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Title: Experiences of older people with dementia: Homecare Enablement to support transitions in daily life at home

Corresponding author:

Pat Chung, Hepworth Building, School of Allied and Public Health Professions, Canterbury

Christ Church University, Canterbury, CT1 1QU, UK. Email

pat.chung@canterbury.ac.uk.

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Abstract

Background: Majority of people with dementia (PwD) live at home. Homecare Enablement Services (HES) are considered an important short-term intervention, using a person-centred approach. Little is known about the PwD' perspectives of the services. This study aimed to explore the users' experiences.

Method: Following ethical approval, participants who had recently used the HES were invited to participate in two semi-structured interviews through HES teams within a Local Authority. Interviews focused on PwDs' narratives' of the impact of HES on their daily functioning. Overall findings were taken back to the participants at the follow-up interviews for member check. Interviews were digitally-recorded, transcribed and analysed using grounded theory.

Findings: 16 participants with dementia and 8 carers took part. Three key themes included: The meaning of enablement in later life; HES as instrumental to support transitions in daily life; and Enablement through activity engagement in everyday life.

Discussion: HES is welcome as instrumental to support transitions at crucial life transition with the dementia pathway, however, scope of the services for PwD is unclear to the users.

Conclusion: The scope of HES is evolving to meet the requirements of Care Act 2014 and NICE guidelines. Services' improvements and redesign must consider the viewpoints of PwD

Keywords: dementia, agency, enablement, homecare, ADL, perspectives of people with dementia

Introduction

Dementia is a global public health priority. In the UK it is estimated that the number of PwD will be around 2 million by 2051 (Alzheimer's Society/AS, 2019). Two-thirds of PwD live at home (Department of Health/DH 2013) and are cared by family carers (DH 2008). Many are being supported by homecare services which are provided or commissioned by Local Authorities (LA's) (United Kingdom Homecare Association 2015). This situation presents challenges to social care systems in supporting PwD's ability to live an active and healthy life at home. Such challenges include: for example, increasing complexity and scope of PwD's care need and support in later life, funding cuts to adult social care in the face of austerity and growing pressures on family carers in their caregiving role (Knapp et al., 2013; Care Quality Commission, 2017; Alzheimer's Society, 2018). Moreover, there is an increasing acknowledgment of the need to listen to the voice of PwD if community-based care is to be effectively delivered (NHS England, 2019; AS, 2017). Homecare Enablement services (HES) have been increasingly adopted as the main mechanism to provide a short-term intervention (usually lasting no longer than 6 weeks) to support adult service users including PwD at home (Glendinning and Newbrunner 2008). This paper discussed the experiences of people with dementia who had used such services.

Literature Review

Dementia is one of the main causes of disability and dependency later in life (National Institute of Centre of Excellence/NICE 2015). It describes the brain disorders that can be caused by a number of acute and progressive illnesses that affect memory, behaviour and the ability to perform everyday activities; and is not a

normal part of aging although age is a strong risk factor (World Health Organisation/WHO 2017).

Over the past decade, there has been a shift of UK government policies in dementia care towards the need to treat PwD as individuals with a 'unique identity and biography' (NICE 2006, p.71). One key influence is shown by the Kitwood's theory of dementia which contended that, despite cognitive loss, individuals can continue to experience a relative state of well-being when a good quality of care is available (Kitwood and Bredin 1992). PwD can be supported through a personalised enabling approach. Government policy has been to support PwD living well by still engaging actively in their daily life as long as they possibly can, through a coordinated personalised approach during the course of dementia. In doing so, it is believed that PwD go into care homes later (NICE 2015, NHS England 2017). Such a personalised approach is in alignment with best practice principles including person-centred (NICE 2018) [*i.e. drawing on the person's strength and considering for declining abilities*] and non-pharmacological intervention (Kales et al. 2015) [*i.e. recognising the benefits of alternative approaches to address behavioural and psychological issues*]. Fundamental to this assumption is that an individual with dementia has a self and a range of psychosocial needs (Kitwood 1997, Sabat and Harre 1992). The threats to one's sense of self and personhood (self-esteem) have disabling effects on those individuals (Kitwood 1997).

