

QUALITATIVE PAPERS

‘Working away in that Grey Area...’ A qualitative exploration of the challenges general practitioners experience when managing behavioural and psychological symptoms of dementia

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Abstract

Background: general practitioners (GPs) have identified the management of behavioural and psychological symptoms of dementia (BPSD) as a particularly challenging aspect of dementia care. However, there is a paucity of research on why GPs find BPSD challenging and how this influences the care they offer to their patients with dementia.

Objectives: to establish the challenges GPs experience when managing BPSD; to explore how these challenges influence GPs’ management decisions; and to identify strategies for overcoming these challenges.

Design: qualitative study of GPs experiences of managing BPSD.

Methods: semi-structured interviews were conducted with 16 GPs in the Republic of Ireland. GPs were purposively recruited to include participants with differing levels of experience caring for people with BPSD in nursing homes and in community settings to provide maximum diversity of views. Interviews were analysed thematically.

Results: three main challenges of managing BPSD were identified; lack of clinical guidance, stretched resources and difficulties managing expectations. The lack of relevant clinical guidance available affected GPs’ confidence when managing BPSD. In the absence of appropriate resources GPs felt reliant upon sedative medications. GPs believed their advocacy role was further compromised by the difficulties they experienced managing expectations of family caregivers and nursing home staff.

Conclusions: this study helps to explain the apparent discrepancy between best practice recommendations in BPSD and real-life practice. It will be used to inform the design of an intervention to support the management of BPSD in general practice.

Keywords: *general practitioners (GPs), dementia, behavioural and psychological symptoms (BPSD), qualitative, neuropsychiatric symptoms*

Behavioural and psychological symptoms of dementia (BPSD) is a term that encompasses a wide range of behaviours and symptoms that affect the majority of people with dementia at some point in their illness [1]. BPSD includes behaviours and symptoms such as agitation, aggression, wandering, depression and sleep disturbance. The presence of BPSD results in an increased risk of admission to long-term

care facilities [2], longer in-patient hospital stays [3] and is a major contributor to caregiver stress and depression, even more significant than cognitive decline [4].

The management of BPSD is complex as there are many contributing factors including unmet care needs, underlying acute medical conditions and environmental triggers [5]. In addition to the complexities in assessment, effective treatments

are limited. Best practice recommendations encourage the use of individualised non-pharmacological management strategies such as music therapy [6], however, these are often difficult to translate into implementable management strategies. Psychotropic medications continue to be used to manage BPSD in both residential and community settings [7, 8], despite their well-known risk to people with dementia [9, 10] and calls for action to reduce antipsychotic prescribing [11].

General practitioners (GPs) play a pivotal role in managing BPSD, however, previous quantitative research has found they lack confidence in this area [12–14]. In one survey most GPs acknowledged the importance of non-pharmacological approaches to managing BPSD, however, they found non-pharmacological difficult to implement in practice and reported using pharmacological management strategies instead [14]. Furthermore, practice constraints such as insufficient time, poor connections with community services and lack of interdisciplinary teams can act as barriers to GPs caring for people with BPSD [15]. Interventions are needed to support GPs in their management of BPSD. However, we are unaware of any such interventions. Recent research has identified education in BPSD as a priority for GPs [16] but we do not have a good understanding of how GPs currently manage BPSD and the root causes of their lack of confidence. An important first step in intervention design is to establish a thorough understanding of existing behaviour [17, 18]. However, GPs' experiences of managing BPSD have not been previously researched. The aim of this study is to identify the challenges GPs experience when managing people with BPSD and to explore how these challenges influence their management decisions. Potential strategies that GPs use to overcome these challenges will also be identified. The findings of this study will be used to inform the design of an intervention to improve the management of BPSD in general practice.

Methods

Semi-structured interviews were conducted with GPs to explore the challenges they experience managing BPSD. Ethical approval was granted by the Social Research Ethics Committee in University College Cork (2016-098).

