Resource allocation in dementia care: comparing the views of people with dementia, carers and health and social care professionals under constrained and unconstrained budget scenarios

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Case Type Development

Case types were developed using the approach adopted by (Challis et al., 2014). As is the case in many jurisdictions, there is no single data set available in Ireland with all the required variables to generate case types, so data from several sources were combined. The case types were developed mainly from an Irish data set of anonymised home care assessments of 277 people with dementia in an urban area (O’Brien et al., 2017). Four variables were used to generate the initial dementia case types: dependency measured by the Barthel Index, falls risk, living alone, communication difficulty (See Table 1). A set of dementia case types with all the possible combinations of the four variables was firstly generated, resulting in 24 case types. A sub-set of six case types, comprising 46 per cent of the dementia case types in the dataset was then selected for the study. The level of cognitive impairment for the case types was derived using a dataset of anonymised InterRai assessments (HSE, 2017) for 453 inpatients over 65 some of whom had been diagnosed with dementia. Further discriminating variables were sourced from the literature, specifically Behavioural and Psychological Symptoms of Dementia (BPSD) and Comorbidities. In previous balance of care studies, the attitudes to care mainly focused on attitudes to nursing home care (Tucker et al., 2016). However, in this study as the research question is more focused on the continuum of care, attitudes to care cover preferences in relation to spending, privacy, day-care attendance, carer preferences and attitudes to nursing home care.

Unit Costs

Unit costs for these services were calculated based on Irish Health Service Executive staff pay scales and the Irish literature on unit costs (O'Shea & Monaghan 2016). The full service cost, including voluntary, public and private funding, was used irrespective of the funding source, so that service prioritisation could be compared on a like for like basis. The full cost of a Psychiatry of Old Age referral and a carer education programme were included in the budget allocation for the hypothetical month, although in practice this cost may be spread over a longer period.


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Background: People with dementia and their carers have a wide range of health and social care needs. People with dementia, carers and health and social care professionals (HSCPs) all have different perspectives on dementia care. Differences among these groups are important for commissioners of services and for front line HSCPs.

Objective: To compare the service recommendations of people with dementia and carers with those of HSCPs, under different budgetary conditions.

Methods: A mixed methods approach, which builds on the Balance of Care method, was used. Nine workshops were held with 41 participants from three groups: people with dementia, carers, and HSCPs. Participants were asked to make decisions on a set of services for case types of dementia under two scenarios: a no budget constraint (NBC) scenario and a budget constraint (BC) scenario.

Results: While each group allocated resources in broadly similar overall proportions, important differences in emphasis emerged: i) people with dementia and carers placed more emphasis on psychosocial supports than HSCPs; ii) carers put more emphasis on respite opportunities for carers; and iii) carers identified residential care as the most suitable setting for the person with dementia more frequently than health care professionals.

Conclusion: Our findings suggest that the importance of psychosocial interventions, including counselling and peer support programmes, are currently under-estimated by HSCPs. The provision of in-home respite is highly valued by carers. Even with unconstrained resources, some carers do not judge home care to be a viable option for dementia case types with high level care needs.

Keywords: Dementia, Balance of Care, Budget Experiment

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Introduction

People with dementia and their carers have a wide range of health and social needs, including
the need for help with personal care, home support, daytime activities and company (Van der
Roest et al., 2009). Previous studies have identified that people with dementia, their informal
carers and health and social care professionals (HSCPs) tend to emphasise different health
and social needs (Cohen-Mansfield & Frank, 2008; Miranda-Castillo et al., 2013; Van der
Roest et al., 2009). HSCPs tend to give more emphasis to clinical needs; carers focus more on
support with daily activities; and people with dementia focus more on social isolation
(Schulmann et al., 2017). Many people with dementia, and their carers, can identify their own
objective and subjective needs (McCabe et al., 2016; von Kutzleben et al., 2012). In addition,
health and social care professionals, through clinical experience and discipline expertise, may
be well placed to identify the needs that their service can address.

In Ireland, as in many other countries, families provide the bulk of care for people
with dementia, with public and private service providers playing a supporting role (O'Shea et
al., 2017). The needs of people with dementia and their family carers can sometimes be
difficult to disentangle (Keogh, Pierse, O'Shea, et al., 2020). Addressing the needs of the
person with dementia will frequently also benefit their carer. Similarly, supporting the carer
is likely to benefit the person with dementia (Thorpe et al., 2009). Therefore, the needs of
both have to be considered separately and jointly to maximise benefits for both and ensure
the most effective use of resources (Bunn et al., 2016; Quinn et al., 2013).

