

## **Practitioners' understanding of barriers to accessing specialist support by family carers of people with dementia in distress**

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### **Background**

Caring for a family member with dementia who becomes withdrawn, agitated, aggressive, or communicates 'unmet need' through other expressions of distress potentially reduces well-being and increases distress among family carers (Moniz-Cook et al, 2017). Any one of these alone or in combination often adversely affects family relationships (Nogales-González et al, 2015) as well as the quality of life of the person with dementia (Hurt et al, 2008). Umbrella terms for distressing symptoms in dementia, which are often used interchangeably, include 'challenging behaviour' (Moniz-Cook et al, 2017), 'behavioural disturbances' (Abraha et al, 2017), behavioural and psychological symptoms in dementia - BPSD (Feast et al, 2016) or 'non-cognitive symptoms and behaviour that challenges' (NICE, 2010). These expressions of unmet needs affect nearly all people with dementia and/or their carers at some time. When persistent, they are associated with breakdown of care at home and moves to care homes (Gaugler et al, 2010). England's National Dementia Strategy (Department of Health, 2009) recommended increasing community-based personal support, reducing use of antipsychotic medication and exploring alternative approaches to the management of challenging behaviour. In this paper, we use the term 'carers' to refer to 'informal' or family carers (including close neighbours or friends providing

substantial support) or caregivers, also referred to in some situations as 'unpaid carers'.

While challenging behaviour in dementia may be used as an overarching term, experiences vary considerably and it is not always easy to define or assess its impact (Nogales-González, et al, 2015). For example, in family care settings, the most frequent behaviours are not necessarily the most challenging for carers. Indeed carers' own characteristics (independent of dementia severity) or their sense of a declining relationship with their relative can contribute to their troubling feelings about specific aspects of their relatives' behaviours (Fauth et al, 2014; Feast et al, 2016). Emotional responses to, and perceptions of such behaviours vary widely (Morgan et al, 2013), ranging from extreme distress for one carer to another regarding the same behaviour as 'no problem'. While most people are distressed by certain behaviours such as screaming, or behaviour of great intensity, in many cases a family carer's individual characteristics are often as important as the severity of behaviour in determining if, or to what degree, it is perceived as challenging. Other factors contributing to how carers perceive these behaviours include: limited understanding of the changes associated with dementia; a lack of support or coping skills; and influences of pejorative attitudes towards people with dementia. Changes in a person with dementia's behaviour may have a negative effect on their carer's mood (Morgan et al, 2013). In an early example of this, Hinchliffe et al, (1995) found that treatment for family carers who were depressed could change their perception of the behaviour from seemingly 'intolerable' to 'no problem'. Thus, a successful intervention could be one where the behaviour remains unchanged but a care no longer perceives it as a problem or at least not so great a problem. There are promising findings from more

recent studies such as application of the START programme which mitigated depression and anxiety in family carers, although no impact on problematic behaviour was observed (Livingston et al, 2014). The START study demonstrated that psychosocial interventions to promote carer well-being can be cost-effective and sustainable.

However, carers consistently report problems with access to effective dementia services in the United Kingdom (UK). For example, Oyebode, Bradley & Allen (2013) found this to be the case among the 11 carers they interviewed in England; views were similarly expressed in Toot et al.'s (2013) study of 15 carers in South-East England taking part in focus groups and in an interview study of 19 carers conducted in one Scottish locality (Gorska et al. 2013). Problems reported include lack of awareness of services, incorrect or poorly timed information but also absence of services or service inadequacy. While the review by Brodaty et al. (2005) noted that limited take-up of services was not associated with problems of availability or access, and Gorska et al, (2013) observed that it was not clear if problems of access or eligibility criteria were associated with inadequate services, the Alzheimer's Society's DEMHOM study (Quince, 2011, para 3.2) found that half of their respondents (50%; n= 712) reported that they were not getting the support and care they needed.

