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Abstract

Aim: There is a lack of conceptual clarity around 'respite' as it relates to people with dementia (PwD) and their carers. This study provides clarification on the use and meaning of the term and considers the concept in relation to the dominant care paradigm in dementia i.e. person-centred care.

Methods: Rodgers' (1989) evolutionary framework was employed. A systematic search was conducted of the Pubmed/MedLine, Embase, Cinahl, PsychInfo, Scopus, Web of Science, and Cochrane databases (1980 – 2016, English) with fixed search terms relating to 'respite' and 'dementia'. Papers with primary qualitative data and literature reviews were included. This search was supplemented with snowballing techniques (back/forward searching, generic search engines). Data was analysed thematically, through an iterative process of constant comparison.

Results: Respite is understood both as a service that provides a physical break for the carer and as a psychological outcome i.e. a mental break for the carer, which can be facilitated by formal services, under certain conditions. The conceptual model outlines how client factors (dyadic relations, recognising/accepting need, carer psychosocial issues, restorative occupation, and stigma) and service factors (model/characteristics, care quality, staff expertise, meaningful occupation for PwD and communication and support), interact to influence a respite outcome. The key antecedent for a positive respite experience is that the carer perceives that mutual benefit is garnered from service use.

Conclusion: The term respite can be interpreted as both a service and an outcome. However, it is clear that 'respite', as currently understood, acknowledges the relational experience of the carer only; it is, therefore, potentially damaging to the planning and delivery of person-centred dementia care. We suggest 'restorative care' as a potential alternative nomenclature to respite care, thereby highlighting the importance of providing mutual, personalised health and social care services that serve to enhance care relationships rather than diminish them.

Introduction

Respite care is one of the most common services that people with dementia (PwD) attend. 'Respite services' generally are provided with a view to 'providing a temporary break in caregiving for the carer', in order to reduce 'stress' and 'burden' for carers of PwD (Maayan, Soares-Weiser & Lee, 2014). Multiple models exist, including residential, in-home, and day care services, and therefore services can differ in terms of provider, location, duration and frequency of care. It has been noted that the very notion of 'respite' is shrouded by uncertainty and conceptual disagreement (Evans, 2013a, 2013b). As a result, research in the area of 'respite' has been stifled by heterogeneous conceptualisations and descriptions of what respite is, who it is for, what it entails, and what it should achieve for the service user(s) (Evans, 2013a, 2013b; Shaw et al., 2009). As researchers and academics, we have a responsibility to build the evidence base of a given area on well-developed and clear concepts that are understood by all to have approximately the same meaning (Weaver & Mitcham, 2008). This is particularly important in relation to concepts that will guide the planning, development and delivery of services providing dementia care over the coming years, as more and more people are diagnosed.

This paper aims to contribute to this effort, by establishing what 'respite' means as a concept, from the perspectives of key stakeholders in dementia, across a range of health disciplines, in both the conceptual and empirical literature. This concept will be considered and appraised within the context of the dominant contemporary dementia care paradigm – person-centred care (PCC). The basic principles of the PCC approach include that formal caregivers demonstrate, in their interactions with PwD, that they i) value and respect them as individuals with their own experiences and perspectives ii) demonstrate and communicate empathy and understanding for their experience, and iii) encourage independence and social engagement for the PwD (Brooker, 2003; McCormack, 2004; Edvardsson, Winblad, & Sandman, 2008; Doyle & Rubinstein, 2014). In recent years, there has been a call for all dementia-based services to adopt more 'person-centred', holistic and individualized approaches to care, thereby counteracting the biomedical and custodial models of care which can often serve to undermine the 'personhood' of PwD (Kitwood, 1997).

Methods

Rodgers' evolutionary method of concept analysis (Rodgers, 1989; 2000) was employed to guide this analysis. The objective of this inductive approach is not only to provide a level of clarification around a concept, but importantly, to also establish a basis for the future development of the concept (Rodgers, 2000). The strength of the approach is that it is systematic and can usefully assist researchers to i) clarify, ii) describe and iii) explain concepts by analysing how a chosen concept has been used within and across health disciplines and contexts (Tofthagen & Fagerstrøm, 2010).

Tofthagen and Fagerstrøm (2010) also propose a number of key questions that researchers should consider when they engage with the core analysis phase of this method in relation to five areas (see Table 1):

Table 1: Key questions to ask during core analysis phase

Surrogate terms: Do other words say the same thing as respite? Do other words have something in common with respite?
Attributes: What are the characteristics of respite?
Antecedents: Which events or phenomena have been associated with respite in the past?
Examples: Are concrete examples of respite described in the data material?
Consequences: What happens after or as a result of respite?

These steps will provide the framework to guide this analysis of the concept of respite, based on conceptual and empirical literature, with particular reference to PwD and their carers.

Search Strategy

A search was conducted of the Pubmed/MedLine, Embase, Cinahl, PsychInfo, Scopus, Web of Science, and the Cochrane databases (date parameters 1980 – 2016). The search strategy aimed to identify all peer-reviewed literature relating to respite as a concept in relation to dementia. Google and Google Scholar were also searched to locate any further unindexed peer-reviewed literature. A hand search of the reference lists of the relevant studies, and of other relevant literature reviews and concept analyses, was also conducted as a 'back search', while the 'cited by' function of Google Scholar was used to 'forward search' for articles that have cited the included studies, and have relevance to the present research question.

Search Terms:

The following terms were used in the search strings: Respite care (MeSH)*, respite*, day care (MeSH), day-care (MeSH)*, residential respite*, in-home respite*, Dementia (MeSH)*, Alzheimer disease (MeSH)*, alzheimers*, cognitive impairment*

In Boolean operators:

Dementia **OR** alzheimer disease **OR** alzheimers **OR** cognitive impairment **OR** older adults **OR** frail elderly

AND

Respite care **OR** respite **OR** day care **OR** day-care **OR** residential respite **OR** in-home respite **OR** in home respite.