Sampling and recruitment

Given the high prevalence of BPSD in residential care settings [19] initial sampling focused on GPs with a nursing home commitment. Twenty-three nursing homes in the southern region of the Republic of Ireland were contacted and the GP who attended the nursing home was identified. From this population a sample was purposively selected to include GPs with differing practice locations (urban/rural), years in practice and dementia workload with the goal of achieving maximum variation. The recruitment process occurred concurrently with, and in response to, the data analysis. During the analysis process it was identified that GPs with no nursing home commitment may have different experiences of managing BPSD, consequently, these GPs

were also invited to participate. Using the same criteria as above this sample of GPs was purposively recruited by identifying GPs in a national medical directory.

GPs were contacted by letter and invited to participate. One week later the GPs were contacted by telephone. If they agreed to participate a further information sheet was forwarded and an interview was scheduled. Criteria for reporting qualitative research as described in the COREQ guidance were followed [20].

Semi-structured interview process

The interviews were conducted in the GP's surgery or in an office in University College Cork between October 2016 and April 2017. The lead author (AJ), a GP with an interest in dementia, conducted all of the interviews. There was one telephone interview. Written informed consent was obtained prior to each interview. All of the interviews, bar one, were audio-recorded and transcribed verbatim. The one interview that was not recorded, at the request of the participating GP, was typed up from field notes. The lead author (AJ) de-identified the transcripts and assigned the transcripts anonymised codes (e.g. GP01) to protect the identity of the participants. Furthermore, to ensure confidentiality identifiable information was removed from the quotes selected. NVivo 11 software was used to manage the data. The topic guide was informed by a literature review of GPs' knowledge of and attitudes towards BPSD and the professional experiences of three of the authors (AJ, TF, CB) all of whom are practising GPs. The literature review identified issues such as self-confidence which were used as prompts during the interview. The topic guide was iteratively developed through a process of consensus with the multidisciplinary research team which included expertise in general practice (AJ, TF, CB), dementia in primary care (TF, AJ), public health and health services research (JB, SMCH). The topic guide was then piloted with a convenience sample of two GPs. Minor amendments were made to the script sheet and use of probes as a result of this piloting. (See Appendix 1 for topic guide.) Throughout the interviews participants were encouraged to discuss their own clinical cases.

Analysis

Data analysis followed the principles of thematic analysis as outlined by Braun and Clarke [21]. Data analysis was performed concurrently with data collection, allowing emerging themes to be further explored in subsequent interviews. An extensive familiarisation process was conducted by two researchers (AJ, TF) who read and re-read all transcripts. The lead author (AJ) open coded all the transcripts. The second researcher (TF) independently open coded a subset of the interviews (>50% of the transcripts) that were purposively selected to ensure a wide range of years of experience and dementia workload. Regular meetings were held throughout the interview process to discuss emerging themes and to examine convergence and divergence of the researchers' findings. Any uncertainties were discussed with

a third researcher (SMcH) who also independently coded two interviews that were purposively selected to include participants with different dementia workloads.

Results

Twenty-four GPs were invited to participate in a semi-structured interview, 16 of whom agreed to participate. The reason for non-participation was documented where possible; the main reason given for non-participation was lack of time. The characteristics of participants are shown in Table 1. Overall, conceptual data saturation was reached after 13 interviews. After this three more interviews were conducted during which no new data emerged, confirming data saturation [22]. Interviews were, on average, 37 min in duration (range 20–63 min).

GPs’ experiences of managing dementia

The complexity of dementia care was highlighted by many of the participants. Overall their attitude to dementia care, and in particular, BPSD, was pessimistic. It was perceived by many to be an ‘an unsolvable problem’.

I think, what is the answer to really challenging behaviour associated with dementia in the community? That’s not just something that I am missing, it is something that we are all missing in this society GP_02

Nearly all the participants struggled at a professional, and sometimes at a personal level, with what they saw as the limited treatment options available. Rather than deciding on the ‘best’ treatment option, they felt they were merely making a decision on whether or not to sedate.