Functional analysis-orientated psychosocial intervention is a systematic, individually-formulated approach to care that is helpful in managing problematic behavioural symptoms in family care settings (Moniz-Cook et al, 2012). For over a decade it has been accepted as the first line alternative to traditional pharmacological management of behavioural symptoms. For example, the National Institute for Health and Care

Excellence (NICE/SCIE) (2007) recommended that carers should be able to access non-pharmacological, evidence-based interventions to ameliorate the impact of cognitive and non-cognitive symptoms on both the carer and the person with dementia and to meet their health and emotional needs. Such interventions for carers may be delivered by a mental health practitioner or therapist (NICE/SCIE, 2007; Moniz-Cook et al, 2012).

The majority of specialist dementia care for older people living at home or in care homes in England has traditionally been delivered by Community Mental Health Teams for Older People (CMHTs-OP) which are situated in all localities. According to Wilberforce et al (2013), CMHTs-OP are the preferred first tier of specialist psychogeriatric support, and, when compared with single-profession services, these integrated multidisciplinary teams are more effective in improving both decision-making and continuity of care. While their remit, composition and size vary (Verbeek et al, 2017), many of the 376 teams who responded to a national survey (Tucker et al, 2014) reported undertaking some outreach work, albeit mostly informal in nature. Three quarters of these teams offered such outreach support to care homes, half to day centres, and over a third to primary care practices, social services teams, home care providers and general hospitals, respectively. The survey authors noted '*A significant minority of teams expressed concerns about their capacity to provide effective services*' (ibid, p.489).

Within these teams a Community Mental Health Nurse (CMHN) is usually the first point of specialist support for people with dementia and carers. Where CMHNs have been trained to apply interventions with family carers, improved carer well-being and

reductions in challenging behaviour have been observed (Moniz-Cook et al, 2008). However many CMHTs-OP in England no longer provide dedicated dementia-focussed services (Tucker et al, 2014; Wilberforce et al, 2015) and the Alzheimer's Society's DEMHOM survey (Quince, 2011) found that only just under a third (31%) of respondents reported that the person with dementia they were caring for, was receiving or had received visits from a Community Psychiatric Nurse (also referred to as a CMHN).

The present paper reports on part of a series of studies that comprised an applied research programme (Moniz-Cook et al, 2017). Set within routine services and practice in England's NHS CMHTs-OP, the aim of the research programme was to train these mental health practitioners to provide functional analysis-orientated interventions for carers supporting people with dementia who had symptoms of challenging behaviour at home. The purpose of the first phase of the research as discussed in this present paper was to: 1) collect data on the numbers of carers supporting a relative with dementia with distressing behaviour, who were referred to specialist CMHTs-OP by primary care practitioners; and 2) analyse any barriers to access that might affect carers seeking this skilled mental health practitioner support. The full study report is available (Moniz-Cook et al 2017).

## **Methods**

This iterative study was developed inductively, drawing on the evidence from three phases of collecting data from services and stakeholder views and experiences. The original ambition was for a cluster randomised controlled trial of a specific intervention for carers. The feasibility study reported in this present paper was designed to

establish if recruitment of carers and fidelity of intervention delivery were achievable in the NHS across England. Ethical approvals for the study were obtained from the York Research Ethics Committee (REC; reference number 09/H1311/28) and revised during the course of the research. Assurances about confidentiality were provided to study participants all of whom provided informed consent. The first phase of the development study was a survey within seven NHS organisations. This was followed by workshops at five of these seven organisations (NHS Trusts), with further workshops and practitioner interviews undertaken two years later at two NHS organisations. These are outlined in the next three sections.

### **1) The survey**

Thirty-three CMHTs-OP within seven NHS Trusts across England were recruited as study sites following a nationwide call for Trust participation. We aimed to recruit a geographically diverse sample across England, spread across the north, midlands and south of the country, broadly representative of rural and city locations and spanning affluent and deprived areas. All these NHS Trusts had common commissioning specifications to provide support for 'challenging behaviour in dementia' through CMHTs-OP. A minority of these NHS Trusts also had Intensive Home Treatment Teams for older people, as a mechanism whereby newly referred cases were not placed on waiting lists but assessed urgently if they were considered in or 'near' crisis, or eligible for intensive mental health support.