Study Selection

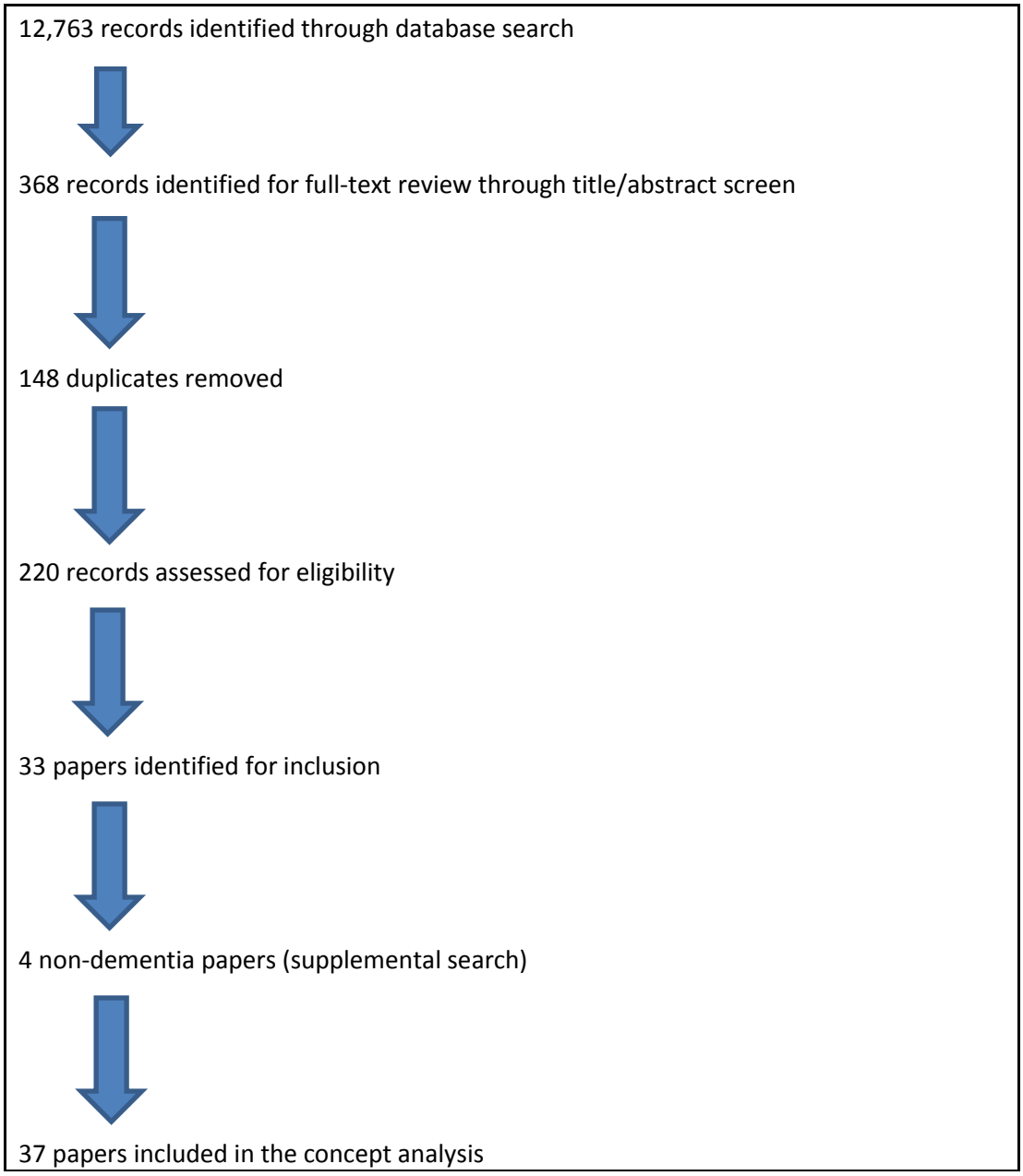
While the aim was to take a broad and inclusive approach to conceptualising respite, with particular reference to dementia, there were criteria guiding study selection, which were required to narrow down the literature and identify relevant papers (see Table 2).

There is a focus on respite as it relates to dementia for this study, as evidenced by the systematic element of the search. However, we sought to supplement the systematic search with snowballing techniques (backwards and forwards searching) and the use of generic search engines, to identify seminal papers focused on the concept of respite, but not necessarily on dementia (see figure 1 for flow chart). Our rationale for doing this is that there is much to be learned from other areas (e.g. intellectual disability, older adults), in terms of the contextual factors that influence the concept of respite.

Table 2: Inclusion and exclusion criteria guiding the systematic search

Inclusion criteria
▪ Peer-reviewed articles focused on dementia and carers of PwD
▪ Articles that present a clear definition of 'respite'
▪ Articles presenting a theoretical framework or discussion of the concept of respite
▪ Qualitative research studies that investigate the meaning of respite
▪ Reviews and discussion papers meeting other inclusion criteria
Exclusion criteria
▪ Books/book chapters/commentaries/editorials/dissertations
▪ Non-peer reviewed articles
▪ Articles not in English
▪ Articles that do not include 1) a definition or 2) a conceptual framework and/or discussion involving respite

Figure 1: Flow Chart detailing the study selection process



After reviewing the titles and abstracts of papers identified in the systematic search to assess eligibility, 220 papers were considered eligible for full-text review. Of these, 33 were considered to meet the criteria for inclusion, independently by two reviewers. A further 4 papers (Whitmore, 2016; Hanson, Tetley, & Clarke, 1999; Chappell, Reid, & Dow, 2001; Evans, 2013a) were identified from the supplemental literature search (respite generally, not just dementia) on Google and Google Scholar. The final sample consisted of 37 papers.

