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Keeping people with Dementia living well in the Community: Exploring the potential of home-based support

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Abstract

Over the past twenty years the increased prevalence, or the better diagnosis, of dementia has led to calls from the World Health Organisation (WHO, 2012) and various advocacy groups for the development and implementation of both national and international dementia policies. Ireland is presently developing a National Dementia Strategy. In the past persons with dementia were either institutionalised or cared for by family and medication was seen as a method of care management. This research explores specific areas of dementia care highlighting the advantages of home- and community-based care for dementia patients and the challenges associated with this type of care provision. The research also highlights the impact of caring for a dementia patient on family members, who provide the majority of care for people with dementia in the community. The findings suggest that enshrining community-based services in statutory or legislative regulation will allow for the development of a defined dementia policy, for home-based or community care, where the dignity and autonomy of the person with dementia can be promoted.

Keywords: Dementia; person-centred care; Alzheimer's; community care; carers.

Introduction

Improvements in the standard of health care over the years have contributed to people living longer and healthier lives; a consequence of this is older people are prone to illness, require more care, and the management of the care required is a constant challenge. Over the years, society has managed this in different ways. Traditionally the family structure was considered the main provider of care reverting to acute hospital settings when necessary, or in the case of no family support being available, to residential care. The scale of the challenge of dementia, which mainly affects older people, is now widely accepted and presents new challenges to these traditional care models.

Dementia: An Understanding of the Condition(s)

Dementia itself is not a specific illness or any one-disease process, rather it is a term used to describe a collection of related diseases and pathologies. Dementia is an umbrella term, used to describe various conditions characterised by progressive and, in the majority of cases, irreversible decline in mental functioning (O'Shea, 2007). A point not always considered is that dementia not only affects the lives of patients but also impacts on carers and family members. In looking at both international and national health policies it is evident that the development of a specific policy strategy on dementia is a relatively new initiative. It could be argued that dementia policy has been catered for within policies on mental health, care of the elderly, or in a broader sense, in policy relating to general geriatric care. This argument is often presented as a defence when explaining the failure to develop an independent national policy on dementia care. Dementia is now emerging as a stand-alone condition requiring a strategic policy response. Increasingly it is recognised that it is important to promote the autonomy and dignity of persons with dementia as far as possible, ensuring the 'person' with dementia does not get lost in the label of dementia. This is a discourse not only amongst dementia care advocates but is also emerging from persons with dementia and their families. The challenge for society is how to respond and promote the delivery of person-centred care.

The primary aim of the research was to explore the potential of home-based support to promote the autonomy and dignity of persons with dementia. This research also aims to provide further information on dementia care to both the academic

community and policy makers which may help them better understand the experience of caregivers enabling them formulate the necessary policy to ensure the needs of persons with dementia are met. In keeping with these aims the focus of the research was to examine the benefits of a person-centred care model for dementia patients in their own homes and within the community.

Literature Review

The literature was reviewed in two sections and informed the research by providing a broad overview of what is already known in the research area. The first section takes an overview of dementia, examining the medical versus the social model of care in the context of the autonomy and dignity of persons with dementia. The second section looks at the different care models and the role and experience of informal carers. The purpose of the review was to explore these debates and emerging understandings of dementia in the context of the model of care for persons with dementia, in particular examining the notion that home-based care, as distinct from residential care, may better promote the autonomy and dignity of the person with dementia. The literature reviewed was drawn primarily from the fields of gerontology and mental health. This reflects the on-going debate regarding the traditional paradigms of care in respect of dementia patients over the years, where it can be argued dementia fell between both disciplines. This debate continues to shape and influence national dementia strategies and agendas as society struggles to deal with one of the world's major healthcare challenges.

Dementia is a complex condition to which we have yet to find a definitive understanding. Whereas each individual case of dementia will dictate a particular model of care, to date the medical model has dominated research and as such the 'individual with dementia' has been lost in the process with little say in the decision making process regarding their continuum of care. Gilliard et al (2005) supports this view by highlighting that research has also demonstrated that care professionals do not consult with people with dementia as service users, although many of them recognized that good practice suggests that they should. Through this process, people with dementia become invisible, and thus a vicious circle is started in which it becomes increasingly difficult to 'find' the person with dementia. Given that

dementia is an irreversible condition it is important to look beyond the diagnosis in order to broaden our understanding.