Data were collected about every 'new referral' over a seven-month period in all CMHTs-OP within each of the seven NHS Trusts between 2010 and 2011. These included older people with a non-dementia diagnosis (e.g. depression, psychosis,

personality disorders, alcohol problems, delirium) and older people with a dementia (including those living in care homes and at home). Data were recorded by each CMHT-OP on the 'type of new referral' to the team and the outcome, but patient names or other identifiers were not noted. Decisions were made on 'type of referral' and associated outcome based on the information available from the initial patient referral record and written decisions made at each CMHT-OP's weekly referral meeting. The anonymous records were collected each week and collated by research assistants at each site. Re-referred patients who had received care previously from the CMHT-OP were included as a 'new' referral at the point of data collection, since they had been referred for a new episode of care.

## **2) Workshops**

A first set of workshops at five of the seven NHS Trusts was conducted between March-May 2011, during collation of the emerging survey results across all participating NHS Trusts. (Two of the seven NHS Trusts were in the process of service reorganisation at the time, and could not participate.) These workshops took the format of discussions between small groups to debate organisational pathways of care. Discussions were audio-recorded and notes made by facilitators. The workshops were facilitated by two members of the research team at each of the five NHS organisations. Framework Analysis (Ritchie and Spencer, 1994) was later used to enable *a priori* as well as emergent exploration of the data which focused on debates about where health and care responsibilities for people living at home with dementia-related distressing symptoms might be located.

A sample of experienced mental health practitioners working in Memory Assessment Services and CMHTs-OP was recruited at each NHS organisation to reflect the range of practitioners providing services to people with dementia and their carers. These practitioners included CMHNs, occupational therapists, psychologists, a speech therapist, a physiotherapist, support workers and their managers (n=93), who participated in the workshops that lasted an average of two hours each. First, facilitators outlined the data relating to the type of patient referrals taken from the examination of every new referral. Second, the nature and impact of challenging and distressing behaviour among people with dementia were illustrated by video and audio clips to share agreements of the types of behaviour that was being explored.

For the discussions a semi-structured tailored topic guide was used in which the following question areas were covered:

1. How can specialist mental health practitioners identify people with dementia and distressing or challenging behaviour who are living at home, to provide timely support to prevent escalation of distress?
2. What are the contextual obstacles to providing timely support to people with dementia and distressing or challenging behaviour living at home, and their family carer?
3. How might these be overcome in their local setting?

A second set of workshops was held in 2013, where themes from the first workshops were presented to an invited sample of senior practitioners and managers from two of the initial five NHS organisations and local stakeholders including family carers (n =

69). These organisations were purposively selected for size and location (both were large NHS Trusts, with rural and urban populations, one in the north and one in the south of England, and each with different operational services, depending on arrangements with local funders and other agencies). One NHS Trust had an intensive home treatment team service whose members were also invited to participate. These senior practitioners, from CMHTs-OP, an intensive home treatment team and staff from a specialist 16-bed acute mental health ward for older people with dementia were asked to consider the team's casework over the past eight weeks, in order to describe the needs and circumstances of people living at home with dementia with carers who might benefit from specialist mental health care.

The semi-structured tailored topic guide for this second set of workshops covered the same topics as the earlier workshops. Detailed notes were taken at each workshop as audio-recording was difficult to arrange. These data were used to familiarise and identify a thematic framework (reported below) by five members of the research team.

### **Practitioner interviews**

A sample of nine experienced practitioners who had not participated in either set of workshops was recruited through invitation by the locality study team (a senior clinician and research assistant) from the two NHS Trusts that had participated in the second set of workshops described above. They were interviewed by two psychologists (SW; EM-C) in 2012. Practitioners were invited to specifically discuss their current caseload (not individuals by name) and services that could support skilled support for carers with a relative with behavioural or distressing symptoms, including obstacles to access and provision. The participants were from: early

Memory Assessment Services (n=2), CMHTs-OP (n=4); and single participants from three other services: Admiral Nursing (community mental health nurses providing support specifically to people with dementia and their carers, who work in some localities in England) (n=1); Day care (n=1); and Dementia in-reach care home services (n= 1).