Data Extraction and Analysis

Each of the included articles was read in full and analysed for any data relevant to surrogate terms, attributes, antecedents, examples and consequences. A coding framework was developed based on the questions outlined by Tofthagen and Fagerstrøm (2010) to assist with conducting this core

analysis phase (see Table 1 above), and information about the year of publication, the methods used and the discipline of the first author was also recorded. The framework and its comprising codes were subsequently reviewed for recurring themes and patterns in relation to respite. Through an iterative process of constant comparison to identify similarities and differences across studies, categories were identified in relation to respite, with a particular focus placed on how this relates to dementia. A matrix was created to check each identified category against each included study to determine presence or absence of the category and to record how the category manifests in relation to respite.

Results

Surrogate Terms and Related Concepts

Identifying surrogate terms (words used interchangeably to express a concept) and related concepts are central to understanding the concept under scrutiny (see table 3) (Rodgers, 2000). The most common surrogate terms for respite in relation to dementia fall into two clusters in the literature, and these indicate respite as either i) a service or ii) an outcome. While discussion of surrogate terms and concepts related to respite is beyond the scope of this paper, they have shaped the analysis and will be discussed later.

Table 3 – Surrogate terms and concepts related to respite

1. Surrogate terms					
A. Respite as a service	in-home services	day care services	residential services	crisis services	emergency care
	domiciliary care	formal services	community care	professional care	temporary care
	in-hospital care	intermittent care	sitter services	support services	overnight care
	weekend care	substitute care	relief services		
B. Respite as a caregiver outcome	temporary relief	time out	rest	short-term break	taking leave
	time away	down time	extended break	emotional rest	free time
	freedom	escape	getting out	getting away	mental break
	psychological relief	mental disengagement	private time	space	
2. Related concepts					
	burden	strain	coping	burnout	stress
	depression	anxiety	quality of life	wellbeing	carer support

Attributes

For Rodgers (2000), the identification of the attributes of the concept enables the comprehension of the core definition/characterisation of the concept. This analysis will describe the ongoing evolution of the term 'respite', as it relates to dementia, and how respite has been primarily characterised over the years as a health and social care service*,* but more recently also, as an outcome for the carer, which can be facilitated through service use.

Since the 1980s, there has been a growing emphasis on the 'strain' and 'burden' that informal caregivers of PwD, the 'hidden victims', experience as a result of caregiving (Abramson, 2009; Woods, 2001). The provision of 'respite services' has been widely advocated as an intervention to reduce carer strain. 'Respite services' are most commonly defined as 'services that provide a temporary break in caregiving for the carer' (Mayaan et al., 2014). The assumption in providing 'respite care' is that a physical break from caregiving will serve to reduce 'burden' and increase the carer's capacity to care, ultimately delaying institutionalisation for the PwD (Mayaan et al., 2014; Vandepitte et al., 2016). However, there are two key problems regarding the conceptualisation of respite as a service: 1) there is high service non-use and attrition, despite high stated need for 'respite' (Donath, Winkler, & Gräßel, 2009; Phillipson, Jones, & Magee, 2014; Parahoo, Campbell, & Scoltock, 2002) and 2) there is mixed evidence for the effectiveness of 'respite services' across service models (see outcomes below).

Qualitative studies have been conducted across disciplines including psychology, nursing, health services research, occupational therapy, social work and medicine to understand caregivers' experiences of and perspectives on 'respite services' in relation to dementia since the mid 1990's (Kirkley et al., 2011; Cotrell, 1996; Beseicker, Wright, Chrisman, & Ashworth, 1996; McGrath, Meuller, Brown, Teitelman, & Watts, 2000). Findings from these studies have indicated that the characterisation of respite as a service is often inconsistent with the meaning of respite for the service users. While carers also refer to 'respite services', they tend to conceptualise 'respite', for themselves, as a psychological break from caregiving (McGrath et al., 2000; Teitelman & Watts, 2005; Teitelman & Watts, 2004; Watts & Teitelman, 2005; Strang & Haughey, 1998; Strang, 2001),which can be facilitated by service use under certain conditions (see antecedents below).

The temporary physical break provided by 'respite services' is not sufficient to facilitate respite for the carer under this conceptualisation; a mental break must also be experienced (Strang & Haughey, 1998; Strang, 2001; Teitelman & Watts, 2005). This has important implications for service provision in relation to dementia, and indicates that the characterisation of respite as a service only, is not only inconsistent with service user conceptualisations, it may be partially accountable for the mixed evidence in relation to service user outcomes and the underuse of formal services for the purpose of respite. It must be noted that, to our knowledge, the meaning of respite has not been explored from the perspective of PwD to date.

Antecedents

According to Rodgers (2000), antecedents refer to those things which have been previously associated with the concept. The antecedents fall into two distinct, but inter-related categories i.e. client factors and service factors, each of which contains elements that can enhance or inhibit the respite experience for carers.

1. Client factors

Here, the term 'client' refers to the service users i.e. the PwD and the carer. This analysis has identified five client factors that impact the carer's ability to experience a mental break through service use: 1) Dyadic relations, 2) Recognising and Accepting Need, 3) Carer Psychosocial Factors, 4) Restorative Occupation, and 5) Stigma.