In Ireland, the processes through which resources are allocated for community
services for people with dementia are complex, with separate administrations and separate
budgets for key services (Keogh, Pierse, & O'Shea, 2020). HSCPs play an important role in
the resource allocation process in a number of ways. HSCPs are central in the staffing and
resourcing of services and in the prioritisation process. For example, public health nurses
play a key role in the assessment of need for home support hours. In addition, front line
HSCPs play an important role by referring clients to various services (e.g. day care,
occupational therapy, physiotherapy, social prescribing) which generates a demand for those
services. Because of the central role of HSCPs in the resource allocation process, it is
important that managers and frontline HSCPs are prioritising needs and services in a way that
reflects the experiences and needs of people with dementia and carers. However, one of the
criticisms of current policy is that the system is primarily supply-driven, with most of the key
decisions made by practitioners, with little or no input from people with dementia or family
carers (O'Shea et al., 2017).

The point when people with dementia move into residential care is a critical juncture,
both from a social and economic perspective (Wübker et al., 2014). Not surprisingly, there
are different views among stakeholders on who should be admitted to residential care and at
what point along the dementia continuum (Saks et al., 2015; Tucker et al., 2016). Carers play
a critical role in the decision to access residential care; residential care placement is typically
initiated by families and moderated by access to public funding. In the absence of extensive
support from a family carer, it is unlikely that a person with dementia with high care needs
can continue living at home (Keogh et al., 2018; McCabe et al., 2016).

Budgets are an important consideration in comparing the resource allocation decision-
making of people with dementia, carers and HSCPs. Decisions are likely to be different in the
presence and absence of budget constraints. Previous research has shown differences in
service recommendations between carers of people with dementia and HSCPs when they
have been asked to make decisions in the absence of any budget constraints (Giebel et al.,
2016). Decision-making in the absence of budget constraints, highlights the potential latent
demand for services that exist when people do not have to worry about costs or budgets
(Keogh, Pierse, O'Shea, et al., 2020); participants have the scope to think about a wide
variety of services, including psychosocial provision, that they may not have ever experienced due to their unavailability within local geographic areas. However, it is equally important to identify how services are prioritised by different stakeholders when there are budget constraints, because that is the reality, most of the time, in the vast majority of countries.

In this study, we seek to identify differences among people with dementia, carers and HSCPs on what constitutes optimum care for a range of dementia case types in two scenarios: when there are no budget constraints (NBC); and when there are budget constraints (BC). The study also seeks to identify differences among the three groups on the most appropriate setting for people with dementia with different needs and with different levels of family support. Differences in the needs that are identified, and how these are prioritised among these three groups, are important to consider for various levels of decision making (Plochg & Klazinga, 2002); so too is understanding variation in preferences for different kinds of services to respond to those needs. At policy and organisational levels, differences among the three groups may result in a misallocation of resources across dementia services - if HSCPs underestimate the need for a particular service this may lead to the under resourcing of that service.

This study builds on previous Balance of Care (BoC) studies in a number of ways (Tucker et al., 2013; Tucker et al., 2008). First, the notional budgeting exercise considered in this paper engages all key stakeholders in the decision-making process. Participants are asked to recommend a set of services with and without a budget constraint; this allows for priority services and needs to be identified under different fiscal constraints. Secondly, a mixed methods design is used to tease out the decision-making process; the quantitative element identifies the type and quantity of service that is prioritised while the qualitative element
provides context and greater understanding as to why some services are prioritised over others.

**Methods**

An explanatory sequential design was used with qualitative phases following on from quantitative phases as shown in Figure 1 (Fetters & Freshwater, 2015). A nominal group method (NGM) was used within an overall BoC methodology to capture both quantitative and qualitative data. The findings reported here are part of a larger study and further detail on the qualitative methods and findings are available in Keogh, Pierse, O'Shea, et al. (2020).

![Figure 1 about here]

**Participants**

There were three groups of study participants who each attended separate workshops: (i) people with dementia (n=4), (ii) current and former carers (n=13), and (iii) twenty four HSCPs. These comprised of: public health nurses (n=6), social workers (n=3), occupational therapists (OT) (n=2), physiotherapists (n=1), speech and language therapists (SLT) (n=1), dieticians (n=1), psychologists (n=1), mental health nurses (n=2), home care coordinators (n=4); and older person’s service managers (n=3).

The people with dementia and carers who participated in the study were recruited through working groups organised by the Alzheimer Society of Ireland (ASI). Four members of the ASI Irish Dementia Working Group, two men and two women, from different parts of the country, at different stages of dementia, with a mix of younger and late onset dementia, participated in the study. Given the complexity of the exercise we decided to hold two workshops for dementia participants, with two people in each. Two groups of current and former carers from the ASI Dementia Carers Campaign Network (DCCN) participated in workshops in different parts of the country. HSCPs were recruited through senior managers...
who had responsibility for older persons services in four regional health organisations. The latter were asked to identify HSCPs from a range of disciplines who had direct experience of working with people with dementia or who had some role in the allocation of services and supports to people with dementia living at home. Participants were recruited from different therapeutic backgrounds, experience and location to give as much variety to the decision-making process as possible.