Detailed notes were taken from the discussions about the illustrative anonymised cases described in the interviews, which were later charted across the themes extracted at the workshops. Themes were refined to combine data from the workshops and the interviews. Finally, data from all sources were synthesised through mapping the emergent themes along a service organisation axis and practitioners' views on the barriers to accessing skilled behaviour management support for people with challenging behaviours living at home with support from a family carer.

## **Findings**

### **Referral data**

Table 1 shows the groupings of 5,360 new referrals in the 33 participating CMHTs-OP in each of the seven NHS Trusts (data were collected over different intervals, ranging from 14-46 weeks, across the teams). All CMHTs-OP in these NHS Trusts contained core members consisting of: a psychiatrist, a group of CMHNs of differing grades, and support staff supervised by CMHNs with additional 'sessional access' to occupational therapists, psychologists and social workers. CMHTs-OP procedures required a CMHN to scrutinise a new referral, make an initial telephone call if more information was required, and if needed to discuss the referral at a weekly team meeting with the

psychiatrist, before accepting the case. Once accepted, the person and carer would usually be offered assessment in their own home, or at the team office.

One-quarter (25.8%) of new cases, that is, 1385 people referred for specialist mental health care in this period, were not accepted by the CMHTs-OP. The highest numbers of new referrals to the teams during this period were for older people who did not have dementia-related needs (37%) and a further substantial group (22%) were living in care homes. Only just over eight per cent of referrals accepted by the teams concerned an older person with dementia who was being supported by a family carer at home.

Table 1 about here

**Table 1: New Referrals to 33 CMHTs-OP in 7 NHS Trusts (n=5360) over 7 month period**

	N	%
Taken on - Non-dementia diagnosis <sup>a</sup>	1985	37.0
Dementia: Referred to other services (see table 2)	1385	25.8
Taken on - Dementia: In a care home <sup>b</sup>	1190	22.0
Taken on - Dementia: At home with carer	452	8.4
Taken on - Dementia: No family carer	307	5.7
Dementia: Died or admitted to hospital before seen	41	0.8
Total	5360	

<sup>a</sup> includes functional illness (n=1839), non-dementia neurological problems, delirium, physical health, alcohol related, learning disability and non-dementia disorders not specified; <sup>b</sup> includes respite care (n=34)

Of the 1385 referrals judged as being outside the operating remit of the CMHTs-OP the majority (61.5%) had been subsequently referred to a Diagnostic Memory Assessment Service (see Table 2) and those in the next group (17%) were either returned to the care of their GP (general practitioner) or signposted to another primary care service. A further group (nearly 10%) was transferred to mental health teams for working age people, or for urgent intensive support, or, if diagnostic decisions were seen a 'complex', they were referred to another specialist (psychologist, psychiatrist or neurologist). Some of those with a diagnosis of dementia were 'signposted' or referred to a local Alzheimer's Society group for general support.

Table 2 about here

**Table 2: Referrals to other services (N=1385)**

	N	%
Early Memory Assessment Services/clinics <sup>a</sup>	852	61.5
Other mental health related specialists/voluntary sector <sup>b</sup>	138	9.96
Hospital services (acute or mental health)	53	3.83
General practitioners; other health care professionals <sup>c</sup>	235	17.0
Type of service not specified	107	7.73
Total	1385	

<sup>a</sup> includes discrete memory assessment services and those provided within CMHTs-OP, <sup>b</sup> includes referrals returned to general practitioners/other primary care services <sup>c</sup>

includes adult mental health teams, intensive treatment teams, psychiatry, psychology, neurology or signposted to the Alzheimer's Society.

In summary, while CMHTs-OP had been initially established as specialist services for people with dementia and their carers, these data demonstrate that the majority of people with dementia referred to them by their GP for support with distressing symptoms were not accepted by the team but were instead referred on to other services, or returned to their GP.