Dyadic Relations

A clear pattern in the qualitative research indicates the significance of the dyadic relationship and how aspects of this can be an emotional barrier in the carers' ability to experience respite. Carers commonly reported feelings of 'guilt' in relation to service use for the purpose of respite (Parahoo et al., 2002; Cotrell, 1996; Myren, Enmarker, Saur, & Hellzen, 2013; Upton & Reid, 2005; Tretteteig, Vatne, & Rokstad, 2017). Negative feelings around service use are amplified for the carer when the PwD indicates that they do not accept the service or they refuse to attend, which can lead to conflict in the dyad, and despair and frustration in the carer (Robinson et al., 2012). Carers can feel that service use is a 'betrayal' and an 'abandonment' of the PwD, because they are not fulfilling the caregiving role to which they 'committed' (Strang & Haughey, 1999; Cotrell, 1996; de la Cuesta-Benjumea, 2010; Phillipson & Jones, 2011b). This feeling was particularly common for spousal and female caregivers and people over 70 years (Cotrell, 1996; Tretteteig, Vatne, & Rokstand, 2016; Tretteteig et al., 2017; Upton & Reid, 2005; Phillipson et al., 2014; Strang, 2001). This commitment to care has been reported by some spouses, despite poor quality relations ('longstanding lovelessness') prior to the onset of the dementia, as it is seen as their 'duty' or 'job' (Upton & Reid, 2005). The duration of the caregiving relationship is also significant and can impact caregivers' readiness to acknowledge their need for a mental break (Strang & Haughey, 1998; Gottlieb & Johnson, 2000). Finally, some carers also saw service use or the need for 'respite', as a 'signal' that this was the beginning of the PwD being 'taken away' from them i.e. institutionalised (Parahoo et al., 2002; Cotrell, 1996). According to Robinson et al. (2012), carers noted that in their experience, 'promoting feelings of safety and security' for the PwD, and addressing their 'fears' around service use, served to foster greater acceptance and willingness to attend. From these findings, it is clear that relational factors differentially affect emotions and beliefs regarding the meaning of respite, which can preclude a positive respite experience for the carer.

Recognising and Accepting Need

The carer's recognition and acceptance of the need for a break is an important factor in service use and achieving a respite experience (Cotrell, 1996; de la Cuesta-Benjumea, 2010; Neville, Beattie, Fielding, & MacAndrew, 2015; O' Connell, Hawkins, Ostaszkiewicz, & Millar, 2012; Parahoo et al., 2002; Phillipson & Jones, 2012; Upton & Reid, 2005; Donath et al., 2009). According to Strang and Haughey (1998, 1999) and Strang (2000), the first key step to achieving a mental break from caregiving is recognising the need, followed by a process of the carer accepting the need and ultimately granting 'self-permission' to come out of carer role temporarily. A number of carers spoke to how it was important to have other people (i.e. 'social referents' [Phillipson & Jones, 2011b]) positively reinforce the idea that a break was necessary for them to enable acceptance of the need for respite (Phillipson et al., 2011b; de la Cuesta-Benjumea, 2010). Perception of need could also be

negatively impacted by others, e.g. family members believing care should be delivered only by family, not formal services (Parahoo et al., 2002). Positive reinforcement regarding need can similarly be garnered from staff within services (Phillipson & Jones, 2012). Alternatively, services can negatively influence the carer's process of accepting the need for respite, particularly when care quality is perceived as poor (Gilmour, 2002). Recognising and accepting the need for respite is vital, and can be fostered by positive reinforcement from 'social referents', but hindered by negative familial beliefs regarding care provision, and perceived substandard care quality in services.

Carer Psychosocial factors

Carers can experience a range of personal psychological and social barriers to respite. Upton and Reed (2005) reported that there can be a relinquishment of the self and personal identity, as the carer struggles to cope with the demands of the caregiving role. The ability to 'get out' of the caregiving 'sphere of existence' and into their own individual world (Strang and Haughey, 1998, 1999; Strang, 2000, 2001), can be impacted upon by carers' coping strategies (Watts & Teitelman, 2005; Gottlieb & Johnson, 2000; Strang & Haughey, 1998), identity issues (Strang & Haughey, 1998; Strang, 2000), social support resources (Strang & Haughey, 1998; Watts & Teitelman, 2005; Teitelman & Watts, 2004), negative beliefs and affect (e.g. equating service use with failure to cope [Phillipson & Jones, 2012] and believing no service could substitute for them [Phillipson & Jones, 2011a, 2011b; Beseicker et al., 1996]), and personality factors and predispositions (Watts & Teitelman, 2005). Carers also experience anxiety around temporarily relinquishing control and decision-making power regarding the care of the PwD (Phillipson & Jones, 2011b). While these psychosocial factors are individual to each carer, they are interrelated with dyadic relational and attachment factors and the perception of need (Strang & Haughey, 1998; Strang, 2001), as well as service factors (see below). Services have a substantial role to play in supporting carers to overcome these barriers and achieve a mental break.

Restorative Occupation for the Carer

Restorative occupation, according to Watts and Teitelman (2005), is essential to achieving a respite experience during service use, and ultimately increases caregiving capacity. A 'beat the clock' feeling has been reported by carers in relation to using services for the purpose of respite (Teitelman & Watts, 2004; Watts & Teitelman, 2005); carers focus on completing as many tasks as possible while the PwD is under the care of services (Watts & Teitelman, 2005; Phillipson & Jones, 2011a), precluding 'any real sense of respite' (Phillipson et al., 2011a). This intended 'respite' time, in reality, is mostly used for 'urgent' functional activities and 'chores' (e.g. shopping, housework) (Parahoo et al., 2002), and/or meeting other family members' needs (e.g. adult children caregivers, who have children and spouses of their own) (Parahoo et al., 2002; Phillipson & Jones, 2012). In this way, the break from caregiving that services provide is often not used for leisure, recreation or relaxing (Parahoo et al., 2002; Teitelman & Watts, 2004; Upton & Reed, 2005), but for catching up with functional tasks that have been neglected as a consequence of the demands of caregiving. Watts and Teitelman (2005) state that it is important that carers engage in 'absorbing activities' (i.e. activities which provide a psychological distraction from caregiving concerns), as these activities are central to 'renewal' and 'mental clarity'.