**Case Type Development**

The development of the dementia case types has been previously reported in (Keogh, Pierse, O’Shea, et al., 2020), for further details see the Supplementary Material file supplied with this paper. In summary, six case types were developed mainly from an Irish data set of home care assessments of 277 people with dementia (O’Brien et al., 2017). Four variables were used to generate the initial dementia case types: dependency as measured by the Barthel Index; falls risk; living alone; and communication difficulty (See Table 1). Additional variables for the case types were derived using a dataset of InterRai assessments (HSE, 2017). Further discriminating variables were sourced from the literature, specifically Behavioural and Psychological Symptoms of Dementia (BPSD) and Comorbidities. Attitudes to care were included to cover preferences in relation to spending, privacy, day-care attendance, carer preferences and attitudes to nursing home care. The case type vignettes were developed in consultation with two people with dementia and two carers as part of public patient involvement (PPI) in the study. A person with dementia was also a member of the Oversight Group for this study.

**Services**

The service list provided to participants was informed by a mapping study of dementia-specific services in Ireland carried out in 2018 (ASI & NDO, 2017). There was
also PPI involvement in the development and appraisal of the service list. In total, twenty community-based services and supports were included on the list presented to participants. Although all of the services are available in some parts of Ireland, many are not universally available. A concise description of the listed services was provided to participants to ensure that they were fully aware of their potential role in addressing need among the dementia case types developed for this study.

Vignettes presented to participants

The key characteristics of each case type were incorporated into vignettes to lend realism to the study and to help participants consider the needs of each case type in allocating services (See Table 1). Six vignettes were presented to the HSCPs (case types 1-6). Three vignettes were presented to the carers (Case Types 2, 4 and 5). One vignette was presented to the people with dementia (Case Type 2). A smaller number of vignettes was presented to the groups of carers and people with dementia to reduce the complexity of the exercise for these stakeholders and to ensure that the exercise could be completed in a reasonable time to avoid over-burdening participants.

[Table 1 about here]

HSCP Workshops

Five resource allocation workshops were run with HSCPs. Each workshop participant was given a computer with a spread sheet workbook pre-loaded. The workbook showed the list of services that could be allocated for each vignette. Unit costs were embedded in the workbook, but were hidden initially. The first exercise was the no budget constraint (NBC) scenario. Participants were asked to read each vignette and allocate the amount of each service that would be of most benefit to the person with dementia and carer in each vignette. Each participant was then asked to discuss their decision-making in relation to one vignette;
they were prompted to focus on the needs they were trying to address and the rationale for their choice of services to meet those needs.

The second exercise involved decision-making under a budget constraint (BC) scenario. The cost of the services allocated for each case type was revealed and participants were instructed to do the same exercise but to work within an overall budget for all six case types for one month of care. This exercise was followed by discussion on what services participants cut in order to meet the budget constraint, and why, with an emphasis on articulating their decision-making process.

For the second exercise, participants were initially instructed to work within an overall budget constraint of €7,000 to provide care for all six dementia case types for one month of care. This level was set with reference to the initial pilot and data from a recent national audit of services used by people with dementia in Ireland (Keogh, Pierse, & O'Shea, 2020). Although participants in the first four HSCP workshops felt that this level of expenditure approximately reflected the current availability of resources, many found it difficult to stay within this constraint and tended to ‘overspend’. It was not feasible to enforce the constraint rigidly in the first four HSCP workshops and the average budget expanded to €8,928, 28% above the initial constraint. For the final workshop, the budget was increased to €10,000 per month across the six dementia case types to explore whether a more relaxed constraint made the exercise easier for participants to complete.

**Carer Workshops**

Two resource allocation workshops were run with carers. In both carer workshops, three case types (Case Types 2, 4 and 5) were presented for the NBC exercise and participants were asked to recommend a set of services. In the first carer workshop, carers were not asked to complete the spread sheet exercise in the BC scenario for any of the three case types. Instead, a discussion took place on service priorities and a consensus emerged on
provision, but without formal consideration of a fixed budget value. However, it was noted by one participant that it was very difficult to prioritise services without addressing the question of costs and budget constraints in the deliberation process. Therefore, in the second workshop, one case type (Case Type 2) was given a specific monthly budget constraint of €1,500, based on the allocation derived from HSCP’s consideration of this case type under BC rules.

[Box 1: Vignette 2 Here]

**People with dementia workshops**

Two workshops were held with people with dementia, each with two participants and two researchers (TP and FK) and only one dementia case type was considered. In the first workshop, Case Type 2 was presented to the two participants along with the list of services. Each service was discussed in terms of the participants own direct experience, or knowledge of the service if they had not used it. The exercise was then completed for this vignette as per the format above for HSCPs; each participant indicated a recommended set of services firstly with NBC and secondly with a BC of €1,500 for the case for one month. For the second group of participants with dementia, the vignette was found to be distracting for the participants and the format was changed to a one-to-one discussion with each researcher, focusing on the services in terms of what they found helpful and what they would prioritise.