### **Barriers to access**

In this section we present findings from our engagements with practitioners (workshops and individual practitioner interviews) focussing on the implications for carers. While there were some differences between the workshop and interviews, the key themes common to both were: 1) practitioners' limited recognition overall of the significant problems facing family carers supporting a relative whose symptoms give rise to distress; 2) lack of professional tools and systems to screen and assess for potential problems associated with the symptoms of dementia; 3) lack of confidence that relevant interventions to prevent escalation of problems were part of their remit and skill-set; and 4) other competing priorities.

In the first set of workshops it emerged that some practitioners had limited knowledge about the prevalence and impact of distressing or challenging symptoms among people with dementia living at home with carers; or how carers might be supported by local NHS community mental health services. A small minority considered that problems might lie in the strained relationship between the carer and the person with

dementia, rather than symptoms being very hard to manage, and some suggested that the carer 'was the problem'. Some practitioners also voiced surprise that quite low scores on standardised challenging behaviour measurement scales that can be used in routine practice (Moniz-Cook et al, 2008; b) indicated severe problems. Some thought it was necessary for things to 'get worse' before specialist interventions could be applied. When used, such interventions did not always result in help with resolving symptoms but instead involved help to separate the carer and the person with dementia by means of the latter moving to a care home. However, many practitioners were understanding and empathic about the problems facing carers and felt that their service was missing potential cases where symptoms were escalating. Some considered that carers might under-report the nature and extent of their problems, and thought that local service protocols lacked a structured assessment tool that might help practitioners to explore difficulties associated with dementia, so that tailored support could be assembled. Passing on such problems to other services was commonly reported because of these understandings and of competing service demands. The outcomes of 'signposting' were not generally known and the action of 'signposting' was referred to by one as rather like the passing of carers into a 'black hole'. Neither resources nor training were considered sufficient. As with the larger workshops, the practice accounts during these interviews suggested that taking on these referrals was seldom a key priority for the CMHTs-OP unless a service-determined level of risk had been breached.

Specific obstacles to improving access to CMHTs-OP for those carers supporting people with dementia and distressing or challenging behaviour, expressed in the interviews, are summarised as:

- Misunderstanding of the legitimacy of distress in carers and people with dementia about behaviours that are hard to manage
- Lack of recognition that early intervention does not just mean early diagnosis, but timely intervention throughout the sometimes unpredictable dementia trajectory
- Limited understanding of the potential of psychosocial interventions to help reduce the impact of distressing symptoms in dementia
- Lack of skills in delivering interventions to reduce or prevent distressing symptoms in dementia
- Limited resource/signposting options
- Limited adaptation of service configurations and models
- Problems associated with balancing attention and resources towards those with distressing symptoms of dementia in the early stages, with those to promote 'living well' with dementia.

Thus, despite their general sympathy for family carers, their understanding that managing behavioural symptoms of dementia was hard for carers, and their knowledge that these problems could escalate, practitioners were not always able to respond effectively or consider where they might effectively deliver psychosocial interventions effectively. Next we consider these findings' implications for family carers, practitioners and researchers.

## **Discussion**

The survey and the interviews were designed to inform the proposed main intervention (see Moniz-Cook et al, 2017). This present paper has highlight the need

to take a system-wide view of access problems and to clearly distinguish particular care-related experiences of distressing symptoms of dementia in family relationships and households, from other settings such as care homes and hospital. The findings from the case-audit suggested that our proposed cluster randomised trial of an intervention as envisaged was not feasible, due to difficult in recruiting sufficient family carers who were receiving support for managing distressing symptoms from specialists in CMHTs-OP. We therefore did not proceed with a trial.

The quantitative evidence from the referral records found that referrals to CMHTs-OP for the management of distressing and challenging symptoms in dementia were not generally accepted. The qualitative opinions and views collected from interviews and workshop discussions highlighted the following reasons for this: competing priorities and lack of capacity to deliver effective support; limited practitioner skills to recognise the significant problems encountered by carers arising from their relative's distressing symptoms; and poor confidence that interventions to prevent escalation of problems were part of their remit and skill-set. These findings will be considered next.