The Person Centred Approach

The term ‘person-centred care’ is derived from the client-centred psychotherapy counselling approach developed by Carl Rogers in the late 1940s. Whereas the legacy of Roger’s ideas can be found in today’s literature about person-centred care, prior to the writing of Professor Tom Kitwood, the term was not used in the dementia care field. Kitwood (1997, p.8) in his acclaimed book, *Dementia Reconsidered: The Person Comes First*, defines personhood as

a standing or status that is bestowed upon one human being, by others, in the context of relationship and social being. It implies recognition, respect and trust. Both according of personhood, and the failure to do so, have consequences that are empirically testable.

To deny a person the right to be recognised, regardless of their medical state, is an issue that warrants consideration and discussion particularly in the light of the continuing debate around the issue of mental capacity legislation, which runs hand in hand with a person-centred approach.

Following on from a three-year study, *Recognising and supporting self in Dementia*, Kelly (2010) discusses a new way to facilitate a person centred approach to dementia care. This study suggests that adopting a different approach in the interaction between the person with dementia and caregivers can lead to a sense of wellbeing reducing the hostility and anxiety of the patients. ‘The emergence of the person in dementia research’ (Downs, 1997) explores this concept by recognising three aspects of the person with dementia: the individual’s sense of self; the person’s rights; and the value to be gained from a concern with the perspectives of people with dementia (Downs, 1997, p.597).

In the context of the literature review person centred care was looked at in the context of keeping persons with dementia living in the community as against the traditional residential care model. The presence of dementia in modern society ‘raises very deep questions about what it means to be a person’ (Kitwood and Bredin 1992, p. 274).

Kitwood (1997) suggests by adopting a person-centred approach, persons living with dementia can achieve an acceptable quality of life. A person-centred approach requires empathetic care to meet care recipients six psychological needs: love; attachment; comfort; identity; occupation and inclusion (Kitwood, 1997, p.82). Adopting a person-centred approach to persons with dementia, allows society to view the person behind the dementia as distinct from the dementia. Defining personhood is difficult as it is both subjective and interpretive by its very nature and is as much about the person looking in as it is about the person looking out. Person-centred care requires engagement between the carer and the care recipient, forming a 'care partnership', whereby the carer seeks to develop a meaningful relationship with the care-recipient and offer personal support and practical expertise, while enabling them to follow the path of their own choosing (McCormack 2003 cited by O'Dwyer, 2013).

Dignity and Autonomy

According to Kitwood and Benson (1995 cited by Downs, 1997) 'until recently it was assumed that people with dementia experienced a steady erosion of personality and identity to the point at which no person remained'. Given how dementia presents it is easy to lose sight of that and in doing so to diminish the person's dignity and autonomy by assuming they no longer have opinions views or wishes. Spending time to converse and listen to the person with dementia is in itself respecting the individual's dignity. In allowing them make the simplest of decisions recognizes and promotes their autonomy. Showing respect for their views and acknowledging their right to do things their way acknowledges them as a person and in turn promotes self-esteem and maintains their dignity and autonomy. Christine Bryden, herself a person with dementia and campaigner for self-advocacy, in her book *Dancing with Dementia* argues for greater empowerment and respect for people with dementia as individuals. She clearly addresses this point in the following extract:

One day I hope we [society] will treat people with dementia with respect, recognize how hard they are trying to cope with getting through each day, and provide them with appropriate emotional support, social networks, and encouragement...there are twenty four million people around the world who are living with dementia, who are worthy of respect (Bryden, 2005, p.11).

Care in the Community

As their independence turns to dependence the carer often loses their own independence compounding to the stress associated with the caring role. Caring is not only an activity but also becomes an identity; as the carer becomes absorbed in the role they are both seen and present as the carer assuming this new identity often in lieu of their own. Sometimes the role is not taken on willingly or voluntarily but rather happens by default and builds up incrementally over time as circumstances dictate. As articulated by Cahill et al (2012), the majority of people with dementia are catered for in the community by family members and this is in keeping with both the wishes of the older person and what was seen as the cultural tradition. In the past persons with dementia were either institutionalised or cared for by family and medication was seen as a method of care management. The emergence of the person behind the dementia with an emphasis on their rights as individuals has resulted in wider acceptance of a person-centred approach to dementia care. It is important to note that this policy is not grounded in statutory or legislative regulation as there is no Community Care Act (Fitzgerald, 2000, p.87). This means that the provision of social services is not an entitlement and those people with dementia have no rights to government-funded community services. Services have traditionally been provided by voluntary organisations and religious orders (Curry, 1998).