Perceived Stigma

According to a review by Robinson et al. (2012), stigma is a key issue in terms of respite for PwD. Carers note that 'leaving home comforts' can make the PwD feel unsafe and increases the 'potential for embarrassment'; it can also increase levels of anxiety for the PwD around how others will perceive them in light of their dementia-related symptoms. Public stigma has been reported towards PwD, causing carers to 'conceal the PwD' to protect them from social rejection (in Robinson et al., 2012). Carer self-stigma has been reported in relation to service use (Hochgraeber, von Kutzleben, Bartholomeyczik, & Holle, 2015); this may be a particular issue for female carers, who feel they may be judged for not fulfilling their gender role regarding the 'obligation' to provide informal care (de la Cuesta, 2010; Strang, 2001). Finally, in a 2014 review by Phillipson and colleagues, the authors described a large cross-sectional study by Montoro-Rodriguez, Kosloski and Montgomery (2003), where higher levels of carer stigma were significantly associated with greater use of 'in-home respite'. This relationship was not statistically significant for carer stigma and 'adult day care', which may indicate that in-home services are more acceptable to carers who experience stigma. The stigma variable in this study was a composite of four items which together indicate that the 'stigma' referred to carers' own embarrassment/discomfort relating to the behaviour of their relative. While stigma is an important and multifaceted factor which can impact 'respite service' use, it is not yet clear how it relates to respite as an outcome.

2. Service factors

Along with the above client factors, four key service factors that impact the carer's ability to experience a mental break have been identified and are outlined below: 1) the service model and characteristics, 2) care quality and staff expertise, 3) meaningful occupation for the PwD, and 4) communication and support.

Service Model & Characteristics

The 'respite service' model and characteristics are also significant in terms of the carer's willingness to use services and ability to experience a mental break.

Mixed carer preferences have been reported in relation to in-home and day care service models (Cotrell, 1996; O' Connell et al., 2012). Factors influencing a carer preference for day care services include 'dementia stage' (Cotrell, 1996) and the nature of the care relationship (co-residing adult children 'overwhelmingly' favour day care, unlike spouses who prefer in-home models [Cotrell, 1996]). Factors influencing a preference for in-home models include the physical environment (less 'clinical' and 'institutional' than other models) (Holm & Ziguras, 2003) and the smaller staff-client ratio compared to day care (Holm & Ziguras, 2003). The acceptability of the model to the PwD also influences carer use and preference (Cotrell, 1996; Strang & Haughey, 1998). Residential/overnight models were the least preferred (Cotrell, 1996; Phillipson & Jones, 2011b) and are often seen as a 'last resort' with a view to delaying institutionalisation (Phillipson & Jones, 2011b). PwD have reported a preference for in-home models as there is more continuity and opportunity to develop relationships (Holm & Ziguras, 2003). Day care services have been found to be particularly unacceptable to older males with dementia and those with early onset dementia (Phillipson & Jones, 2012; Parahoo et al., 2002).

There were two important themes relating to respite service characteristics, across models, which influenced the acceptability of the service from the carers' perspectives. Carers have called for services to be more flexible and responsive in terms of meeting the dyad's needs e.g. regarding availability, opening hours, duration, activities, transport and meals (Beisecker et al., 1996; Holm & Ziguras, 2003; Kirkley et al., 2011; O' Connell et al., 2012; Phillipson & Jones, 2011a; Tretteteig et al., 2016, 2017; Tang, Ryburn, Doyle, & Wells, 2011). Continuity was also vital, in relation to both care and staffing (Hochgraeber et al., 2015; Holm & Ziguras, 2003; Kirkley et al., 2011; Parahoo et al., 2002; Cotrell, 1996; Phillipson & Jones, 2011a), particularly as the condition progresses (O' Connell et al., 2012).

Care Quality and Staff Expertise

Dementia care quality was a prime concern for carers regarding respite. For carers, absence of trust in the quality of care provided by a service for the PwD is a crucial barrier to a positive respite experience (Cotrell, 1996; Beisecker et al., 1996; de la Cuesta-Benjumea, 2010; McGrath et al., 2000; O' Connell et al., 2012; Phillipson & Jones, 2011b; Strang & Haughey, 1998; Strang, 2001; Tretteteig et al., 2016). Perceived poor care quality indicates that service use is not mutually beneficial for the dyad, precluding a mental break for the carer (McGrath et al., 2000; de la Cuesta-Benjumea, 2010; Hochgraeber et al., 2015; Phillipson & Jones, 2012). Staff approaches to, and expertise in, dementia care were central to carers' perceptions of care quality (Tretteteig et al., 2016; Cotrell, 1996; Beisecker et al., 1996) and influence carers' ability to experience respite (Beisecker et al., 1996; Donath et al., 2009). Staff should be 'kind' and 'empathic' in their approach (Beseicker et al., 1996; O' Connell et al., 2012), demonstrate 'respect' for the PwD, and get to know and understand them as people (O' Connell et al., 2012; Parahoo et al., 2002; de la Cuesta-Benjumea, 2010; Donath et al., 2009; Phillipson & Jones, 2011a). Carers attribute poor outcomes for the PwD, in part, to a lack of appropriate training in dementia care for the staff (Phillipson et al., 2011a; Cotrell, 1996; Hochgraeber et al., 2015; Phillipson et al., 2014). Respite service managers emphasized the importance of recruiting 'the right staff' and supporting them appropriately, with supervision and peer meetings, to deliver PCC (Kirkley et al., 2011). This was considered challenging however, given the substantial barriers (e.g. resource constraints, pay levels, staff knowledge and skills, leadership style) service managers face in implementing organisational cultural change in 'respite services', which were originally designed to benefit only the carer.