It is awful to watch somebody who has dementia and it seems to be awful to experience dementia so the temptation is to just sedate people through that

Table 1. Characteristics of participants

	Participants, n (%)
Length qualified	
<10 years	4 (25)
10–19 years	7 (44)
>20 years	5 (31)
Nursing home commitment	
Attends Weekly	8 (50)
Attends Monthly	3 (19)
No formal Nursing Home commitment	5 (31)
Practice location	
Urban	6 (37)
Rural	3 (19)
Mixed	7 (44)
Type of practice	
Small (1–3 GPs)	7 (44)
Large (>3 GPs)	9 (56)
Sex	
Male	8 (50)
Female	8 (50)

process and it is hard to decide. When you step back and think about that it seems awful that you just sedate them through this end part of their lives. GP_05

In the context of this experience three main challenges of managing BPSD were identified.

- (1) Lack of clinical guidance
- (2) Stretched resources
- (3) Conflicting expectations

The impact of each challenge on the GP’s management decision was identified. Factors identified by GPs as helpful in overcoming the challenges of managing BPSD were also established (Table 2).

Challenges of managing BPSD

Lack of clinical guidance

Assessment and management of BPSD was seen as a clinically complex area. The lack of clinical guidance, both in terms of GP-specific guidelines and access to clinical advice, was identified as a challenge. Thus, the management of behavioural and psychological symptoms was seen as a ‘grey area’.

In the absence of what the GPs considered to be implementable guidelines for the management of BPSD they felt they were often making decisions in a vacuum. While accepting that the evidence for the various pharmacological options was limited, participants wanted clarity on what medications were appropriate or not.

I think there is probably no magic solution to this but I think a clear algorithm of medications that are appropriate [is needed]. I think [it] would be the most practical thing... maybe they do not have a massive amounts of evidence but GPs, they would feel they need something in their armoury. GP_05

The lack of available guidelines, in particular pharmacological guidelines, meant that prescribing decisions were primarily informed by the GPs own personal beliefs about the drug. These beliefs were shaped by their previous experience of prescribing the drug. Experience was often viewed as being superior to knowledge acquired through formal learning.

In my experience I have learned on the job, it’s not that I do extensive reading, it’s not that I go to a lot of meetings... It’s very easy for me because it’s intuitive – I do it all the time. GP_04

In addition to professional experience, personal experience of having a family member with dementia was identified by several GPs as being a very valuable source of knowledge.

While many participants found the lack of guidelines challenging, others seemed quite content to base their decisions on their own experience rather than evidence and felt this was an inevitable part of general practice.

A lot of what we do on a day-to-day basis isn’t written in any journal, you know, while you try to be evidence based, a lot of it is from experience. GP_10

Although most participants wanted guidelines in BPSD, some participants argued that having a guideline in this area may not be appropriate. As they saw it, there was no ‘one-size fits all’ solution to the problem.

I just think that it is such a variable-like hypertension is hypertension and hypertension it isn't really, you know. I think the problem with dementia is that it affects everybody completely differently. GP_15

As well as prescribing dilemmas participants frequently spoke about the difficulties associated with assessing for potentially reversible causes of BPSD, such as pain. Several participants wanted clinical guidance on how to better assess for alternative causes of these behaviours.

In addition to lack of guidelines many participants also experienced difficulty accessing clinical advice from secondary care. Some participants were uncertain about what service to access. They found the lack of clear referral pathways to secondary care challenging.

[If] you need to talk to someone about a chest pain well you clearly know who to go to whereas it is not as clear here I think. GP_01

There were some suggestions that the lack of a GP expert in the area of dementia meant that they lacked the support

of a colleague with a special interest in the area. As a result, although colleagues were mentioned as important sources of emotional support, other GPs were not usually considered as sources of clinical support.

Some participants described how they relied on personal contacts to access advice and reassurance from secondary care colleagues.

You know, when you just want to ask a simple straight forward question but it isn't easy to access people, you know... I probably call in favours... GP_10 [GP with no nursing home commitment]

This view was usually expressed by GPs who had no nursing home commitment. In contrast, where the participating GP had a nursing home commitment there was often an established relationship with either a geriatrician, or old age psychiatrist who attended that nursing home. This relationship gave GPs what they sought most from consultant colleagues- reassurance.

Neither of them mind me calling them directly on their mobiles, they are very very accessible... just the reassurance that you are probably doing things okay, you know. GP_09 [GP who attends several nursing homes]

The challenge of lack of guidance impacted on their management (Figure 1).