Generally people with dementia being cared for in the community do not come into contact with the health and social services until a crisis occurs, involving the person with dementia, their carer, or both parties. The result is a system geared to providing substitute inpatient care rather than providing anticipatory and on-going community care in partnership with older people and their family carers (O'Shea, 2003). Addressing this point is key in understanding the role of community care and is further highlighted by Cahill et al, who states that the consequences of an underdeveloped and fragmented community care system is significant and, in the long-term, unsustainable care burdens fall disproportionately on family carers, resulting in some people with dementia being admitted to long-stay care that could and should be cared for at home if adequate support services were available (Cahill, 2012, p.90).

Summary

There appears to be a consensus that the main focus of dementia care must be on the person living with the illness (Kitwood, 1997). The social context within which people who suffer with dementia are cared for, needs to be one that encourages people with dementia to cope and to manage their lives in as useful a way as they possibly can. Services for people with dementia and their families need to be set up to assist this process, enabling the person to hold on to their sense of self whilst also appreciating the deep emotional trauma that is involved. While there will always be debate surrounding the medical versus the social model of care, I argue it does not have to be a case of 'either or'. Whereas there is no denying that the definitive diagnosis of dementia will be medical, it does not mean that the initial treatment has to be exclusively medical. The best prescription may very well be in the social context, where an awareness and understanding is communicated to the family, extending to friends and the community. Innes, (2002, p.483) makes the point that: 'Dementia care is in transition and the potential exist for radical reform of the provision of services to people with dementia'. The values and beliefs of society are reflected in how it chooses to provide care. I argue that there is an opportunity to move away from the traditional 'containment out of fear approach' which is found in the 'comfort zone' of residential care, by establishing that 'positive risk taking' and a more holistic approach to dementia care within the community setting is medically, socially and economically achievable.

Methodology

The study employed a qualitative research approach, with a thematic analysis of the views expressed regarding people with dementia living in their own homes and community. This has two distinct sections; a review of both secondary data sources and the broader debates surrounding the approach to dementia care, together with data collected through one to one semi-structured interviews with family carers of persons with dementia, a GP directly involved in Dementia care and a senior policy officer with the Alzheimer's Society of Ireland.

Semi-structured, open-ended interviews, with the aid of a topic guide, were used due to their flexibility and ability to facilitate in-depth probing of the interviewee's experiences (Ritchie and Lewis, 2003, p.111). The data was analysed to extract core

themes that could be distinguished both between and within transcripts of selected sections of the semi-structured interviews and the findings presented as per the themes identified. Direct quotations from participants were used to provide personal testimony with a particular relevance to the research. Having analysed the data, six themes emerged as follows:

1. Dementia poses challenges for individuals and society.
2. Dementia's disabling perception.
3. Dementia a life changing experience.
4. Carer isolation.
5. Generic services instead of Dementia Specific Services.
6. Give a voice to persons with dementia and their carers.

Data Analysis

A framework approach to the thematic analysis of the data gathered was conducted as outlined by Bryman (2012, p.579). Thematic analysis was chosen as it allows patterns and themes within data to be identified while offering an accessible and theoretically flexible approach to analysing qualitative data (Braun and Clarke 2006, p.83).

The discourse surrounding dementia, be it in the medical or social context, is relatively in its infancy. Despite continued medical research there is still no definitive medical treatment to reverse the onset of dementia. Changing demographics and an increase in life expectancy has improved social awareness, and led to greater debate surrounding the societal impact of dementia. Despite this unless you are directly involved either professionally, or through personal circumstances, it is evident that there is still a lack of appreciation and understanding of the impact of dementia on one's life. This lack of awareness while limiting the ability to broaden the research in the area of community based programmes in particular, equally emphasised the need for the further research in order to create a greater social awareness.

In the context of dementia, adopting a qualitative research approach under these four headings was considered as follows:

- Contextual: the experience and different forms of care for persons with dementia together with the experience of the informal carer.

- Explanatory: the change in one's life since the onset of dementia, the circumstances surrounding those changes and the outlook for the future.
- Evaluate: examine the interventions and available support.
- Generate: recommend, strategies or actions in an effort to assist persons with dementia.