**Qualitative Data Analysis**

All recordings from the nine workshops (including two pilots with HSCPs) were transcribed and data was managed using NVIVO software (v.12). A thematic framework was developed to summarise the themes and main categories and to show how these related to each other. In this article, qualitative findings are used to provide nuance and support or qualification to the qualitative results. A more detailed description of the qualitative methods
and thematic analysis of the HSCP qualitative data are reported in Keogh, Pierse, O'Shea, et al. (2020).

**Quantitative Data Analysis**

The data from seven workshops was compiled from the spreadsheet workbooks; quantitative data from the two pilots was not included as the number of vignettes differed. In total, quantitative data from 17 HSCPs, 13 carers and 3 people with dementia was included in the analysis. The type and amount of services which were allocated for each case type for both the NBC and the BC scenarios were compiled. For the BC scenario, all participant information was included irrespective of whether the person achieved the target budget level. In situations where an individual recommended nursing home placement, this observation was not included as a denominator in the averaging of community service costs.

**Results**

Table 2 shows the average spending on each service by people with dementia and carers relative to HSCPs in the NBC scenario. In Section A of Table 2 the service recommendations of HSCPs are compared with the recommendations of carers and people with dementia. These are shown for Case Type 2 only, as this is the case type that all three groups examined. For this case type, with NBC, people with dementia and carers recommended spending 1.1 and 1.4 times more respectively than HSCPs. Both carers and people with dementia spent more on counselling for carers, Alzheimer’s cafés, dementia social clubs and dementia friendly activities than HSCPs. The peer support, which can be provided in normal social venues, was emphasised by the participants with dementia, particularly for people at an early stage of dementia.
I see people’s lives turn around in a heartbeat when they get to sit with somebody else [with dementia]. And, you know, it’s not all doom and gloom, you take the Michael and you laugh as much as you can. We’ve got to keep reaching out to people who have been diagnosed and being there for each other because, because we just need to.

(Person with dementia, group D1)

The people with dementia did not recommend cognitive therapies for Case Type 2 due to the age of the case (79 years). Carers spent slightly less on home care and substantially more on all forms of respite – day care, nursing home based respite and in home respite. The qualitative discussion revealed their rationale:

“just to give them a break and the minimum you’d want is two hours, even if you just want to go to the shop or go to the dentist or get your hair done or something like that.” (Carer, group C2)

Case Type 2, shown in the box, contained information that the person with dementia did not want to attend day care. Many participants were influenced by knowledge of this preference and none of the people with dementia allocated this service. However, a small number of HSCPs and carers did recommend the day care service for this case type. Some carers were conflicted in their recommendations, based on their own experiences. One carer described this situation as:

My mum dislikes day-care profoundly, but she will go one day a week because it gives me a break and because there’s a physio available there who is willing to work with someone with advanced Parkinson’s... But there is no stimulation, there’s no chat,
there’s no engagement from the dementia side of things for her. She doesn’t gain that there. (Carer, group C1)

Meals-on-wheels was recommended much more by carers and people with dementia than HSCPs. A participant with dementia described how even the brief interaction as meals are dropped off may be an important form of social engagement, particularly for those living alone.

All groups allocated a similar number of visits from community health professionals. However, one participant pointed towards the importance of the quality of interaction with people with dementia and the need to really engage with the person.

it screams out at me that nobody is listening to him. So whichever one of these people has time to sit down and listen to him, whether it’s the home help, the public nurse or probably the dementia advisor. (Person with dementia, group D1)

A high volume of services may not be beneficial if they are not connecting with individual needs.

Section B of Table 2 shows the comparison of HSCPs and carers recommendations for three case types (Case Types 2, 4 and 5). As the people with dementia reviewed only one case type they are not included in this comparison. Overall, carers recommended spending 1.4 times more than HSCPs on these three cases under the NBC scenario. With the exception of visits from HSCPs, carers recommended spending more on all of the service categories. Within the category of support in the home, carers recommended spending slightly less on home care (0.9 times) and more on in-home respite (2.0 times).

[Table 2 about here]
The total and sub-totals in Table 3 shows the average expenditure by people with dementia and carers on each service category for the BC scenario, relative to HSCPs. The proportion of expenditure on each service or category is also shown to identify the scale of each service. Overall, a similar proportion of resources were allocated for each category of service by the three cohorts. For example, both groups spent between 53 and 60 per cent of expenditure on the Supports in the Home category. The maximum difference between the groups in the amount spent on any service category was 7 per cent.

However, there are some important differences in emphasis between the three groups. Relative to HSCPs, people with dementia and carers allocated a higher level of resources to supports in the home. Within this category, the carers focused substantially more resources on in-home-respite - 31 per cent of funding compared to 11 per cent and 4 per cent by HSCPs and the people with dementia groups. The potential for substitution between home support services in some situations is described by a carer:

I took away the home help and used the in-home respite and cut back on the dementia advisors visits and the respite – the nursing home respite, brought it down to two weeks – I'm still over budget. (Carer, group C1)

People with dementia and carers spent more on psychosocial supports (excluding Dementia Cognitive Therapies). People with dementia and, in particular, carers, spent substantially more on counselling services than HSCPs. However, it was noted by carers that it could be difficult for carers to justify the time away from caring to go to counselling, which links in with the need for in-home respite. The main area where people with dementia and carers spent less than HSCPs was on cognitive therapies and Psychiatry of Old Age Services respectively.