Meaningful Occupation for the PwD

An important way in which carers can perceive mutual benefit from service use is when the service engages the PwD in meaningful activity (Donath et al., 2009; Holm & Ziguras, 2003; McGrath et al., 2000; Parahoo et al., 2002; O' Connell et al., 2012; Phillipson & Jones, 2011a; Myren et al., 2013; Tretteteig et al., 2016, 2017). Meaningful activity/occupation means different things to different carers; e.g. physical exercise and games (Donath et al., 2009), tailored activities that the PwD enjoys (Holm & Ziguras, 2003; O' Connell et al., 2012), 'stimulating' activities (Beseicker et al., 1996), an opportunity for social interaction (McGrath et al., 2000) and/or the promotion of personal abilities (McGrath et al., 2000; Parahoo et al., 2002; Hochgraeber et al., 2015; Myren et al., 2013). However, regardless of the activity, it was clear from these studies that it was not acceptable from the carers' perspectives for PwD to be just 'kept busy' (Hochgraeber et al., 2015). Holm & Ziguras (2003) outlined how services providing meaningful activity can be more acceptable to the PwD. Phillipson &

Jones (2011a) reported this is also true for the carer, and can boost their confidence in the service as an acceptable substitute. Carers believe that PwD benefit from being engaged in 'positive occupation' that recognises their skills, abilities and capacity, as this enhances their 'personhood' and 'sense of self' (Phillipson & Jones, 2012). When positive occupation for the PwD is observed, carers are more likely to perceive mutual benefit and achieve a respite experience.

Communication & Support

Carers have highlighted the importance of service-dyad interactions, in terms of communication, support and information, for perceiving benefit from service use for the purpose of respite (O' Connell et al., 2012; Donath et al., 2009; Gilmour, 2002; Phillipson & Jones, 2011a; Tretteteig et al., 2017). Poor service-dyad and within-service staff communication negatively impact carer's perceptions of the quality of care and the safety of the PwD (O' Connell et al., 2012). Phillipson and Jones (2011a) reported that carers felt services could support them better if staff made an effort to engage with them about the PwD, their care needs, and the dyad's existing care routine. Carers feel that services are a worthy substitute when they demonstrate an intimate knowledge of the PwD, as this is a key element of family care (de la Cuesta-Benjumea, 2010). Gilmour (2002) states that for a service to be acceptable, staff must relocate themselves in 'non-traditional' and 'secondary' supporting care roles, where the clients direct the care and the staff support and deliver this. There must be an ongoing dialogue between the dyad and the service, which fosters a triadic partnership based on understanding and trust; this may be the cornerstone of facilitating a positive respite experience for carers in relation to dementia. Services should also design and deliver 'context-specific interventions' for the carer, which are tailored to their individual relational, psychosocial and practical needs, to facilitate them in achieving a 'legitimate' break from caregiving (de la Cuesta-Benjumea, 2010, 2011).

Mutuality: The Key Antecedent?

It seems likely that the client and service factors outlined above interact differentially to influence the respite outcome for each dyad. However, mutuality may be the over-arching prerequisite for carers in relation to achieving a respite experience. Here, we posit, in line with the findings of other authors, that not only must the carer believe that they can benefit from service use, the carer must also perceive that the PwD is satisfied with and benefitting from service use, before they can allow themselves to experience respite (McGrath et al., 2000; Phillipson & Jones, 2012; Holm & Ziguras, 2003; O' Connell et al., 2012; Robinson et al., 2012). In this way, service use must be perceived as *mutually beneficial* by the carer, if the carer is to achieve a mental break (McGrath et al., 2000; Holm & Ziguras, 2003). The need for perceived mutual benefit can be understood as a need for the carer to trust that the service is at least an adequate substitute, in order to limit the relational and psychosocial barriers to accepting the need for a respite experience. The respite service must also have strong person-centred origins and attributes if the carer is to believe that it is an adequate substitute.

While the centrality of the PwD is very clear for carers in the papers outlined above, it must be noted that the perspectives and experiences of PwD themselves have been largely neglected to date in relation to the respite literature; this is important and will be considered further in the discussion.

Consequences

Consequences, according to Rodgers (2000) are themes or outcomes that arise from the concept. Two recent systematic reviews of the effectiveness literature in relation to 'respite services' for PwD and their carers have been conducted by Maayan et al., (2014) and Vandepitte et al. (2016); these reviews indicate that the evidence for the effectiveness of 'respite services' across service models, for a range of outcomes, including institutionalization and caregiver burden is largely mixed (Maayan et al., 2014; Vandepitte et al., 2016). There is evidence to suggest that day care is effective in relation to 'reducing caregiver burden and dementia-related behaviours'. However, adverse outcomes including 'increased caregiver burden and distress' have been reported in relation to the use of residential respite services, while day care use was associated with accelerated nursing home placement (Vandepitte et al., 2016).

The qualitative findings regarding outcomes in relation to 'respite service' use are also mixed. Some carers reported improved coping and emotional regulation (Cotrell, 1996; Beseicker et al., 1996) and a perceived increased capacity to care for longer (Beisecker et al., 1996; Phillipson & Jones, 2012). Day care services are considered beneficial for the PwD in terms of social interaction, cognitive stimulation, quality of life, self-esteem and enjoyment, by carers, as well as allowing the carer to maintain employment (Phillipson & Jones, 2012; Beseicker et al., 1996). However, carers also report negative outcomes of 'respite service' use, including: functional decline, broken teeth, pressure ulcers, malnutrition, weight loss, reduced mobility and deterioration in dyad relations (Phillipson & Jones, 2011b; O' Connell et al., 2012; Cotrell, 1996).