Table 2. The challenges of BPSD, how they impact on the GP's decision making and what factors help GPs to overcome these challenges

Challenge	⇒	Impact of challenge on management of BPSD	Factors that helped overcome this challenge
Lack of clinical guidance - Guidelines - Access to expert advice	⇒	Decreased physician confidence	Experience of managing BPSD Ability to utilise personal contact to access experts
Stretched resources	⇒	Decreased ability to recommend non-pharmacological strategies	Relationships with community-based allied health care professionals
Conflicting expectations - Families - Nursing Staff	⇒	Increased pressure to prescribe	Having family on-board Continuity of care leading to good working relationships

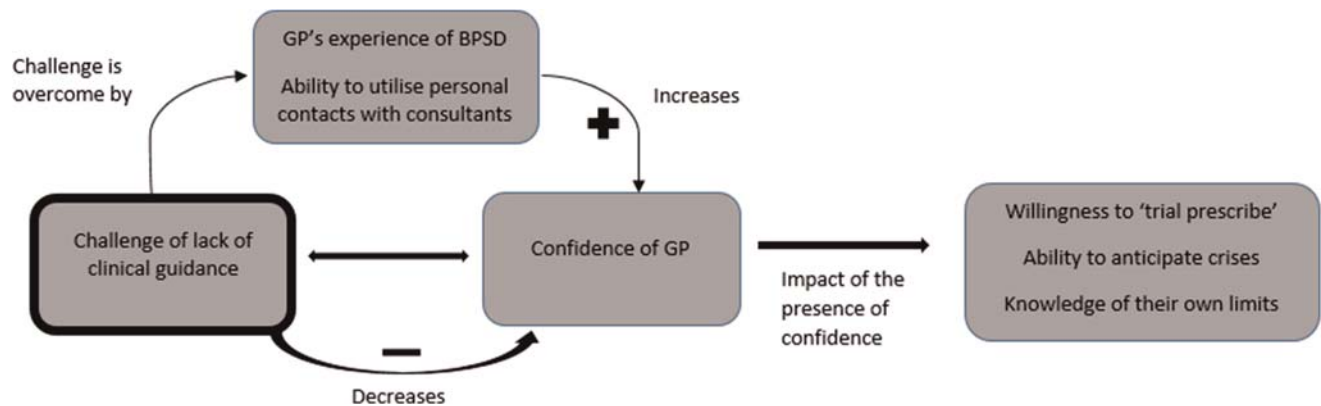


Figure 1. The challenge and impact of lack of clinical guidance

The challenges general practitioners experience managing BPSD

The participants who had significant experience of managing dementia and who were supported by access to consultant advice appeared to have more confidence in managing BPSD. This confidence influenced their management, making them more willing to engage in trial prescribing, more cognisant of avoiding crisis presentations and more aware of their own limits.

What I've learnt, that lingo from the psychogeriatricians, is that you 'give it as a trial' and sometimes it's absolutely bingo and sometimes it bounces off and you move off it pretty quickly and try the next one. GP_04 [GP with large nursing home commitment]

However, this confidence did not seem to extend to non-pharmacological management strategies. Even the GPs with extensive professional dementia experience often lacked confidence in recommending non-pharmacological strategies to family carers. Some participants either underestimated, or were unaware of, advice that they could provide to families of people living with dementia in the community. Other GPs did not think it was their role to give advice on non-pharmacological strategies. They felt they lacked the time and the skills to do this. However, the majority felt that it was their role to refer a patient to the relevant person who could provide this advice.

I mightn't have the skills myself but I would be able to refer them to people who would have the skills. GP_15

In general, GPs who had personal experience of dementia strongly advocated for non-pharmacological strategies and were more confident in giving non-pharmacological advice. They had little faith in the role of medications for BPSD beyond its role to sedate. They actively sought to identify and manage carer burden.