Considering the nature of dementia and how it manifests itself in many different forms and interpretations, adopting a qualitative approach in keeping with the above classifications was considered most appropriate. It is important to acknowledge the limitations in this research. At times, due to the vulnerability of the participants and the sensitivities associated with the questions, it was necessary to restrict a particular line of questioning during the course of the interviews. This emphasised the importance of taking a semi-structured interview approach.

The qualitative nature of the research provided a personalized understanding of the experience of dementia. It is difficult to generalise given that each individual story and particular set of circumstances is unique. Aspects of the research and the shared experience of participants will be familiar to some for whom dementia is now part of their daily lives while informing others who have yet to experience dementia.

Findings

The research findings were presented using the thematic structure that emerged from the data analysis. The themes and sub-themes are supported by direct extracts from interviews with participants and present a personalised view of topics discussed both in the literature and policy review. The findings have explored the views of two allied healthcare professionals directly involved in dementia, together with the experiences of informal carers, the challenges they face and the availability of community supports.

As highlighted earlier, 'dementia care is in transition and the potential exist for radical reform of the provision of services to people with dementia' (Innes, 2002, p.483). There is an opportunity to provide imaginative and comprehensive supports while addressing the different elements associated with dementia care in Ireland leading to a

better quality of life for persons with dementia. In saying this, the challenge of implementing a person-centred approach to dementia care should not be underestimated as articulated by the GP interviewed:

Person-centred care flies in the face of usual medical management. From a moral and ethical point of view I think it's marvellous but very time consuming. My fear is with the numbers of people with dementia coming down the line it is going to be quite difficult to be fully person-centred.

The research findings provide an insight into the dementia journey as experienced by both the person with dementia and their carers while posing the challenges that need to be addressed in the forthcoming National Dementia Strategy. In general it could be said that the findings are reflective of the literature researched and in keeping with current debates around dementia care. Looking closely at the themes and sub-themes particular findings were specific in identifying a number of issues, the failure to view dementia as a stand-alone condition requiring a specific response, the failure to address community care and more specifically the failure to define, develop and implement it.

As result, carers feel isolated and society's response to dementia creates a disabling perception. Challenging that perception by recognising the person with dementia rather than 'the dementia' is central in enabling continued everyday participation and social interaction for persons with dementia. This was a point emphasised by one of the participants who stated:

Once labelled with the term dementia you are put into a non-social grouping, labelled with different characteristics, you are isolated and your ability to make decisions is taken away from you.

Despite this, implicit in the research, was the resilience of all participants who found individual and partial solutions to their particular circumstances despite fragmented services. The research also showed a system that failed to adequately support or foster the informal carers they so much rely on.

A senior policy officer with the Alzheimer's Society of Ireland stated that the values and beliefs of society are reflected in how it chooses to provide care and that may

very well mean as a society we have to ‘deconstruct the meaning of dementia and reconstruct it again’. The research has highlighted the need for policy makers, health care professionals and society at large to embrace the social challenge of dementia.

In general the research while personalising the experiences of both the person with dementia and their informal carers, confirmed many of the findings of similar research. Particularly in the areas of, the emphasis on the medical model, the stigma associated with dementia, the public perception of persons with dementia and the wish of both the person with dementia and their family to have them remain within their community, at home, for as long as possible. What was particularly apparent from the data analysed through the themes and sub-themes was the lack of dementia specific services together with the failure to define and develop home based community care. Despite this, informal caregivers improvised to find partial solutions to their particular circumstances and worked within a system where people with dementia have no rights to government-funded community services (Curry, 1998). The research also showed a system that greatly relied on informal carers but equally failed to adequately support or foster them.

The complexities and challenges presented by dementia can best be summed up by the contrasting perspectives as viewed through the lens of the different players. A simple approach would be to think of persons with dementia and their informal carers as two points on a triangle. The other point of the triangle is society / policy makers who are clearly at the top of this triangle and as such both the person with dementia and their carers are dependent on them for services and support. The practical problem is that these three perspectives have differing priorities and the interfaces between them, as shown in the research, are complex. Instead of looking at three points on the dementia triangle, the forthcoming National Dementia Strategy presents an opportunity to look at this triangle as an operational whole, while addressing the different elements associated with dementia care in Ireland.

