic approach at a systems- and practice-level. Some suggest that the implementation of a biopsychosocial model is difficult because there is no tangible definition or protocol to guide implementation (Farre & Rapley, 2017). Others attribute this to the difficulty reconciling the flexibility needed for the biopsychosocial approach to be effective, with the necessary focus on technique and method in the biomedical approach, which requires a certain level of "machineness" to be efficient (Gibes, 2014). This tension between the models can be seen to reflect the trade-off between effectiveness and efficiency; and in health systems, efficiency is valued more than effectiveness (Gibes, 2014). This is clear according to Wade and Halligan (2017), in how the biopsychosocial model has had little influence on the larger scale commissioning, organisation, or funding of health and social care services. Therefore, while we cannot speak directly to the relevance of these findings regarding respite access in other countries, it is unlikely that this issue regarding the adjudication of respite need is unique to the Irish context.

We feel that within these findings regarding the construction and adjudication of need, there are two particularly important issues; these relate to, 1) the boundaries of the state's responsibility to identify and meet respite needs for dementia dyads, and 2) the constraints of 'respite' as a concept. These two issues will be now considered in turn, as they relate to respite access.

The concept of need is crucial to the issue of negotiating respite access, based on these findings. Many providers and policy-makers felt that there was enormous under-provision of respite services,

especially in rural areas, which left PHNs sometimes unable to even probe dyads' psychosocial and respite needs, because they could not assume responsibility in the absence of appropriate or acceptable services. Furthermore, even where services are notionally available, they sometimes don't have the capacity, in terms of staffing and/or staff competency, to admit someone with dementia. Providers note that this is especially true when people with dementia present with "challenging behaviours", leading to problems for dyads that are arguably *most* in need of support; if respite 'need' was really the primary trigger for marshalling service access, then those with behavioural issues, which indicate significant unmet needs in the person and likely high stress in the informal carer, would be *prioritised* for access, not rejected. In this way, 'need' can seem somewhat extraneous to the issue of access, because respite needs often only earn legitimacy when there are significant physical/functional needs present also. This under- and inequitable- provision, coupled with service impermeability until physical needs arise, and lack of provider capacity to manage non-cognitive symptoms, exposes the continued dominance of a biomedical approach at the systems-level; since 'respite' is a psychosocial 'need', it is somehow less legitimate, and the boundaries and scope of the state's responsibility to provide access to care of this nature, are not delineated.

These findings reflect those of a study by Donnelly et al. (2017), in which 38 interviews with carers of people with dementia and healthcare professionals were conducted to explore how inadequacies in the Irish health system can impede aging in place. From professionals' perspectives, their ability to provide access to community supports was hindered because of how little they have to offer dyads, as in the present study. The providers specifically underlined that while they do recognise unmet support needs, because of under-resourcing and -provision, they cannot always assume responsibility for such needs. Furthermore, some of the providers also acknowledged, as in this study, that inequity is rife and that access to services is not always based on need, but on factors including geographical location and how loud carers/advocates 'shout'. Our findings reinforce the stark policy-practice gap at play here; the under-provision and -resourcing of community supports and services for dementia contradicts government policy in Ireland to support ageing-in-place through timely access to support services.

As regards considering what these findings mean for social policy, it might be useful to take a political lens, to understand some of the normative assumptions influencing the access negotiation process. Many authors have noted the detrimental role of neoliberal political ideologies and policies for how care is organised, provided and accessed (McGregor, 2001; Rotarou & Sakellariou, 2017; Sakellariou & Rotarou, 2017; Sevenhuijsen, 2003; Tronto, 1993, 2017). The basic premise of neoliberalism is that a market-based approach, with minimal state intervention, is best. What is most valued therefore, is individual and/or familial self-reliance and responsibility (McGregor, 2001; Rotarou & Sakellariou, 2017; Sakellariou & Rotarou, 2017; Sevenhuijsen, 2003; Tronto, 1993, 2017). In relation to the effects on care specifically, this has been characterised by 'a relocation of care from the public to the private' (Sevenhuijsen, 2003). Many countries, including Ireland, the United Kingdom, Canada, the United States of America and Australia, have undergone reforms in the structuring and financing of their healthcare systems, in line with neoliberal ideology, since the 1970s and 80s, and more recently again, because of economic austerity measures driven by the 2008 global recession. Such reforms are signified, for example, by spending cuts, downsizing, deficit-cutting, user-pay fees, and two-tier and for-profit health care (McGregor, 2001). In Ireland financial cutbacks have resulted in some families resorting to private out-of-pocket payments in order to support people with dementia, leading to significant growth in the private market for care in the past decade (O' Shea, Cahill, et al., 2017).