Putting signs up everywhere and all these small things that actually to people who are living it day to day probably make a big difference.... I don't personally think this is a problem that is going to be solved by medication. This patient has dementia. This is part of the illness. Unless you just sedate them all to the point where they are sitting asleep all day – which with having a Dad with dementia you would sometimes have to wonder would that just be easier. GP_05

Stretched resources

Participants found it difficult to recommend non-pharmacological strategies when the appropriate resources were not in place to support these strategies.

You would like to be able to say 'I think this patient will benefit from art or music therapy'. You can suggest those but it might be easier to see those happen if there was a primary care element that was providing them. GP_05

In particular, the absence of sufficient community-based resources, such as adequate home-help hours, were frequently mentioned as a barrier to providing optimal care in the community.

There isn't enough home help anyway ... If he had more support at home he could stay at home and he would love to stay at home but he can't. GP_14

Resources available depended upon whether the GP was supported by a fully functioning primary care team and on the extent of voluntary support agencies in the area. Availability of resources was not related to the size or setting of the GP practice. Participants felt the challenge presented by the inadequacy of resources was outside of their control, describing how this challenge stemmed from government policy or from nursing home management decisions. Good working relationships with allied health care professionals helped participants to overcome this challenge. However, several participants reiterated that, although helpful, good relationships alone could not overcome the challenge posed by limited resources.

Resource limitations in nursing homes also impacted on GPs' decision making as it reduced their management choices. For example, several participants reported that low staffing levels acted as a barrier to recommending labour-intensive non-pharmacological strategies.

To be honest it is kind of awkward because I am not going to be the one doing the work and I am asking people who are working very hard and are very stretched. GP_03

Many participants described being unable to access resource-intensive management strategies, such as one-to-one nursing care, when needed. This, in turn, resulted in increased prescribing of sedative medication.

The only thing that would work is if somebody stayed talking to her continuously. Which wasn't practical so we tried every pharmacological intervention that was possible. Eventually she got the ultimate cure, a PE [pulmonary embolism] which was, unfortunately, I think the only thing that gave her relief. GP_13

Conflicting expectations

Tension arose when the family had expectations, deemed unreasonable by the GP, of what the GP could do to improve these behaviours.

It's their children that are very difficult, you know, very demanding, expecting us to provide a lot of stuff that we just can't. GP_14

The expectations of the family at times influenced the GP's decision to prescribe.

I feel you are just prescribing things to keep the family happy because they are at their wits end with it. GP_06

Having the family 'on-board' with the management plan helped GPs overcome this challenge. While different strategies were employed to engage families, most focused on improving communication with family members.

So I don't interact with them on the phone now anymore. I need to see them in front of me because I need to get a better feel for what they understand that I am trying to do, or not trying to do. GP_15

Managing the expectations of nursing home staff was also identified by many participants as a challenge. Some participants described how they struggled to maintain their advocacy role for their patients in a nursing home setting.

From a nursing home point of view patients that sleep through the night are the easiest patients to manage... and I think that if patients want to be night owls and stay up late and sleep in that they should be allowed to do that, if that is their own natural way. GP_03

As a result of these conflicting priorities many GPs described feeling pressurised to prescribe sedative medication. Poor pathways of communication between the general practitioner and the nursing staff further exacerbated the conflict caused by these competing priorities.

... but the Matron is standing over you saying chart it down PRN [as required] and you are saying 'well are they constipated?' 'I don't know, well we have to have to go and ask Mary. Jane will you go and find Mary to ask her.' And then she would say 'oh I wasn't looking after her last night' and twenty minutes later you're like 'oh God okay Seroquel'. GP_05

In situations where there was a long-standing relationship of trust between the nursing home staff and the GP their priorities were more aligned and there was consequently less pressure. Consistency of care was considered an important factor to building this relationship of trust. Structured visits were seen to facilitate the provision of continuity of care and led to good communication channels between the GP and nurses.

I listen to them because I trust them. I trust the nursing staff. GP_11

In addition to the expectation of family members and staff in nursing homes, two participants commented on how they felt an expectation from consultant colleagues to follow advice given. They described feeling 'compelled' to follow advice even if it conflicted with their own views on what was best for the patient.

If you ask for a review and you are given a review and someone has prescribed something. You feel compelled to go with that then. You know... it is very hard to call them back a second time if you don't take their opinion on the first occasion. GP_12

However, this view was not held by the majority of participants who felt that consultant colleagues valued their opinion.