Challenges

The provision of community-based services requires a new approach and initiative to meet the challenges of the anticipated demographic change and predicted growth of persons with dementia. To ensure these challenges can be met any new initiative on

the delivery of community based services has to ensure all elements work in partnership, effectively seeking to promote the autonomy and dignity of persons with dementia. Given that dementia is an irreversible condition and its progression is somewhat unpredictable, the level of support needed can vary from day to day. This presents a constant challenge for both the person with dementia and their carers. In general community care services as presently delivered are not comprehensive enough when presented with these changing needs to enable persons with dementia live in their own homes.

In both the literature reviewed and from the interviews conducted the impact of the burden of care on informal carers is evident, initially coping with the reality of the situation they find themselves followed by the challenge of delivering a level of care, which promotes the wellbeing and autonomy of the individual with dementia. Cheston and Bender (1999), expressed the view that carers need support to be able to offer the necessary caring environment and O'Shea (2003), makes the point that carers need better support services from the state, especially day care and respite care facilities, both domiciliary and inpatient. Informal carers are an integral part in the delivery of community care, without the proper resources this challenge can easily appear insurmountable.

Perception seems to run hand in hand with dementia and it is easy for persons with dementia to be thrown into the category of 'non persons', either by their own actions or the actions of others. From the initial symptoms to the later stages of dementia there is constant reference as to how the person with dementia views the outside world and conversely how the outside world views them. In the backdrop of this the challenge for the person with dementia is to maintain their sense of identity within the community for as long as possible, living their lives to the fullest while maintaining their autonomy. Equally communities have to ensure they don't become a barrier to promoting a dementia friendly society by the way they socially engage with each other often excluding persons with dementia.

The challenge for service providers is to conform to the regulatory standards as provided for in statutory legislation within the resources made available. On the other hand the challenge for the State, who are the biggest service provider, is to move

beyond the rhetoric around dementia care and ensure community services are placed on a statutory footing and sufficiently resourced. Challenging the medicalised view of dementia using a more person-centred approach is perhaps the first step towards building services and policy that will address and respond to individual needs and experiences (Wilkinson, 2001).

The forthcoming national dementia strategy can be the catalyst to deliver a model of care that supports a person centred care philosophy throughout the various stages of dementia. Developing the strategy is the easy part; the greater challenge is its implementation and the commitment of adequate funding. If the strategy results in no more than aspirations based on volunteerism it will simply not be sustainable. We as a society have to move on from the traditional ‘containment out of fear approach’ which is found in the comfort zone of residential care, by establishing that ‘positive risk taking’ and a more holistic approach to dementia care within the community setting is medically, socially and economically achievable.

Recommendations

Evidence based research is the core of good policymaking and should run hand in hand with any future policy initiatives. Subsequent to the points that emerged in the research findings with reference to both the literature and policy review the following recommendations are presented:

- An appropriate legal framework that both acknowledges the States obligation while supporting the voluntary nature of caring for persons with dementia needs should be addressed in the forthcoming National Dementia Strategy.
- Policy emphasis should be on home care so that persons with dementia, particularly in the early stages of their illness can be cared for at home, in their own environment, thereby retaining their sense of self identity.
- Dedicated dementia trained healthcare professionals, similar to district nurses, should be placed in the community to provide the necessary support to both persons with dementia and their carers.
- Allow for access to a dementia friendly ‘designated person’ as part of a community based primary care team to help navigate through the various stages of dementia.

- Promote dementia friendly communities with trained dementia volunteers who know how to communicate and support persons with dementia.
- Invest in dementia specific practical supports for informal carers, such as day-care and home-based respite, to ensure persons with dementia can remain in their own homes for as long as possible.
- The continued public financing of residential care should not be at the expense of resources for home care.
- Adopt ‘an invest to save attitude’ by developing a scheme similar to the Nursing Homes Support Scheme - A Fair Deal (DoH, 2012), for home based care to enable carers receive the support they require to support dementia patients in their own community and home.
- Provide practical support and training for informal carers many of who are facing life-changing situations.

Conclusion

Dementia poses a significant challenge for, people with dementia, carers and service providers in both health and social policy. Enshrining community-based services in statutory or legislative regulation will allow for the development of a defined policy, for home-based or community care, where the dignity and autonomy of the person with dementia can be promoted. From the research and literature reviewed it appears that this can best be achieved by adopting a triad of care between the person with dementia, their carers and policymakers. It is proposed that future research should explore how this can best be delivered and sustained.

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