The referral audit highlighted sub-optimal practitioner support for family carers to help them with the management of challenging or distressing symptoms in dementia. In keeping with studies of CMHTs-OP in England, these findings confirm that the proportion of people with dementia on their caseloads may have declined as it increased in respect of people with functional mental health problems (Tucker et al, 2014). Practitioners seemed to have an generalised appreciation of the problems faced by carers' but, in practice, severity and risk assessments or screenings did not reach levels at which attention to the situation of family carers would be prioritised by

the team. Neither did recognition of an opportunity to improve outcomes for family carers through CMHTs-OP practitioners' advice, treatment or therapeutic programmes of care, result in prioritisation. Acceptance of referrals was based on perceived risk and severity, often thought to be higher in care homes than in home care settings, and not on the capacity to improve outcomes by proactive intervention.

The analysis of data from stakeholders and practitioners suggesting that limited practitioner skills and confidence that interventions to prevent escalation of problems were part of their remit, may be explained by the shift in dementia-specific care towards the different skills-set needed to support those with functional mental health problems. This may have undermined continued professional development and knowledge about ways to support carers and decreased practice experience with a range of case presentations. This conclusion is further supported by our data analysing CMHTs-OP support to carers, where no reduction in distressing symptoms over a six-month period occurred (Moniz-Cook et al, 2017 pp 115), despite previous research (Moniz-Cook et al, 2008 a;) demonstrating that this was possible.

Discussions with practitioners and managers during the workshops also confirmed findings from other studies that CMHTs-OP manage substantial caseloads of people with dementia in care homes and are called upon to work with older people living alone or with non-cognitive problems (Challis et al, 2014). Understandings of a dementia 'pathway' appeared to focus on responding to crisis and facilitating transfer to care homes rather than how to support carers with significant problems such as repeated questioning, disorientation, depression and apathy. While not generally offering 'nothing', further referrals or 'signposting' were seen as sufficient. Such a

finding offers important messages about the nature of 'signposting' or other advisory services if carers are being 'successfully' referred, only to be deemed as not 'eligible' or not a 'priority' for the receiving service. In dementia care there are similarities with the 'information merry go-round' identified as occurring in respect of carers' enquiries about planning for loss of capacity to make decisions where they got passed between agencies (Manthorpe, Samsi and Rapaport 2012).

Relevant to the timing of the workshops and interviews (2011-13) were changes in the NHS and local authorities in England especially associated with reactions to new funding arrangements. These were a common theme among the overarching reasons as to why individually-formulated targeted interventions to support carers could not be accessed or delivered. Commissioning activity entailed prioritisation of new service models to respond to national imperatives, such as England's National Dementia Strategy's (Department of Health, 2009) emphasis on early diagnosis and reductions in the use of antipsychotic medications for people with dementia. In some of the participating NHS Trusts there were additional local reorganisations. Other broader contextual factors concerned planning around implementation of the controversial Health and Social Care Act 2012, which redefined the roles of GPs in England, and the financial pressures affecting local authorities which necessitated revision or cessation of their contracts with the third or 'not for profit' sector. While these contexts are relevant to the locations of this study, they highlight the need for researchers everywhere to be mindful of 'real world' settings, service changes and the need for flexibility in data collection and timings.

### **Implications for carers**

For carers there are important points arising from this developmental research process which have implications beyond the findings of the main study (Moniz-Cook et al, 2017). Carers may wish to draw on some of our findings when engaging with NHS commissioners and participating in service consultations or with their equivalents internationally. While people with dementia and their carers should be able to access effective psychosocial interventions to help manage significant distressing symptoms in a timely way to minimise escalation of these and reduce other adverse effects on quality of life and relationships, simply stating this is unlikely to improve access and service acceptance. The gaps in provision identified here mean that some carers are continuing to experience avoidable distress. It is of course recognised that shifting skilled support to family carers, from care home residents for example, would not be ethical if other people were consequently at risk of ill-being, but 'whole-system' research such as this is yet to be conducted. Our findings about the influence of contextual systemic factors on the delivery of evidence-based interventions in dementia may be relevant to other national contexts. For example, a review of high quality evidence for individually tailored interventions for challenging behaviour in dementia noted that the majority (13 from the 18 studies) occurred in family settings (Moniz-Cook et al, 2012). Yet there are few international examples of wide application of such approaches to support family carers in the management of challenging or distressing behaviour among people with dementia at home (Holle et al, 2016).