In terms of considering the relevance of this political lens to the issue of respite access, we will now turn to the 'phases of care' framework proposed by Fisher and Tronto (1990); the first three phases are of particular relevance. Phases one and two, '*caring about'* and *'caring for'* are interconnected. During phase one, needs should be recognised and given the appropriate attention (i.e. assessment), while phase two refers to the willingness and capacity of services to take responsibility for meeting the identified needs. Some primary care professionals and informal carers here state that an initial problem relating to this is lack of knowledge, and signposting capacity regarding the available supports. However, some PHNs specifically highlight how being informed is of no use to them in the context of under-provision; some simply feel that it would be futile to assess for respite needs, because of the lack of services. Phase three is '*care-giving'* and relates to delivering care in practice, and having the resources and competency to meet the needs in question. In this study it was clear that this was a secondary road block for respite access; even where services exist in an area, managers might refuse referrals from primary care, and prevent access at that point, because they feel they are not equipped in terms of either staffing or skill mix, to take a person with dementia under their care. In line with the work of Tronto (1993, 2017) we suggest that perhaps the most important issue impeding timely, equitable access to respite in relation to the above three care phases, is the failure to prudently allocate care responsibilities and draw unambiguous boundaries around what will (and will not) be provided by the state. Essentially, this is about creating entitlements for people post-diagnosis, to remove the current uncertainty, and the personal discretion of healthcare professionals in the adjudication of need, which ultimately drives inequity. Creating rights and entitlements is likely to incur additional costs to the taxpayer and the state, but such is the current gap between need and provision, that this may be the only way forward.

We will now turn briefly to a second novel finding of this study, i.e. the issue of what the term 'respite' means to different stakeholder groups, and the potentially constraining impact of this on informal carers' willingness to seek access to supports and services, in a timely manner. It was clear that 'respite' can be understood quite differently by carers and providers, and that this mismatch in perspectives on the meaning of respite can make it significantly more difficult for informal carers to seek and accept help labelled as 'respite'. Most informal carers here conceptualise respite as a psychological break from caring, but many stipulated that this could only be achieved if they felt that the person with dementia is being cared for in a person-centred manner; in other words, when they perceive that there would be mutual benefit for the dyad. However, it was clear that many primary care and respite providers did not share this conceptualisation. Some even stated that they explicitly indicate to carers, albeit with the intention of validating the informal carer's need for service use, that respite is categorically *not* for the benefit of people with dementia, but for the purpose of relieving them of their 'burden'; thus implying that the person with dementia is the source of burden. This negative construction of people with dementia, and the suggestion that their well-being is not the providers' central-most concern, makes it difficult for informal carers to relinquish their perceived duty of care, because this means handing the person over to a respite service which they feel is not an adequate substitute for them in terms of care approach and quality.

We would argue that it is not necessarily true that service providers who understand 'respite' in this way always provide poor dementia care, but that the language of respite is value-laden with stigmatising connotations about the person with dementia that providers can be blind to, but informal carers often are not; it is possible that informal carers experience and understand this narrative as an implicit indication of how the service will approach the care of the person with dementia, which reduces the likelihood of service use. These findings are in line with a recent concept analysis of 'respite' in relation to dementia, which questioned the utility of this concept going forward; the

authors concluded the term ‘respite’ is discordant with the principles of person-centred dementia care and mutuality, which paradoxically, informal carers must perceive as present to actually ‘let go’, and achieve a meaningful psychological break from caregiving (O’ Shea, Timmons, O’ Shea, Fox, & Irving, 2017b). The authors proposed that the term ‘restorative care’ might better fit with the notion of mutual benefit for the dyad, and does not position the person with dementia in a stigmatising way, e.g. as something that a break is needed from.