[Table 3 about here]
Nursing home placement was included as an option for all case types. Table 4 shows the choices that HSCPs and carers made under the NBC scenario. For all three case types, carers more frequently identify long term care as the most suitable care setting, particularly for Case Types 4 and 5. For Case Type 5, the case with the highest level of needs, 27 per cent of HSCPs recommended nursing home placement compared to 62 per cent of carers. No participants with dementia recommended nursing home placement for Case Type 2.

[Table 4 about here]

Discussion
Our study compares how HSCPs, carers and people with dementia allocate resources in the presence and absence of budget constraints. There are very few studies that have compared the perspectives of all three of these groups in an integrated manner (Miranda-Castillo et al., 2013). Moreover, including a budget constraint allows for the differences in priorities between the different groups to be compared when difficult choices have to be made, thus building on previous BoC studies which compared the recommendations of HSCPs and carers in the absence of a budget constraint (Giebel et al., 2016). Our study also holds up a mirror to the decision-making process, providing insight into how stakeholders think about choosing one service over another and in what circumstances. Currently, health and social care planners often make decisions about service provision without a transparent system for allocating resources, especially one that takes explicit account of the views of key stakeholders (Airoldi & Morton, 2011; Merlo et al., 2015).

In Ireland, people with dementia and carers are not involved in decision making around resource allocation and their priorities in relation to a broad menu of service types are not typically sought (Donnelly et al., 2019). This exercise points to the potential and implications of greater consultation with people with dementia and their carers in relation to priority-setting in dementia care. Both groups demonstrated an appreciation of the merits of
various services and supports in addressing specific dementia needs and an awareness of budgets and budget constraints. The overall amount/proportion of resources allocated to different services was broadly similar across the three decision-making cohorts - the maximum difference among them in the amount spent on any service category was 7 per cent. This is important new information indicating that the needs of people with dementia are broadly interpreted correctly by HSCPs, but there are important differences in emphasis.

One area where there are substantial differences is in the provision of in-home respite, with carers putting more resources into this service than HSCPs or people with dementia. In common with many other European countries, services to support carers, such as in-home respite, are not well developed in Ireland (Keogh, Pierse, & O'Shea, 2020; Spasova et al., 2018). While previous studies have shown that in-home respite for people with dementia is a cost effective service (Vandepitte et al., 2020), this study reinforces the value placed on the service by family carers. A recent systematic qualitative review on respite care reported some divergence in stakeholder perspectives around the barriers to implementation of new models of person-centred respite care (O’Shea et al., 2017). Organizational tension was evident among frontline staff and management in respite services, hindering the cultural change necessary to facilitate service development in line with the expressed needs and preferences of people with dementia and their carers.

Another area of difference among the three cohorts was the attention given to psychosocial supports. While many studies have focused on normative (usually professional-identified) needs (e.g. difficulties undertaking ADLs), our work suggests that more attention should be given to incorporating clients’ felt and experienced needs, including preferences for social and psychological support (Clarkson et al., 2017). People with dementia and carers highlighted the importance of psychosocial supports, allocating them more often than HSCPs. In addition, Turjamaa et al. (2014) advocate that home care services must take greater
account of the significance of the individual’s psychosocial needs, such as social contact and meaningful activities. Similarly, Hansen et al. (2017) highlight the importance of meeting the psychosocial needs of people with dementia and carers living in the community, recognising the existence of different perceptions and practices among providers.

Peer to peer support for people with dementia at the early stages of dementia was emphasised by participants, particularly the people with dementia themselves. This peer to peer support can be provided in a range of ways, such as one-to-one or support groups and has different functions, such as sharing coping mechanisms and reducing social isolation (Keyes et al., 2016). Counselling services were also referenced more often by people with dementia and carers than by HSCPs, a finding that reflects the international evidence on the role and importance of psychological interventions, especially for the carers of people with dementia (Elvish et al., 2013). These differences are also consistent with the heuristics identified in the detailed qualitative analysis of the decision-making process, whereby HSCPs reluctantly focused more on supporting the physical care needs of the person with dementia and placed less emphasis on psychosocial supports in conditions of constrained resources (Keogh, Pierse, O'Shea, et al., 2020).

Day care was recommended more by carers than by HSCPs. The contribution of day care to the well-being of carers may be under-appreciated (Orellana et al., 2018). In England, the development of personal budgets for care has led to inadequate attention to congregate services, such as day care, and a reduction in provision (ADASS, 2011; Needham, 2013). There is sometimes a divergence between the needs and preferences of the carer and the person with dementia in relation to day care. While a carer might need a break, people with dementia are frequently reluctant to use the service (Rokstad et al., 2017). In such situations, HSCPs often play a balancing role (Quinn et al., 2013), seeking to adjudicate on relative need.
and advocating for the needs of the person with dementia whose needs are not being fully recognised.