Discussion

The lack of optimism towards the management of BPSD was pervasive. The challenges associated with BPSD were viewed

by some participants as insurmountable and outside of the GP's control. Many participating GPs struggled at an ethical level with the decision to prescribe potentially harmful sedative medication but felt they had little else to offer. Overall, GPs felt that when managing people with BPSD their role as an advocate for their patient was often compromised. What was best for the person with dementia was complicated by competing expectations of family caregivers and the conflicting priorities of nursing home staff. In the absence of appropriate resources for non-pharmacological strategies and in the face of such pressure, GPs felt they had no viable alternatives to sedative medications. In addition to prescribing pressures and resource constraints, GPs were further challenged by the lack of appropriate clinical guidance in the area.

The GP's own experience with a drug emerged as the critical factor that influenced their prescribing decisions. In general practice the practitioner's previous experience with the drug plays an important role in prescribing decisions [23]. It is possible that the lone-working nature of general practice means that GPs are more likely to rely on and trust their own experiences. However, previous qualitative research that explored old age psychiatrists' prescribing decisions in BPSD also found that in most cases choice of medication was based on familiarity and past experience with a drug [24]. This suggests that, in BPSD, the importance of previous experience with a drug when making prescribing decisions might be a reflection of the lack of robust evidence for prescribing in this area rather than particular professional characteristics. In our study GPs' experience of managing BPSD increased their knowledge which subsequently led to greater confidence (see Figure 1). This study builds on existing literature that demonstrated that GPs lack confidence in managing BPSD [12–14] and extends our understanding by explaining the factors that affect GPs confidence – namely experience and access to clinical guidance. This study goes further by exploring the impact that this confidence has on their management of BPSD. Confidence allowed GPs to engage in trial prescribing, gave them an awareness of their own limits and enhanced their ability to anticipate potential crises. This finding is supported by existing research suggesting that confidence in dementia care has the potential to positively influence practitioner behaviour [25].

GPs reported that the paucity of resources made the implementation of non-pharmacological strategies unfeasible and increased the prescribing of sedative medication. This is supported by previous research that has identified the challenge resource constraints creates for GPs managing BPSD [15] and research that has recognised the influence of resource inadequacies on GPs' prescribing of antipsychotics in dementia [26]. Resource constraints clearly act as a barrier to non-pharmacological strategies. However, in our study there was also evidence of a lack of ownership of non-pharmacological strategies by GPs. Whether this role should fall to GPs or is more appropriately led by community-based occupational therapists or psychologists who have been trained in this field is debatable, but in the absence of these resources it does inevitably fall to the GP.

Many participants highlighted the important role of the family caregiver and found managing expectations of family, to be very challenging. However, the GPs expectations of family involvement could be, in itself, an unreasonable expectation. In the context of inadequate resources, it is possible that a reasonable request for support from a family member was seen by the resource-poor GP as being an unrealistic expectation. From a nursing home perspective the existence of a good working relationship with nursing home staff helped GPs to manage conflicting priorities. This finding supports research which has shown the importance of good relationships between staff when managing people with dementia in a nursing home [27]. Our study further identified that continuity of care, which was enabled by structured GP visits to the nursing home, facilitated positive working relationships.

The common thread throughout was the challenge posed by insufficient resources. Difficulty accessing advice from secondary care colleagues probably stems from an inadequately resourced service. Inability to meet expectations of family caregivers is influenced by the lack of community-based services and supports. The pressure from nursing home staff is related, at least in part, to understaffing and what is often an unsuitable environment.