The development of HES resulted from the government initiatives in Social Care, particularly Putting People First (DH 2007), Transforming Adult Social Care (DH 2009) and the Care Act (DH 2014). However, the term 'Enablement' is not well defined, being used interchangeably with re-enablement, restorative care and recovery, depending on the focus of Enablement Services. Generally, the Services aim to encourage service users to participate actively in the development of their own care plan for independence (Glendinning and Newbrunner 2008). LAs consider such an approach as an alternative to traditional domestic homecare because the latter has been criticised for fitting the users into services which led to them becoming over-reliant on care packages (Glendinning et al. 2010, Francis et al 2011). Central to the enabling approach is the need to focus on improving or extending ability of the users so as to support them in achieving identified goals of their own choice (Glendinning and Newbrunner 2008), and also to stress the need to

empower people to do things for themselves, rather than having things done for them (Jones et al 2009). The role of Occupational Therapists (OTs) are recognised as crucial in the implementation of Homecare Enablement Services including staff training (Social Centre for Institution of Excellence 2011, Francis et al, 2011; DH 2014). However, there is no consensus on how enablement could be achieved (Parker 2014, Whitehead et al 2013, Cochrane et al 2016). Homecare Enablement Services are delivered using different methods, based on the local needs and resources available, depending on local commissioning decisions and models of health and social care services. For example, many HES are provided or commissioned by LAs whereas some are joint-funded by health and LAs. Some LAs deliver HES in-house by training their homecare staff to adopt an enablement approach to homecare. Some HES are part of an inclusive service, i.e. available to adult service users who are referred for homecare services and meet the eligibility criteria for the service; whereas other HES focus on supporting service users who need hospital discharge services. Moreover, HES often have access to occupational therapists although some HES have occupational therapist(s) based within their teams (Glendinning et al. 2010). Generally, HES is seen as a new approach to homecare provision because it aims to enable independency through a person-centred method, within a timeframe. Evidence of the effect of the HES on PwD is limited although such services have been shown to be beneficial to many people with early to mid-onset dementia (Glendinning et al. 2010, Pitts et al 2011, Cochrane et. al 2016, Poulos et al 2017). Research has pointed out that if Enablement Services are to be effective, there is a need for a clear understanding of users' views, needs and preference (Trappes-Lomax and Hawton 2012; Dawson et al 2015) as such information is crucial to inform service commissioning for Enablement Services (King's Fund & Nuffield Trust, 2012). Moreover, there is a lack of evidence on the most effective way to support PwD living at home (NICE, 2015). This research aimed to explore the experiences of PwD who had used the HES.

Methodology/design

When little is known about the topic under study, a grounded theory (GT) approach can be adopted to understand the social process involved (Holloway 1997). A GT method was relevant to this study, providing a systematic approach to study processes, actions and meanings (Charmaz 2006; Strauss and Corbin 1998). This

research addressed the processes by which PwD experienced the Homecare Enablement Services within a LA. Using this GT approach, the researcher (author) listened to PwD's narratives on their actions, and the meanings they attributed to their actions, relating to the topic under study (Charmaz 2006; Strauss and Corbin 1998).

Purposive sampling was used with participants recruited via nine LA Homecare Enablement teams (HES), delivered 'in-house'. The HES was available to adult service users who were referred for home care and considered to have the potential to benefit from an enabling approach to maximise independence in the community. Generally, each team consisted of a locality organiser, supervisor and others, e.g. enablement support workers supported by specialist occupational therapy interventions with oversight by a senior occupational Therapist. The occupational Therapists offered daily support to team members including decision-making on eligibility criteria for the services, complex OT assessment and interventions.

