"It's the One-Size-Fits-All Approach" – Differing Experiences of Formal Dementia Home and Community Care in Ireland

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Background

Many European countries have adopted strategies to promote timely recognition of dementia[1-2], and the right type and quality of home- and community-based dementia care services seems to allow people with dementia to remain living well at home for longer[3].

Access to formal dementia care services varies widely within and across EU countries[4-5], and research has shown that people with dementia and their informal caregivers experience many difficulties accessing services even when they have a diagnosis of dementia. Also, some available services seem to be under-used and informal caregivers often wait a considerable time before seeking help[6].

The uptake and utilisation of services is a complex process. While psychosocial and cultural factors are widely thought to influence service use decisions, service-related factors are also thought to play an important role[7].

The Actifcare project (www.actifcare.eu) is being conducted in 8 countries (DE, IE, IT, NL, NO, PT, SE, UK). It will analyse the pathways to care for people with dementia and their families in an attempt to better understand the reasons for inequalities in access to dementia care services. This first Actifcare study explores the personal experiences, and perceived barriers and/or facilitators to accessing dementia care from the perspectives of people with dementia. The results of the Irish group are presented here.

Methods

An exploratory qualitative design with purposive sampling was used. Two focus groups were held with people with dementia who were using, or had previously tried to access, formal dementia services.

- Group 1 took place with older participants who attend a dementia-specific day centre in a central Dublin neighbourhood (*n*=3; mean age = 83.7).
- Group 2 comprised of younger participants with early onset dementia from urban and rural locations in Ireland (*n*=4; mean age = 57.3).

Discussions followed a questioning route that had previously been piloted by the German Actifcare team. They were tape-recorded, transcribed and analysed using inductive content analysis.

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Results

Six common themes the emerged across the two focus groups:

(1) The Personal Impact of Dementia

Older participants linked functional decline to advancing age, whereas younger participants were keen to stress that there was more to their lives than just their diagnosis of dementia.

> *"I'm too old for driving."*

> *"Don't put me in a box and say I'm gone, because I'm not."*

(2) Capacity and Rights

All participants expected to remain living at home, independent, and in control of their lives for as long as possible. Younger participants did not want to be forced into unsuitable services and they felt that their ability to advocate for themselves would result in better support in the future.

> *"I would prefer to do what I can for myself while I can."*

> *"But the more we can advocate for ourselves, the more we can tell people… and not be afraid to say we have it, our society is going to become a better place."*

(3) Service Availability and Acceptability

Two distinctly different experiences with formal services emerged.

Younger narratives focused on Barriers to care and experiences were predominately negative.

> *"No services other than diagnosis"*
> *"We are not for day centres"*
> *"It would be very nice if the HSE acknowledged that we, under 65, existed… only if we are really bad, then we are put in over 65 care."*

Positive experiences were more common among older participants who valued the opportunities for social interaction, but stressed the need for service-specifc transport.

> *"It's a very nice place"*
> *"And you are meeting other people and you are out of the house."*
> *"They collect you now…"*

(4) The Impact of Caring on Families

All participants acknowledged the support of family and friends but were concerned about over-burdening them. Younger participants expressly wanted to protect their children.

> *"I certainly think I will try to keep it as little [as possible]."*

> *"Well, the people I would bring with me are my sons, who I have no intention of doing that to at this stage."*

(5) Education and Awareness

Only the younger participants reflected on their awareness of their condition. They spoke of the lack of information at diagnosis, a lack of knowledge among the general public, and in some GPs.

> *"Do they think it's contagious?"*
> *"Should I have just stopped working?"*
> *"We all have different needs and we all have different requirements"*
> *"The bit of literature, if you do get it, is hand over your bank account…"*

Results (continued)

(6) Best Practice

The positive impact of good care was evident across all participant groups. Age appropriate services were seen as essential by younger participants. All participants expected that formal dementia care would have a significant focus on social interaction and activities that were meaningful to the individual.

> *"I didn't like a number hanging over my head. It shouldn't matter. It should be about my illness not my age"*

> *"I think you need a purpose more than anything."*
> *"simple things helped me"*
> *"somebody there to talk to"*
> *"Someone calling in… you know, and chat and stuff…"*

Discussion

The findings from the two focus groups support an increasing body of evidence that highlights the very clear gaps that exist between the formal home- and community-based services and supports that are available in Ireland, and the care advocated for by an increasingly diverse population of people living with dementia.

People with dementia want formal services that are individualised, concentrate on maintaining function, and address emotional and social needs and not just physical and personal care needs. Misconceptions of dementia were themselves barriers to appropriate services and supports, and people diagnosed with dementia can find themselves walking away from aspects of their life when they could be maintained with appropriate support. Continued community involvement should therefore remain a focus of formal dementia care throughout.

The recent Irish National Dementia Strategy[8] has selected better awareness and understanding, timely diagnosis and intervention, integrated services, supports and care for people with dementia and their carers, training and education, and leadership as priority action areas. The challenge will be implementing this strategy alongside other current and significant health and social care policies, but it presents an opportunity to identify appropriate home- and community- based care that will truly benefit people with dementia and their families.

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