While the mixed results regarding the effectiveness of service use have been attributed to heterogeneity in service models and characteristics, as well as in research designs (Maayan et al., 2014; Vandepitte et al., 2016), it is probable that the traditional conceptualisation of respite as a service, is partially accountable. It is more likely that service user outcomes are influenced by whether or not carers actually experience a restorative mental break from caregiving while using services (Strang & Haughey, 1998; Strang, 2000). To date, there is an absence of research defining the desired or anticipated outcomes of a mental break for the carer, or evaluating the association between mental breaks and outcomes for the dyad. In practice, it seems important that services that aim to facilitate respite strive to understand what each individual dyad values in terms of outcomes, and determine how best these could be achieved.

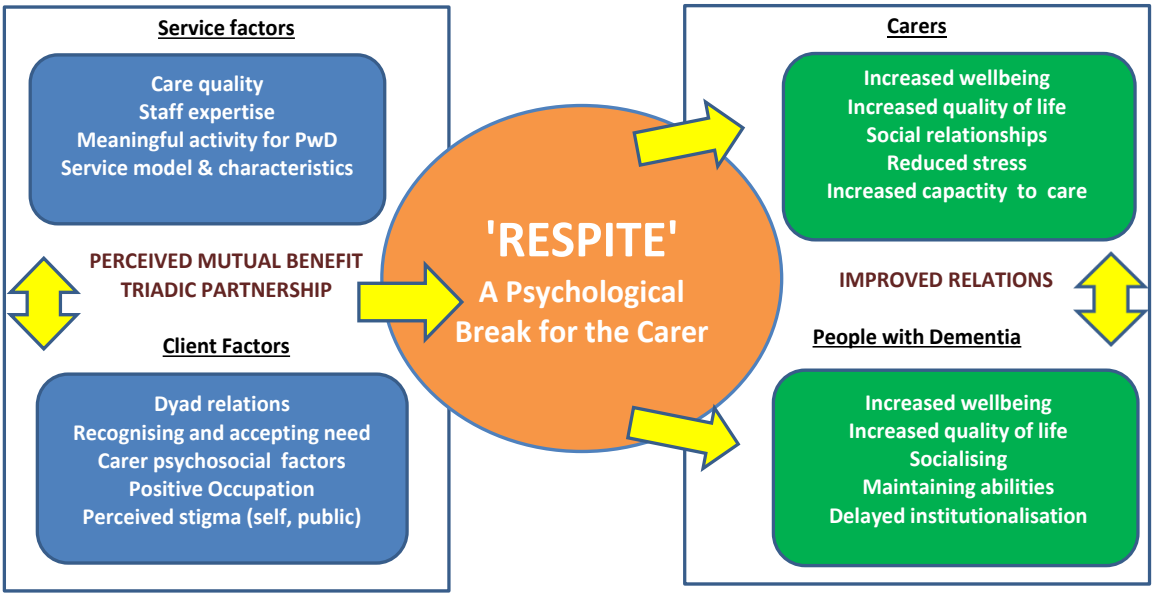
Concept Definition and Model

Based on the analysis of the attributes, antecedents and outcomes of 'respite', it seems that, from the perspective of carers of PwD, 'respite' is more usefully conceptualised as:

> a psychological outcome of a mental break for caregivers, which can be facilitated by the use of formal health and social care services under certain conditions, when the carer perceives that service use is necessary and mutually beneficial for the dyad.

A conceptual model of respite, as it relates to dementia, is outlined in figure 2. This model depicts the range of interconnected client and service factors (outlined above), which influence the carers ability to achieve a respite experience through service use, as well as the potential outcomes associated with respite under this conceptualisation, again from the carers perspective.

Figure 2 – The role of health and social care services in facilitating respite as an outcome for carers of people with dementia



Discussion

This aim of this paper was to establish a level of conceptual clarification around respite in dementia, from the perspectives of key stakeholders, as they are found in the literature, across health disciplines. An ancillary aim of this paper was to consider the concept in the context of the PCC paradigm, which will be further deliberated below.

Respite is still characterised, as it has been historically, as a service. However, in more recent years it is coming to be understood from the carer's perspective i.e. as a psychological outcome of a mental break for carers. The achievement of such a mental break through the use of formal services, can be influenced by a range of complex and interconnected (i) client (dyadic relations, recognising and accepting need, carer psychosocial factors, restorative occupation and stigma) and (ii) service (service model and characteristics, care quality and staff expertise, meaningful occupation for the PwD and communication and support) 'antecedents'. The key antecedent underlying the achievement of a positive respite experience for the carer is that the carer perceives a 'mutual benefit' being garnered from service use, such that the PwD is safe and well, is satisfied with the service and is engaged in meaningful occupation/activity, during this break in the caregiving relationship. It is also important for the carer, that the care is underpinned by the principles of personhood, and that the PwD is treated with dignity and respect, is valued and meaningfully included in decision-making, that staff demonstrate empathy, and that the strengths, interests and skills of the PwD are nurtured. From the carers' perspective, communication and information are key to fostering trust in the service and the quality of care. Communication is also vital to nurturing a triadic partnership, and enables the carer to trust that the service is indeed mutually beneficial for

the individuals comprising the dyad; this is essential to facilitating a meaningful respite experience for the carer.

'Respite' in Other Related Contexts

These findings have some parallels as well as dissimilarities with concept analyses of respite, which are not focused specifically on dementia, but other related contexts e.g. older adults and intellectual disability (Hanson et al., 1999; Whitmore, 2016; Evans, 2013a; Chappell et al., 2001).