The participants were people who: i) had a confirmed or suspected diagnosis of dementia who lived at home (as indicated in the referral for HES; ii) had recently been supported by a HES team. The justifications for these criteria were that such people: i) would have been identified as suitable for HES and likely to have been working on strategies to enhance their coping abilities with everyday functioning; ii) and been assessed as capable to give informed consent following a mental capacity assessment. Exclusion criteria included those people who were unable to: i) consent to participate in the research due to a decline in health circumstances during and after the HES; ii) communicate freely due to other medical conditions, e.g. stroke. In the information sheet, participants were advised to discuss with carers the information about the nature of the research and to invite them to join in interviews, as their supporters, if they preferred. In these cases, the carers gave consent to join in the interviews and were aware that this research focused on seeking the voice and experiences of PwD in the context.

Following approval of management governance and the University Research Ethics Committee, participants were invited verbally and in writing to participate in two semi-structured interviews (initial and follow-up). Once the potential participants had given written consent to be contacted by the researcher, the researcher contacted

them to arrange interviews. 16 participants with dementia took part in their own home (8 male, 8 female, aged from 70 to 90 years old). The participants varied in gender, age, relationships to carers, types of dementia and co-comorbidities. This allowed the generation of the diversity of relevant data and facilitated constant comparisons of concepts and categories as discussed earlier (Strauss and Corbin 1998). 8 carers were invited by the carers to participate in the interviews (3 male, 5 female: 5 spouse, 2 daughter-in-law, 1 son). Generally, it was noted that carers were keen to encourage the participants to talk about what mattered to the participants themselves even though carers disagreed with them at times. The presence of these carers provided a rich context for data being collected to understand the social context of PwD. This, in turn, facilitated the researcher's further understanding of the interdependent nature of PwD and their carers and the meanings they attached to such a relationship in a social care setting. The detailed perspectives of the carers are beyond the scope of this paper. The first interview explored how PwD perceived the processes of being involved in the HES including strategies developed and outcomes together with their reflections and feelings. Interviews lasted between 1 and 1½ hours. Follow-up interviews were conducted for member checking (Charmaz 2006). The researcher took issues (emerging concepts) which had been identified from the analysis of around two to three interviews back to each participant for their comments. All interviews were digitally-recorded and transcribed verbatim. Each transcript was read, re-read and coded to develop concepts further by constant comparison (Strauss and Corbin 1998).

During the research process, data collection and analysis were on-going. The researcher used the constant comparison method to compare the incoming data/concepts for their similarities and differences, as well as relationships to one another. This iterative analysis enabled the researcher to maximize opportunities to generate variations among concepts, as well as to check and refine concepts that resulted in the development of categories which are rich with meaning (Charmaz 2006; Strauss and Corbin 1998). Moreover, sets of coding procedures were used for analysis including: i) line-by-line open coding provided a basis for constant comparison and development of concepts from emerging data, allowing the study of actions and events within the data; ii) axial coding explored variations in data patterns and to further develop their characteristics; iii) selective coding for further

conceptual and focused analysis at later stages of the interviews/research. This analytical process was ongoing until saturation of relevant concepts was reached (Strauss and Corbin 1998).

A steering group, consisting of key stakeholders including a service user, was set for periodical meetings in order to offer advice and opportunities to discuss emerging issues and findings throughout the research process.

Rigour was maintained using various guidelines to maximise the trustworthiness. For example, firstly, the researcher adopted a reflexive approach to keep an open mind and avoid preconception of learnt concepts (Charmaz 2006). She also maximised her theoretical sensitivity through measures such as conference presentations (Strauss and Corbin, 1998, Charmaz, 2006). Moreover, she sought alternative interpretations of emerging concepts through discussions with members of the research at steering group meetings. Secondly, the researcher regularly sought out 'negative instances' or 'contradictory cases' (Mason 1996, p.94) to compare the similarities and differences between existing data and contradictory data so as to develop further the variations of the concept (Holloway and Wheeler 2002, Charmaz 2006). Thirdly, memos were used to organise retrievable data for sorting, and cross-referencing in a systemic manner (Strauss and Corbin 1990, 1998; Charmaz 2006).