Strengths and limitations

The systematic sampling process and the discussion of clinical cases in the interviews, allowed in-depth access to information-rich, real-life cases of BPSD and its management. Concepts emerging in the analysis were brought forward to subsequent interviews and the extent to which emerging themes resonated with the experience of participants was assessed, improving the credibility of the research. The use of analyst triangulation helped to increase the confirmability of the findings. The interviewer was a GP. We believe that having a GP interviewer facilitated recruitment and encouraged GPs to participate in the study. Clinician researchers interviewing other clinicians has the potential to introduce bias as the interviewee might see the clinician researcher as an expert who will judge both their clinical and moral decision making [28]. However, it is also acknowledged that when participants in interviews recognise the researcher as a clinician the interviews tend to provide richer and more personal accounts of attitudes and behaviour in clinical practice [28]. Indeed in this study, having a clinician researcher facilitated the in-depth discussion of clinical cases as part of the interview. We found that having a GP interviewer allowed participating GPs to discuss their experiences in a safe non-judgemental, collegial environment. This facilitated rich descriptions of the clinical challenges they experienced. Attempts were made to reduce the risk of professional bias by involving a non-clinician in the analysis process.

Implications for research and practice

This study provides a better understanding of GPs' behaviours when managing BPSD which will facilitate the design

of a more targeted intervention to support GPs in their delivery of care to these patients [18]. There is a role for educational interventions for GPs in BPSD, in particular interventions that focus on assessment of BPSD and non-pharmacological strategies. However, the complexities of the challenges identified in this study highlight the need for additional interventions to support any educational initiatives. Shared decision making tools may help overcome the challenges presented by managing conflicting expectations from both family caregivers and nursing home staff. However, in order for a shared decision making tool to be effective, the GPs need to have the confidence, knowledge and skill to discuss and give advice on the various treatment options [29]. Another challenge in the development of an effective shared prescribing decision tool is the insufficient evidence on the benefits of pharmacological options in BPSD. Furthermore, although there is a need for clinical guidance for GPs in BPSD, formal guidelines may not be appropriate given the heterogeneity of these behaviours and symptoms. However, a flexible management algorithm may be helpful. Clinical pathways or algorithms can help bridge the gap between best practice recommendations and the practical implementation of these recommendations at the coal-face [30], an approach which would be particularly pertinent in BPSD. It is important that future research and practice focuses on appropriate assessment of BPSD in order to identify potentially reversible causes of BPSD rather than choosing between various medications that are largely ineffective and potentially harmful. This requires a culture shift in how BPSD is managed. Such a culture shift will require appropriate resources, education and clinical guidance.

Conclusion

In the context of rising dementia prevalence the demand for community-based dementia care will increase. This is the first study to investigate the challenges GPs encounter when managing BPSD. This study helps to explain the apparent discrepancy between best practice recommendations in BPSD and real-life practice. The findings will be used to inform the design of an intervention to support the management of BPSD in general practice.

Key Points

- When managing BPSD GPs found a lack of clinical guidance, stretched resources and expectations of carers and nurses challenging.
 - As a result of inadequate resources and pressure to prescribe GPs felt they had no viable alternatives to sedative medication.
 - Professional experience and access to consultants increased the GP's confidence and positively impacted the care they gave.
 - These results will inform the design of an intervention to support GPs managing BPSD.
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Supplementary data

Supplementary data mentioned in the text are available to subscribers in *Age and Ageing* online.

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Conflict of interest

None.

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Scaffolding and working together: a qualitative exploration of strategies for everyday life with dementia

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Abstract

Background: living with dementia has been described as a process of continual change and adjustment, with people with dementia and their families adopting informal strategies to help manage everyday life. As dementia progresses, families increasingly rely on help from the wider community and formal support.

Methods: this article reports on a secondary analysis of qualitative data from focus groups and individual interviews with people with dementia and their carers in the North of England. In total, 65 people with dementia and 82 carers took part in the research: 26 in interviews and 121 in focus groups. Focus group and interview audio recordings were transcribed verbatim. A qualitative, inductive, thematic approach was taken for data analysis.

Findings: the article applies the metaphor of scaffolding to deepen understanding of the strategies used by families. Processes of scaffolding were evident across the data where families, communities, professionals and services worked together to support everyday life for people with dementia. Within this broad theme of scaffolding were three sub-themes characterising the experiences of families living with dementia: doing things together; evolving strategies; and fragility and fear of the future.

Conclusions: families with dementia are resourceful but do need increasing support (scaffolding) to continue to live as well as possible as dementia progresses. More integrated, proactive work is required from services that recognises existing