Hanson et al. (1999) considered the concept of 'respite care', as opposed to just the term 'respite' in relation to older adults. This analysis is slightly more limited in scope than the present analysis, in that consideration of the term 'respite care' delineates respite as a service from the outset. However, even under this characterisation, the authors concluded that, in relation to older adults generally, 'the concept of 'respite care' has to be broadened to encompass the needs of family carers for education, information and support', somewhat intimating the present point that effective communication, information and support are important service factors in relation to respite. Similar to Hanson et al. (1999), Whitmore (2016) also explored the concept 'respite care', but in relation to children with special healthcare needs, unsurprisingly also characterising it as a service 'providing caregivers with temporary relief from their responsibilities of caregiving'. However, Whitmore (2016) does acknowledge that an 'adequate break' for the carer has to be more than the physical break from caregiving which the service perspective generally intimates, noting that awareness of the need for respite services, acceptance of the use of respite services, the service characteristics and the quality of respite care are key to improved outcomes (e.g. 'decreased caregiver stress' and 'improved family quality of life').

Evans (2013a) also explored 'respite' as a concept in relation to older adults. However, he characterised respite as a 'complex intervention', which on the surface, is more in line with characterising respite as a service, than as an outcome. However, this is less passive than the basic 'service' characterisation as it indicates, similar to the argument in this analysis that the service must actively interact and intervene with the clients. In this way, merely taking custody of the PwD and facilitating a physical break for the carer is not sufficient. Evans (2013a) concluded that the concept of respite consisted of three distinct attributes, i.e. partnership (relationship with service), service (characteristics, assistance and engagement) and outcomes (for the carer and care-recipient). These attributes, correspond with some of the present findings relating to the importance of service-dyad communication and the development of a triadic partnership between service users and the service, as well as the service characteristics, care quality and approach, and finally in relation to improved outcomes for carer and the PwD.

The findings that most closely align with those reported here are from Chappell et al. (2001) in their seminal study on the meaning of respite, which involved in-depth interviews and focus groups with 294 caregivers of older adults, including PwD. None of the caregivers, according to the authors, 'spoke of their experience of respite in relation to service provision'. The authors concluded that respite should be reconsidered as an outcome, in line with the caregivers' perspectives on the meaning of the term, as opposed to a service, and that policy and practice in this area should be based on evidence, informed by the voice of the service user.

'Respite' and Person-Centred Dementia Care: Irreconcilable Concepts?

It is clear from the findings of this analysis, and the findings of previous concept analyses (Chappell et al., 2001; Evans, 2013a; Hanson et al., 1999), that the care-recipient and their experiences and perspectives are not generally considered in relation to the term 'respite'.

'Respite' is laden with ambiguous meaning that serves to create an imbalance of power in relation to the caregiving relationship, falling almost exclusively on the side of the carer. From the 'related terms' section above (Table 3), it is clear that concepts related to 'respite' are fundamentally connected to the carer's experience of providing care to the PwD, and more often than not, represent their experience of the relationship in a negative light as a result of the dementia condition (e.g. 'burden', 'strain', 'depression', 'stress', 'burnout', 'anxiety', 'coping', 'carer support'). This narrative tends to omit the experience and perspective of the PwD in the caregiving relationship, even as experienced through the lens of the caregiver.

This omission of the PwD is problematic for the conceptualisation of respite as an outcome, given that in order for carers to realise a respite experience through service use, they are clear that the PwD and their wellbeing, must be the foremost consideration. Given that the term 'respite' does not encompass the experience of the PwD, it is inherently limited in its ability guide the design and planning of services and care in such a way that can facilitate carers to achieve a respite experience, and certainly is not consistent with a person-centred approach to health and social care service delivery for PwD. Therefore, it seems logical that the term 'respite' cannot sensibly be employed going forward, in relation to the experience of the PwD, without us knowingly neglecting the reality of the PwD.

There is a need for a new term that connotes, and indeed embraces, the perspective and experience of the carer *and* the PwD in relation to the use of health and social care services which provide a break in the caregiving relationship. Clearly, this term must indicate that the care provided by formal services should have a dual focus of (i) facilitating and supporting a respite experience for the carer (as defined and outlined above) and (ii) engaging the PwD in person-centred occupation and activity that is meaningful and beneficial, from their own perspective.

We propose 'restorative care' as a useful alternative to describe the process whereby PwD and their family carers mutually benefit from the experience. This term acknowledges the intricate interdependence involved in the dyadic attachment relationship and suggests the central role that services could play in delivering tailored, personalised interventions and supports to both dyad members in a way that is acceptable to them, and that satisfies individual and dyadic needs. It is through adherence person-centred values that services can deliver the outcomes that matter to both sides of the care relationship.

We postulate that the employment of this term, 'restorative care', is vital to offsetting the limitations that conceptualising respite (either as a service *or* a mental break) as being only for the carer, has put on the aptitude and capacity of formal services to recognise and meet the individual needs of the carer and the PwD over the years. Services must re-evaluate their goals in relation to providing 'respite' and consider that care must be delivered in line with person-centred values for the PwD and the carer.

Conclusion

This analysis has indicated that 'respite' in relation to dementia is still conceptualised as it has been historically understood, i.e. as a service for the carer; one that relieves 'burden' and reduces the strains and stresses of caring. However, there has been a shift more recently towards viewing respite as a psychological outcome for carers, which can be facilitated by the use of formal health and social care services, if the carer perceives that mutual benefit will be obtained from the care provided. That can only be achieved if such care is rooted within personhood and puts the person with dementia at the centre of decision-making. Mutuality depends on the direct engagement of the person with dementia in the process of care. We outline why 'respite', as a concept, is not fit for purpose in this respect and is irreconcilable with the PCC paradigm. We propose 'restorative care' as an alternative term; this can encompass the perspectives of both the carer and the PwD in relation the use of health and social care services that currently aim to provide a break in the caregiving relationship. Furthermore, the use of this term would be helpful for service providers in reimagining, recalibrating and reorganising services to reflect the needs and preferences of PwD and their carers. Future research must explore the perspectives of the PwD specifically, as well as the carer and other key stakeholders (e.g. service providers, healthcare professionals), in relation to service use for the purpose of restorative care. This is necessary to determine what acceptable, appropriate and effective restorative care would look like.

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