Findings

This paper focuses on three key themes which emerged from the voices of participants with dementia (PwD), discussed below. The first theme, '*meaning of enablement*', revealed how participants perceived the concept of enablement which had important meaning to PwD with multiple-chronic illnesses in later life, in terms of maintenance of a continuing sense of agency and the 'able' self. The second theme, '*Homecare Enablement Services as instrumental to support transitions*', discusses how, following significant life-events, many participants valued the HES as instrumental in supporting them when in transition back to daily life routines and reducing the burden on their family. The third theme, '*Enablement through activity engagement*', discusses how PwD welcomed a range of strategies. These were used for enabling their activity engagement in daily life, although it was not without challenges. Pseudonyms are used throughout.

The meaning of enablement in later life

Most participants had a confirmed diagnosis of dementia in recent years including: Alzheimer's Diseases, vascular-type and Lewy-body. Almost all of them also had multi-morbidities, e.g. diabetes, COPD, Parkinson's disease, heart conditions, chronic pain, suspected cancer, sensory impairments and mobility difficulties, which had a disabling effect on their ability to manage their daily routine activities including personal care, household management and recreation. Despite these challenges, many participants talked about the meaning of enablement and how they strived to maintain a sense of the continuing self and agency in daily situations by enabling themselves.

Striving for self-reliance: Despite memory difficulty and increasing disability, participants expressed the desire and need to seek for self-reliance and be part of the decision-making for issues which mattered to their daily life. Mary said:

Enablement for myself... It means being capable of coping with most things in life yourself. But also having the sort of mind where you don't, and having the right people around you, that's important'.

There was a strong sense of being their own agents to take control and adapt to ongoing changes through self-initiating actions.

Adjusting to ongoing changes: Participants talked about how, in the face of adversities and life-changing events throughout decades, they continued to adapt and adjust their attitudes and enabling strategies so as to carry on with life. Strategies adopted included acceptance, positivity, resilience and laughter. George said,

Just to get on with life as it hits you... You have to be resilient and you take life as it treats you.... we have to look at ourselves with a sense of humour.

Keeping active: Finding ways to keep themselves mentally and physically active were important. In doing so, they attempted to prevent themselves from rapid deterioration in health status. Richard said,

If we can keep well and keep moving and keep doing things, it's good for us and it's good for the people we're dealing with... Well, I try to live as independently as I can.

There was a sense that they wished to keep away from becoming a passive care-recipient to their family. Nevertheless, for many, with increasing risk and fear of falling, they lost confidence in their functional mobility (access certain parts of the house and outdoors) and gradually adopted a sedentary lifestyle to avoid trips and falls.

Going out for stimulation: Those who were able to go out (alone or with support) kept regular trips outside the house because going out offered them a distraction from their worries and gave opportunities for self-reflection and learning. Tom said,

I go out and walk a lot... While you're actively engaged in doing something for yourself, you can also look at life around you.... you take notice and you wonder to yourself "what would I do in that situation?" ... If you don't reflect you don't learn.

Having a meaningful routine with purpose: With family support, many participants utilised sets of routines as their memory prompts for their daily activities such as having a schedule to remind them to prepare lunch, take medication, feed a dog etc. This can be illustrated by Elise with vascular dementia with severe mobility problems and constant pain in her joints, who developed a routine to prevent herself from dehydration and falls. She said:

I put things in the places, and I know I've got three things to drink from there.... It makes me keep drinking which is very important. It's an effort to pick that up sometimes... I think it's very important to work out a system.