### **Implications for practice**

For practitioners working with people with dementia in primary care or social care settings our findings suggest that they are not failing to refer people with dementia

and carers to specialist services such as CMHTs-OP, but that these referrals are not generally accepted. Thus, the question is not one of carers' problems being overlooked or unrecognised by all. Instead the pathway expected by primary care practitioners of access to secondary mental health services support (CMHT-OP practitioners) seems often to end with their referrals being further passed on to other agencies, such as memory clinics who are generally only able to offer limited post-diagnostic support or to social care services who may only be able to offer practical help for high level needs, or to make yet a further referral to the not-for-profit sector that may not be equipped to offer skilled individually-formulated behaviour management support.

Many practitioners working within the CMHTs-OP participating in this study seemed aware of the problems facing carers of people with dementia whose symptoms are distressing. Their accounts of practice, however, conveyed a sense of the work pressures that led to a recent judgement that UK services and support for people with dementia and their families are inadequate overall (Knapp et al 2007). Such pressures are not confined to the UK but are likely to exist in other contexts.

It would be naïve to assume that previous efforts to shift resources in dementia care had been easy to implement and that simply pointing out that carers are not getting access to skilled help with behavioural problems will improve matters. Banerjee's (2009) report on the risks from the use of antipsychotic medication for people with dementia, for example, drew attention to the need to offer prompt non-pharmacological management of distressing and challenging symptoms to people with dementia living at home and their carers. He outlined a range of options drawing

on preventative approaches such as education and skills building among carers, through to signposting people to specialist CMHTs-OP or other programmes that might be able to deliver a range of specific therapeutic and psychosocial interventions. Banerjee anticipated a significant immediate role for CMHTs-OP, in liaison with primary care, to help reduce antipsychotic prescribing for people with dementia in the community and to deliver alternative interventions. The survey, workshops and interviews reported in this paper suggest that, in practice, carers were not benefitting from easy access to CMHTs-OP services that would lead to improved outcomes. This gap in provision may potentially leave people with dementia and their carers 'in the lurch' – managing distressing or challenging symptoms as far as they can without support from medication or psychosocial interventions.

### **Implications for applied health and social care research**

There are limitations to this developmental approach to research in terms of the time needed to discuss the nature of the problem or research question and to analyse initial findings. Since this first phase of the research programme took place there have been further organisational changes in the study areas and so referral outcomes to CMHTs-OP may have changed since our data collection. However, involving stakeholders early in the research process in the development and delivery of any complex intervention is an important strategy for the conduct of resource intensive research (Vernooij-Dassen and Moniz-Cook, 2012). When later considering the planned intervention study (Moniz-Cook et al, 2017) it proved particularly relevant to have heard the views of frontline practitioners about the impact of contemporary service changes and multiple pressures, and that skilled behaviour management

programmes and other carer support did not feature as a mainstream part of their practice.

## **Conclusion**

There are multi-faceted reasons why practitioners working in specialist mental health services for older people CMHTs-OP in England do not generally offer support to family carers who support people with significant challenging or distressing symptoms associated with dementia. We identified some lack of knowledge about the negative impacts of such symptoms on carers and their relationship with their relative; and a lack of confidence about the effectiveness of professional interventions. Many practitioners and managers thought that they were mostly responding to referrals people with dementia, but in reality this was only a very small proportion of their work. At service or team level there were other competing priorities associated with providing support to large numbers of older people with functional mental health problems, leading to lack of capacity to take on further cases, especially those with dementia living with carers. We found substantial evidence of this. At the system level, the shift from dementia-focussed CMHTs-OP towards those with functional mental health problems limited dementia-focussed resources and contributed to an expectation that carers will cope or not make great complaint. Our study concluded that access problems to specialist support with dementia-related symptoms that carers find most difficult to manage should be considered as systemic rather than professional failings. While professional practice may need to be improved, they also need capacity to take on the range of cases that present with significant need for specialist support, within defined dementia service pathways of care that also facilitate development of practitioner skills-sets.

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