Family carers play a critical role in supporting people with dementia to remain living at home in all European countries (Spasova et al., 2018). Many studies have shown that carer stress is associated with admission to residential care (Eska et al., 2013; Paulson & Lichtenberg, 2011). Previous BoC studies have shown that HSCPs are strongly influenced in long term care placement by the preferences of family carers (Tucker et al., 2016). Our study shows that even when extensive community-based support was provided, as under the NBC scenario, the majority of carer participants were of the view that the case type with the highest care needs (Case Type 5), should be in residential care. In this situation, the needs and preferences of the person with dementia may sometimes diverge from the needs and preferences of their carer. Sometimes, the provision of additional resources to keep very dependent older people with dementia living at home may lead to high co-ordination and integration costs for care recipients and their families. The involvement of multiple health and social service providers can make coordinated communication challenging and costly (Tan et al., 2014).

**Strengths and Limitations**

In this study a framework is provided for identifying differences in service priorities among people with dementia, carers and HSCPs. Key strengths of this study are the involvement of key stakeholders, the provision of a wide array of services that participants could choose from, the inclusion of a realistic budget constraint and the mixed methods design. A limitation of the study is its exploratory nature and the relatively small number of participants, particularly people with dementia. While this limits the generalisability of our findings, our results point towards differences in emphasis among the groups in relation to resource allocation, including decision-making on residential care placement.
Conclusion

People with dementia, carers and HSCPs all have an important role in influencing how dementia care is delivered, in both a positive and normative sense. In this paper, we have shown that the key stakeholders are able to grapple with complex decision-making in the presence and absence of budget constraints. The results highlight differences among the three groups in relation to service provision for different dementia case types, including placement decision-making. This allows us to identify elements of provision that may not be receiving sufficient attention from health and social care providers at the moment. Taking account the views of people with dementia and carers is of particular importance, given the very limited funding that is currently available for community services in Ireland. It is important that their voice is more prominent in resource allocation decision-making in the future.

For the commissioners of services and supports in the home, this study demonstrates that the provision of in-home respite and psychosocial care, such as social clubs and activities for people with dementia and counselling for carers, are important to people with dementia and carers. HSCPs should be more conscious of directing people with dementia and their carers towards peer and social supports in their day to day practice. This study also shows that increasing resources to the home care sector may not always be enough to allow people with dementia to remain living at home. If carers believe that it is not viable for them to continue to support the person with dementia living at home, then increasing resources may not always succeed in delaying admission to long term residential care.

Ethics

Ethical approval for the study was provided by the [removed for blind review]. Information sheets were given to all participants in advance of the workshops and again at the venue (the study was conducted pre-Covid), with opportunities to ask questions at all stages of the
process. Signed consent was obtained from all participants.

**Funding Details**

[removed for blind review]

**Disclosure statement**

The authors have no conflicts of interest.

**Data availability statement**

The data that support the findings of this study are available from the corresponding author, TP, upon reasonable request.
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Fig. 1 Research Design

Quantitative
Select supports and services for six dementia case types
No Budget Constraint

Qualitative
Discussion focused on needs and related factors of the various dementia case types

Quantitative
Select supports and services for six dementia case types
Budget Constraint

Qualitative
Discussion on prioritisation and decision making following the introduction of fixed budget constraint
### Table 1: Variables and data sets used in the development of the case types

<table>
<thead>
<tr>
<th>Case Type</th>
<th>Dependency (Low, Medium, High)</th>
<th>Falls risk (Y/N)</th>
<th>Communication difficulty (Y/N)</th>
<th>Living alone (Y/N)</th>
<th>% of cases</th>
<th>Age</th>
<th>Sex (M/F)</th>
<th>Cognition (Mild, Moderate, Severe)</th>
<th>BPSD</th>
<th>Comorbidity</th>
<th>Amount of informal support (Low, Medium, High)</th>
</tr>
</thead>
<tbody>
<tr>
<td>2</td>
<td>Medium</td>
<td>N</td>
<td>N</td>
<td>N</td>
<td>5.0</td>
<td>79</td>
<td>M</td>
<td>Mild</td>
<td>Depression and anxiety</td>
<td>Coronary Heart Disease</td>
<td>Medium</td>
</tr>
<tr>
<td>4</td>
<td>Medium</td>
<td>Y</td>
<td>N</td>
<td>Y</td>
<td>9.9</td>
<td>86</td>
<td>M</td>
<td>Moderate</td>
<td>Wandering and hallucinations</td>
<td>None</td>
<td>Low</td>
</tr>
<tr>
<td>5</td>
<td>Medium</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td>3.4</td>
<td>83</td>
<td>F</td>
<td>Severe</td>
<td>Apathy and sleeping problems</td>
<td>Stroke</td>
<td>Medium</td>
</tr>
</tbody>
</table>
Case Type 2

Home Situation: Mr Twomey is 79 years old and lives in the centre of a large town with his wife.