Taking risk: When participants perceived something of great value and importance, they would act on it even though they were aware of the risk involved. Sue said,

With the weather, being hot and all this rain, I find it very hard to walk up the garden and not pull up weeds ... my daughter was so cross when I did this...and her attitude was, "I told you not to go up there" ... Well, she can't tell a gardener not to go up the garden... I said, "I can't wait until I got the gardener because when I fell last time I broke one of my little specimen trees. I need to have it bandaged up". But with two sticks, you've got to let go of one in order to do that ... and then you're vulnerable because you will fall... that is where I'm stupid

Enhancing interdependency: Participants were keen to maintain their sense of self, reciprocity and being able to continually engage in daily activities as far as practical. Nevertheless, over time, they gradually relinquished some of the everyday tasks and decision-making responsibilities to them through negotiations. Antony said,

As you can look around (the house), everything's in a mess. My children had been here to tidy up the mess because they think I need help...But, the mess will never go away because I am the one who creates the mess. I mean- I have to use my abilities and keep doing what I can to stay sane and not screaming. ... I want to keep them happy and I know they're happy when they're looking after me.

Participants aspired to work on strategies to enable themselves and, at the same time, seek for cooperation and interdependent relationship to support them at home. This reflected that enablement was a way of living to maintain a continuing sense of self and agency, through engaging in meaningful 'doing', within a trusting relationship. The process became more complex and challenging as their dementia and physical status deteriorated.

HomeCare Enablement Services as instrumental to support transitions in daily life

The majority of the participants were transferred to the HES following a period of hospitalisation. Some were referred to the Services by their families and community-based professionals following a personal crisis, e.g. a slip or the recent death of a spouse. Many perceived the provision of HES as instrumental to: i) support them in transition to their 'usual' daily routine at home; and ii) offer support to alleviate burden and strain on their family.

i) Transition to usual daily routine:

For many participants, services which aimed at enabling them to return to, or remain in, a familiar environment was a welcome option as this was crucial to their sense of hope and belonging. This was particularly important for those who believed that admission into a care home would start a journey of meaningless life. Lilian said,

Well, the care homes... they sit round the room, half of them with their backs to the windows and the nothingness.... sitting by somebody who couldn't talk or didn't want to talk to them'.

At time of health and personal crisis, many participants valued the HES as they made it possible for them to stay at home, especially when they experienced a real threat to being institutionalised. A carer, Lucy, said,

When my husband was in the hospital...the doctors said to us, if he doesn't come through the weekend we are going to do palliative care ...But he pulled through... and then they sent him home but only on the care plan (Enablement).

Many participants felt that the HES supported them to be an active partner in the intervention process, leading to a sense of security, achievement and stability.

Stephen said

Coming out of the hospital, I couldn't walk... I felt I could do more on my own at home... Another day I can get up and I'll walk right the way through...I can do it by myself ...but I feel, I do feel safer yeah

Participants welcomed the HES which aimed at doing things with them, rather than doing things for them. Nevertheless, it appeared that the participants' motivation to engage with the services were negatively influenced by staff approach when they failed to listen to participants' viewpoints and to enable them to understand their care plan. Some felt being ignored by staff who seemed to spend a lot of time writing reports rather than offering time for a meaningful conversation with them. George said,

They (staff) can study me as much as they like. But if they think that they are going to get anything from me without me understanding it, they're wrong.... All they do is come in and write down and observe what the person before them wrote down.

ii) Instrumental in offering family support:

Many participants were willing to accept the HES because they considered the acceptance of the services as a way to ease the worry for their family. Many

acknowledged that their family had their best interests at heart even though some considered their family over-protective and over-concerned at times. There was a sense of reciprocity, caring and maintaining a harmonious relationship with family, as Antony said:

I'm happy to go along with it (enablement care package)... I do realise now, at this stage in my life that there are things that I can't do for myself and I let them organise everything...