Limitations

Unlike previous studies in this area, the present study included a wide range and sizeable number (N=35) of stakeholder perspectives on respite access, including people with dementia. We employed purposive sampling, with a view to capturing a spread of characteristics (e.g. male/female; rural urban; respite model; management/frontline; dementia type; spousal/child carer). However, some limitations must be noted. We encountered gatekeeper issues in recruitment which made access to people with dementia difficult. It is possible, given that this was part of a larger study on stakeholders’ perspectives on respite services that the service providers, who acted as gatekeepers in terms of recruitment for this study, chose people with dementia and carers that they felt would reflect their services in a more positive light. A second issue worth noting here is that we interviewed clients who have used/are using at least one model of respite. Therefore, this data may not reflect the experiences of those who have failed to gain access completely. Finally, the informal carers and people with dementia here are English-speaking people of Irish or British nationality, so this data cannot account for any additional access barriers that non-English-speaking individuals, non-nationals, and/or those of ethnic minority might encounter in trying to negotiate access to respite services.

Implications

Negotiating timely access to respite services for people with dementia remains a substantial challenge. In terms of addressing this issue, we need to think about building signposting and needs-identification capacity in primary care, including replacing the term ‘respite’ with non-stigmatising nomenclature. We also need to think about expanding dementia care capacity within respite services. Many of the issues regarding access rely on us taking more seriously the issue of expanding the boundaries of public responsibility for respite care. While the stakeholders here considered this to be an issue driven, at least in part, by the biomedical configuration of the health system, in which the respite needs of informal carers of people with dementia especially have little legitimacy, we would suggest that this has been even further compounded by the adoption of neoliberal economic and social policies. Such policies further weaken state intervention thereby encouraging the privatisation of care, especially psychosocial supports. Within this issue of delineating responsibility, we also need to consider whether the types of support that people with dementia and informal carers want, i.e. community-based and home-based supports that cater to the social and engagement needs of people with dementia, should fall completely under the remit of health and social care. Perhaps as part of us acknowledging that people with dementia are citizens, not just patients, we should also consider the role of other governmental departments in assuming some responsibility for the non-health related support needs of dementia dyads? Future research should interrogate the issue of the boundaries of care in relation to service planning and delivery, with particular reference to client preferences for community and in-home provision.

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Table 1: Examples of initial and final codes

Data segment	Examples of initial code(s)	Final code(s)
"there are fewer residential services in rural areas anyway… and then the amount of respite beds in those services might be even less because a lot of those services are full up with residents… its far more difficult in rural areas, whereas in the cities there are so many respite places available… well, a lot more at least"	Availability Rural versus urban	Inequitable provision
"We need someone, one person, who can direct you on where to go to meet your needs... The PHN should be able to tell you all that because that is their job, but a lot of times they are overworked and they are generalists, so really not every PHN, or GP even, will know everything about supports and information for every health area..."	Sign-posting Role of PHN[a] PHN workload Lack of specialist knowledge	Single point of contact Primary care capacity
"The system isn't great either, for instance we have people on our list for respite who might die before the date comes up, but the time isn't actually reallocated because that's not been communicated to us from primary care and so we need to offer it out maybe the day before, or even day of, and that's too short notice for people…"	Wasted resources Communication	Service fragmentation

a: PHN = Public health nurse

Table 2: Characteristics of the participants in each stakeholder group and their experience of using, providing and/or planning respite services.

	N	Male	Female	Experience using/working in/planning/ researching:		
				Residential Respite	Day Services	In-Home Care
People with dementia	6	3	3	5	5	2
Informal Carers	9	2	7	7	8	7
Respite Managers	8	1	7	4	3	1
Respite Frontline Staff	4	1	3	2	1	1
Primary Care Professionals	3	1	2	3	3	3
Policymakers/Academics	5	2	3	5	5	5

Table 3: Demographic information relating to the people with dementia and their care arrangements

Participant	Sex	Age	Age at diagnosis	Diagnosis[a]	Dementia Severity[b]	Marital Status	Living arrangements	Ethnicity
P1	M	80	74	Alzheimer's disease	Mild	Married	Wife, 81; Urban	White Irish
P2	F	66	64	Fronto-temporal	Moderate	Married	Husband, 71; Rural	White Irish
P3	M	80	74	Alzheimer's disease	Moderate	Widowed	Son, 44; Urban	White Irish
P4	F	86	82	Alzheimer's disease	Moderate	Widowed	Friend, 76; Rural	White British
P5	F	58	56	Alzheimer's disease	Mild	Married	Husband, 60; Urban	White Irish
P6	M	74	70	Vascular dementia	Moderate	Divorced	Daughter, 37; Urban	White Irish

a, b: Dementia diagnosis and severity were self-reported by informal carers/respite staff, they were not formally assessed for the purposes of this study.