Activities of Daily Living: Mr Twomey struggles to bathe and needs to be reminded to wash and maintain personal hygiene. He has difficulty dressing himself and needs assistance both dressing and undressing.

Cognitive impairment: Mr Twomey’s has been having mild problems with his short-term memory and concentration for about two years. He sometimes forgets to eat and often doesn’t feel hungry.

Physical and mental health: Mr Twomey suffered a minor heart attack 12 months ago. Mr Twomey used to enjoy going to GAA matches but recently has lost interest and refuses to go. He frequently does not want to get out of bed. He gets very worried about small things and is preoccupied with things that might go wrong. He has been prescribed medication for depression but he sometimes refuses to take it.

Informal Support: Mr Twomey is supported by his wife, 73 and their daughter who live nearby. They are coping well but are worried about his low mood.

Care preferences: Mr Twomey has said that he does not want to go to dementia day care.
Table 2: Relative budget allocation between Health and Social Care Professionals (reference group), People with Dementia and Carers, No Budget Constraint (NBC) scenario

<table>
<thead>
<tr>
<th>Service</th>
<th>Section A: Case Type 2 only</th>
<th>Section B: 3 Case types</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>HSCP (Ref Cost)</td>
<td>HSCP (Ref)</td>
</tr>
<tr>
<td>Support in the Home</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Home Care</td>
<td>€910</td>
<td>1.0x</td>
</tr>
<tr>
<td>In-home Respite/Sitting Service (eg visiting service)</td>
<td>€427</td>
<td>1.0x</td>
</tr>
<tr>
<td>Reablement / Dementia support worker</td>
<td>€44</td>
<td>1.0x</td>
</tr>
<tr>
<td>Sub-Total</td>
<td>€1,381</td>
<td>1.0x</td>
</tr>
<tr>
<td>Day care</td>
<td>€161</td>
<td>1.0x</td>
</tr>
<tr>
<td>Psycho-social support</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Alzheimer’s Café, Dementia Social Clubs, Dementia Friendly Activities, or other support group for people with dementia</td>
<td>€20</td>
<td>1.0x</td>
</tr>
<tr>
<td>Dementia Cognitive Therapies</td>
<td>€255</td>
<td>1.0x</td>
</tr>
<tr>
<td>Sub-Total</td>
<td>€275</td>
<td>1.0x</td>
</tr>
<tr>
<td>Visits from Health and Social Care Professionals</td>
<td>€136</td>
<td>1.0x</td>
</tr>
<tr>
<td>Service</td>
<td>Cost</td>
<td>Quantity 1</td>
</tr>
<tr>
<td>--------------------------------------------</td>
<td>-------</td>
<td>------------</td>
</tr>
<tr>
<td>Caregiver Support Groups</td>
<td>€10</td>
<td>1.0x</td>
</tr>
<tr>
<td>Counselling for Family Carer</td>
<td>€11</td>
<td>1.0x</td>
</tr>
<tr>
<td>Carer Education Programme</td>
<td>€82</td>
<td>1.0x</td>
</tr>
<tr>
<td>Nursing home based respite</td>
<td>€78</td>
<td>1.0x</td>
</tr>
<tr>
<td><strong>Sub-Total</strong></td>
<td><strong>€181</strong></td>
<td><strong>1.0x</strong></td>
</tr>
<tr>
<td>Other Services</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Referral to Psychiatry of Old Age Team</td>
<td>€453</td>
<td>1.0x</td>
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<tr>
<td>Meals on Wheels</td>
<td>€17</td>
<td>1.0x</td>
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<tr>
<td>Transport</td>
<td></td>
<td></td>
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<tr>
<td><strong>Sub-total</strong></td>
<td><strong>€469</strong></td>
<td><strong>1.0x</strong></td>
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<tr>
<td><strong>Total</strong></td>
<td><strong>€2,604</strong></td>
<td><strong>1.0x</strong></td>
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</table>
### Table 3: Relative service allocation by for Case Type 2: Health and Social Care professionals, People with Dementia and Carers. Budget Constraint (BC) scenario