It was noted that some carers were sceptical that PwD had been 'sent' home with the HES inappropriately without sufficient assessments and resources in place. This resulted, in some cases, with the individuals being readmitted to the hospital shortly after discharge from hospital. In other situations, carers felt that the HES discharged their relatives too early due to an over-reliance on participants' self-reporting in the assessment process. This resulted in family feeling frustrated and unsupported.

Enablement through activity engagement in everyday life

Continuing activity engagement was considered important for many participants. Many were frustrated that their ability and confidence to continue with their taken-for-granted everyday activities had been adversely affected by ill health and memory. They valued the opportunity to be re-engaged in their daily activities through a range of approaches offered by the HES as discussed below.

i) Re-engaging through re-learning skills and routine in daily life:

Many participants talked about how they were supported to re-engage in various activities by re-learning skills and re-developing routine in daily life. In doing so, they felt that they became more positive and hopeful by reaching their optimal level of functioning and regaining a sense of identity and purpose. David said,

When I came home from the hospital, they (the enablement workers) came in to help me wash and dress... Well now I get up in the morning, wash myself, go in the bathroom, I clean myself... my wife used to have to help me (when no one was around) but I can't put her in that position ... I said to myself ...I must do something about it, pull your socks up, be a man... you know I can stand up ... and I can walk. I'm still not a hundred percent... I can walk to the dustbin

An issue raised by many carers was, despite the fact that the range of daily activities which participants still engaged in were wide-ranging, the HES appeared to enable mainly personal care activities. Also, both participants and their family often were unsure the scope of the services.

ii) Re-engaging through regaining functional mobility:

Mobility problems and frequent falls were common. Participants found the process of relearning how to walk challenging without appropriate intervention. Chris said,

I think what a lot of people don't realise is.Learn to walk again with my walking frame...a big thing... And the older you get the harder it is to learn, but I don't give in...I feel confidence that I can do it myself

Often, participants and family carers were keen to be referred for rehabilitation, however, they found that the services were usually short-term or had a long waiting list.

iii) Re-engaging through supporting the acceptance of changes

With increasing needs to adapt and adjust to on-going changes in daily life, participants found the process of adapting to changes difficult including acceptance of external equipment and home adaptation for support. Some participants appreciated that OTs had the knowledge and skills to enable them to accept and make changes in difficult circumstances. Mary said,

Months, months. ..I was falling down stairs ... an occupational therapist sent a man along to put up grab rails...eventually they suggested I'd to move the bed down.... I used to creep up after dark upstairs...I've got to learn that the downstairs is now my home ... I can still maintain some independence.

iv) Re-engaging through facilitating social interaction

Some participants talked about having had been referred to a day centre for socialisation. Despite being sceptical about the potential benefits of the day centre at first, many were surprised by the potential benefits of attending the centres. Gill said,

It's opened so many doors, it really has... Well, it's not just sharing yourself with staff, it's sharing yourself with younger members of the group from the day centre... um, I can share and benefit them by my experience.

Some kept an open-mind to try new services so as to make contributions to others. However, many participants also talked about the negative experience of attending the day centre when they felt that they were treated solely as a passive care-recipient and felt devalued by the atmosphere.

Discussion and implications

The aim of this paper was to discuss how people with dementia (PwD) perceived the effects that the Homecare Enablement Services had on their everyday living skills following a recent input from the services. The discussion drew on the concept of enablement in Occupational Therapy Practice in which practitioners support individuals to explore and maintain balance in their everyday activities so that goals become achievable (Creek 2003). Through engagement in occupations, individuals are enabled to gain a sense of meaningfulness through the process of doing and being (Wilcock 1998, Hammell 2004) and maintain a sense of agency (Christiansen and Townsend 2004). Moreover, this study also built on Kitwood's theory of dementia, stating that the relative wellbeing of the individuals can be adversely affected by not only neurological impairment but also the lack of appropriate support for their psychosocial needs, i.e. identity, occupation, attachment, comfort and inclusion (Kitwood 1997). Failure to address such needs may lead to the development of excess disability, indicating that the person's level of functioning is less than one would expect on the basis of the actual level of brain disease (Brody et al 1971). This in turn may trigger signs of ill-being (e.g. apathy, unresponsiveness and anger).