<table>
<thead>
<tr>
<th>Service</th>
<th>HSCPs (Ref Cost)</th>
<th>HSCPs (Ref)</th>
<th>Carers</th>
<th>People with Dementia</th>
<th>% Funding (HSCPs)</th>
<th>% Funding (Carers)</th>
<th>% Funding (People with Dementia)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Support in the Home</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Home Help</td>
<td>€593</td>
<td>1.0 x</td>
<td>0.6 x</td>
<td>1.5 x</td>
<td>40%</td>
<td>24%</td>
<td>56%</td>
</tr>
<tr>
<td>In-home Respite/Sitting Service (eg visiting service)</td>
<td>€157</td>
<td>1.0 x</td>
<td>3.1 x</td>
<td>0.4 x</td>
<td>11%</td>
<td>31%</td>
<td>4%</td>
</tr>
<tr>
<td>Reablement / Dementia support worker</td>
<td>€26</td>
<td>1.0 x</td>
<td>1.9 x</td>
<td>0.0 x</td>
<td>2%</td>
<td>3%</td>
<td>0%</td>
</tr>
<tr>
<td><strong>Sub-Total</strong></td>
<td>€776</td>
<td>1.0 x</td>
<td>1.2 x</td>
<td>1.2 x</td>
<td>53%</td>
<td>58%</td>
<td>60%</td>
</tr>
<tr>
<td><strong>Day care</strong></td>
<td>€0</td>
<td>0.0 x</td>
<td>0.0 x</td>
<td>0.0 x</td>
<td>0%</td>
<td>0%</td>
<td>0%</td>
</tr>
<tr>
<td><strong>Psycho-social support</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Alzheimer’s Café, Dementia</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Social Clubs, Dementia</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Friendly Activities , or other support group for people with dementia</td>
<td>€11</td>
<td>1.0 x</td>
<td>2.1 x</td>
<td>2.3 x</td>
<td>1%</td>
<td>1%</td>
<td>2%</td>
</tr>
<tr>
<td>Dementia Cognitive Therapies</td>
<td>€107</td>
<td>1.0 x</td>
<td>1.0 x</td>
<td>0.0 x</td>
<td>7%</td>
<td>7%</td>
<td>0%</td>
</tr>
<tr>
<td><strong>Sub-Total</strong></td>
<td>€118</td>
<td>1.0 x</td>
<td>1.1 x</td>
<td>0.2 x</td>
<td>8%</td>
<td>8%</td>
<td>2%</td>
</tr>
<tr>
<td><strong>Visits from Health and Social Care Professionals</strong></td>
<td>€84</td>
<td>1.0 x</td>
<td>1.2 x</td>
<td>1.5 x</td>
<td>6%</td>
<td>7%</td>
<td>8%</td>
</tr>
<tr>
<td><strong>Carer Supports</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

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<table>
<thead>
<tr>
<th>Service</th>
<th>Cost</th>
<th>Case Type 2</th>
<th>Case Type 4</th>
<th>Case Type 5</th>
</tr>
</thead>
<tbody>
<tr>
<td>Caregiver Support Groups</td>
<td>€9</td>
<td>1.0x</td>
<td>1.5x</td>
<td>1.2x</td>
</tr>
<tr>
<td>Counselling for Family Carer</td>
<td>€2</td>
<td>1.0x</td>
<td>10.7x</td>
<td>3.3x</td>
</tr>
<tr>
<td>Carer Education Programme</td>
<td>€72</td>
<td>1.0x</td>
<td>0.8x</td>
<td>1.0x</td>
</tr>
<tr>
<td>Nursing home based respite</td>
<td>€50</td>
<td>1.0x</td>
<td>1.4x</td>
<td>1.6x</td>
</tr>
<tr>
<td><strong>Sub-Total</strong></td>
<td><strong>€133</strong></td>
<td><strong>1.0x</strong></td>
<td><strong>1.2x</strong></td>
<td><strong>1.3x</strong></td>
</tr>
<tr>
<td><strong>Other</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Referral to Psychiatry of Old Age Team</td>
<td>€309</td>
<td>1.0x</td>
<td>0.7x</td>
<td>0.9x</td>
</tr>
<tr>
<td>Meals on Wheels</td>
<td>€26</td>
<td>1.0x</td>
<td>0.9x</td>
<td>0.0x</td>
</tr>
<tr>
<td>Transport</td>
<td>€19</td>
<td>1.0x</td>
<td>2.1x</td>
<td>0.0x</td>
</tr>
<tr>
<td><strong>Sub-Total</strong></td>
<td><strong>€353</strong></td>
<td><strong>1.0x</strong></td>
<td><strong>0.8x</strong></td>
<td><strong>0.8x</strong></td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>€1,465</strong></td>
<td><strong>1.0x</strong></td>
<td><strong>1.1x</strong></td>
<td><strong>1.0x</strong></td>
</tr>
</tbody>
</table>

Table 4: Nursing home placement, No Budget Constraint.

<table>
<thead>
<tr>
<th>Cohort</th>
<th>Case Type 2</th>
<th>Case Type 4</th>
<th>Case Type 5</th>
</tr>
</thead>
<tbody>
<tr>
<td>HSCP</td>
<td>0% (0 of 15)</td>
<td>7% (1 of 15)</td>
<td>27% (4 of 15)</td>
</tr>
<tr>
<td>Carer</td>
<td>8% (1 of 13)</td>
<td>31% (4 of 13)</td>
<td>62% (8 of 13)</td>
</tr>
</tbody>
</table>