This study showed insights into how PwD perceived the meaning of enablement. In the face of memory decline and vulnerability, they continued to fight for maintaining their sense of the 'able' self and continuing identity, through exerting their agency and autonomy within the context of engagement in their daily living activities (ADL) in their home environment. They lived by their long-standing values and continued to utilise their strengths and resilience the best they could in order to cope with challenges and adversities. Some PwD took risk so as to engage in daily activities which were valuable to them, showing self-determination. This is consistent with literature which highlights the importance of recognising the assets-approaches and making services dementia-friendly (Rahman and Saffer 2018). This study provided

further insights into the factors of how PwD, over time, exerting their agency to relinquish some decision-making and responsibilities to their carers (especially family). This was so that they still maintained a sense of being in control and interdependence as far as practical. Participants often acknowledged how 'lucky and fortunate' they were because their family were able to offer them support and acted as their 'second memory'. Such process can be described as collaborative agency by Bandura (2006, p165) in which individuals recognise the importance of utilising their collective capabilities and interdependent endeavours so as to achieve a desired goal. This highlights the importance for practitioners to balance the tensions between the need to promote the independence of PwD against the need to support the enabling role of family carers in their caregiving situations. In this study, family carers were frustrated that they were often ignored by staff involved throughout the care planning and left to deal with the everyday management. It is crucial that, if person-centred dementia care is to be adopted fully in a home setting, practitioners work with family-carers in order to help them understand the unfamiliar activity patterns and thus develop relevant coping strategies (Chung et al 2017). Otherwise, families may misunderstand the patterns, viewing them as irrational and irresponsible (Chung et al 2008) which could be detrimental to the caregiving situations.

Another significant finding for practice was that many PwD who were referred to ES experienced many significant life transitions associated with health issues. This study echoed a report which highlighted the need for health and social care services to be adapted so as to meet the complex care needs of older people with higher levels of dependency including dementia and multi-morbidities (Kingston et al 2018). This study showed that dementia and chronic illnesses impacted negatively on older individuals' abilities to carry out ADLs. It is crucial to carry out appropriate assessment to ascertain individuals' abilities before interventions are implemented to maximise ADL performance because PwD vary greatly in their capability of related skills and performance, depending on the underlying pathologies and levels of disabilities in cognitive, physical, behavioural and emotional areas (Mlinac and Feng 2016). However, carers in this study were critical that: i) ADLs were mainly assessed by the self-reporting of PwD without performance-based measures; ii) many staff involved did not seem to understand the complex ADL needs of PwD resulting from

dementia combined with other illnesses; iii) there were limited rehabilitation services, e.g. functional mobility, falls and fear for falling. This study supported the NICE guidelines (NICE 2017), highlighting the need for staff within re-enablement services to work across organisations so as to coordinate review and reassessment.

The findings highlighted that PwD (and some of their carers) appreciated the process of regaining skills and confidence through re-engaging in a range of ADLs which in turn led to a sense of safety, self-respect, achievement, belonging, and hope for the future. This reflected the importance of meaningful activity engagement for PwD. However, this study also found that some PwD experienced challenges which discouraged their active engagement in the HES. For example: staff did not communicate effectively with them about the goals for intervention; and spent much time in writing a report rather than communicating with and listening to them in a meaningful way. Moreover, many (and their carers) thought that HES would only cover personal care which restricted their opportunities to obtain 'enablement' in other aspects of ADL which would be meaningful to their daily life, e.g. re-engaging in previous interests. Such issues could unwittingly create an environment which is disabling rather than enabling, therefore adversely impacting on the wellbeing of PwD in terms of a sense of agency, social confidence and hope (Kitwood 1997), thus resulting in the failure to slow down the rate of neuropathological decline in dementia (Kitwood 1997a). This study echoed the WHO's Global Action Plan on the public health response to dementia 2017-2025 which advocates that care services should offer a range of provisions including not only diagnostic but also rehabilitative, preventative and social support for PwD (WHO 2017).

It was noted that the continuing engagement in daily activity of PwD was affected by whether they perceived the environment and staff approach as being empowering, offering opportunities for them to 'share themselves' and 'feel dignified'. This in turn enabled them to feel they were contributing and not being stigmatised by their disabilities.

This study also found that care plans were often delivered by enablement workers and reviewed by their supervisors prior to discharge from the ES. Some PwD and carers had met an Occupational Therapist and recognised their role in the assessment of and advice on major equipment and adaptations. This was likely

reflected in the model of HES being adopted by the LA at the time when this study was conducted. This study echoed the findings of a systematic review which examined the evidence of the re-enablement of older people in the community (Pettersson and Iwarsson 2017, Whitehead et 2015), concluding that the role of specific professional (including occupational therapists) and staff groups within the service were often unclear and that there is a need for further research into this area.

A strength of this study is the knowledge and insight were grounded on the PwD' narratives, regarding the impacts of HES on them. This adds to the existing knowledge about the need to research into understanding of the needs and experiences of PwD and how they perceived themselves as active agent of the enabling process in everyday life. The findings contribute to the debate around the question of involving PwD in research process (Morgan et al 2018). This is important as evidence points out that PwD who were older and with complex needs were being marginalised in intervention research because they were excluded from many studies (Livingston et al. 2017). The findings of this study have implications for practitioners, service providers and commissioners to facilitate the development of effective strategies for assessment and interventions in order to enable PwD to achieve the optimal outcomes, in the most cost efficient way. There are methodological issues which limited the transferability, e.g. all participants were older PwD, hence, the findings may not be applicable to those with young onset; and those who do not experience other co-morbidities. The PwD might not represent the type of support provided by services/staff in different LAs/regions using different organisation format with different funding arrangements. The findings may or may not be relevant to this wider population due to the different contexts (e.g. team dynamics and organisational culture) involved. Nevertheless, it is hoped that the findings contribute to a deeper understanding of PwD's experiences of a short-term HES at home. Many participants acknowledged that it was helpful for them to talk about their experiences.

Conclusion: Older people with dementia are vulnerable due to memory decline, illnesses and effects of aging, with complex ADLs needs. They have a desire to continue engaging in meaningful activities and to use their remaining abilities. Free short-term Homecare Enablement services have the potential to support individuals at crucial life transitions within the dementia pathway, promoting their wellbeing at

home. The nature of Enablement Services is evolving to meet the requirements of Care Act 2014 and recent NICE guidelines (2018). Services' improvements and design must take into consideration the viewpoints of PwD.

Key findings:

- Many PwD with multi-morbidities are referred to Homecare Enablement for short-term intervention. Appropriate performance-based ADL assessments by qualified staff are crucial if person-centred outcomes are to be achieved.
- Homecare Enablement is welcome as instrumental to support transitions at crucial life transition with the dementia pathway; however, scope of the services for PwD is unclear to the users and their carers, including the range of benefits of OT input are often unclear to people with dementia and their carers.
- PwD value the concept of enablement. They attributed the meaning of enablement to meaningful daily activity engagement, maintenance of a sense of the 'able' self, interdependency and collaborative agency.

What the study has added:

- A generic Homecare Enablement service model (i.e. a one size fits all where services are designed for all adult users) may not be sensitive to meet the complex needs of PwD with complex health conditions

Research ethics

Ethical approval was obtained from Faculty of Health and Wellbeing Research Ethics Committee. Ref: 16/FHW/16 004 in 2016

Consent

All participants provided written informed consent to be interviewed for the study.

Declaration of Conflicting interests

The author declared no potential conflicts of interest with respect to the research, authorship and publication of this article.

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