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ORIGINAL ARTICLE

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Maximising the engagement of older people with mental health needs and dementia with social care

David Niman⁴

Mark Wilberforce¹ | Louise Newbould¹ | Sue Tucker² | Wendy Mitchell³ |

Health and

Social Care

¹School of Business and Society, University of York

²Division of Population Health, Health Services Research & Primary Care University of Manchester, Manchester, UK

³Person living with dementia

⁴Former carer of person living with dementia

Correspondence

Mark Wilberforce, School of Business and Society, Church Lane Building, University of York, Heslington, York, Y010 5DD, UK. Email: mark.wilberforce@york.ac.uk

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Abstract

Older people with mental health needs and dementia often face difficulties with daily living and community participation, requiring the intervention of social care services. However, cognitive and emotional needs often mean that mainstream support is not appropriate. In England, mental health support workers may attempt to address these concerns, to prevent mounting care needs and the potential for institutional care. Yet, their work has not been researched to identify good practices and to understand the mechanisms through which they engage older people. A new qualitative study used semi-structured interviews and focus groups with specialist support workers (n = 22), managers (n = 7), homecare staff (n = 4) and service users and carers (n = 6). The latter group were interviewed by co-authors with lived experiences of dementia and care. Participants were recruited from mental health services, home care organisations and third-sector agencies across the North of England in 2020-2021. The study identified three themes that described support worker activities. First, 'building trusting relationships' identified steps to establish the foundations of later interventions. Paradoxically, these may involve misleading clients if this was necessary to overcome initial reluctance, such as by feigning a previous meeting. Second, 're-framing care' referred to how the provision of care was positioned within a narrative that made support easier to engage with. Care framed as reciprocal, as led by clients, and having a positive, non-threatening description would more likely be accepted. Third, 'building supportive networks' described how older people were enabled to draw upon other community resources and services. This required careful staging of support, joint visits alongside workers in other services, and recognition of social stigma. The study was limited by constrained samples and covid context requiring online data collection. The study recommends that support workers have more opportunity for sharing good practice across team boundaries, and improved access to specialist training.

KEYWORDS

community, dementia, long-term care, mental health, older people, social care, support work

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The growing population of people reaching later life, while welcome, is accompanied by an increase in the number of older adults with chronic mental health needs including anxiety, depression and dementia (Wittenberg et al., 2020). These needs, together with, or independent of, other frailty and disabilities, can impair people's ability to lead fulfilling lives (Ames et al., 2016), necessitating longterm (social) care to support activities of daily living and community participation. Aids, adaptations and technologies can help people remain at home, but more progressed needs often require physical help (Kingston et al., 2018), including assistance from families and friends (informal care). In most western nations, however, assistance from paid homecare workers (employed by local care organisations) forms the basis of people's support (formal care) (Rechel et al., 2013). Yet, even in the face of evident need, such care is not always accepted (Newbould et al., 2021).

Care may be declined for a myriad of reasons, including personal choice and preference. For example, it may be seen as inappropriate and/or expensive (for private payers) or be associated with past bad experiences (Herron & Rosenberg, 2019). Other reasons for declining care relate to how the need for support is viewed, including links to stigmatised visions of ageing and fears of 'being a burden' or of losing one's independence (Allen & Wiles, 2014; Breheny & Stephens, 2012; Rapaport et al., 2020). The admission of care staff into one's private home may highlight not only the precariousness of life, but the potential future need for residential support (Angus et al., 2005).

People with mental health difficulties (including dementia) may have additional reasons for declining care. Some people with reduced awareness and reasoning skills 'lack insight' into their own needs (Rokstad et al., 2021), and may see any proffered care as an intrusion (and all-the-more threatening for being without perceived justification). Lack of engagement with care can also reflect other unmet needs, such as physical discomfort or pain, or be symptomatic of difficulties in communication or caregiver understanding (Kovach et al., 2005). For people with low mood, further factors including apathy and lack of motivation can make it harder for staff to engage them. In addition, both mental health and dementia bring societal stigma which, when coupled with the need for social care, create a double disadvantage (Jolley & Moniz-Cook, 2009).

Further difficulties arise from the design of homecare services, which do not always take account of mental health needs (Leverton et al., 2021; Wilberforce et al., 2018). Time-bound visits for set tasks can prevent care workers adjusting their support for people with different needs, while rushed visits, in particular, have been linked to problems engaging older people, as there may not be time to clearly communicate care tasks, allow people to actively participate in them or sequence support in a meaningful way (Tiilikainen et al., 2019). Workforce problems also play a part. Across western nations, care work is financially and socially undervalued, and there is a failure to recognise the significant emotional intelligence and interpersonal skills required (OECD, 2020). Fast turnover, high

What is known about this topic

- Not all older people with social care needs accept support easily.
- Specialist support workers provide mental health support that adapts social care provision to make it more acceptable
- No research has examined how support worker interventions work.

What this paper adds

- Support worker interventions hinge on trusting relationships, but these can be challenging to establish
- Support workers reframe care, by embedding their interventions in a narrative that makes it more acceptable to older people
- Building bridges to other community services requires staged activity and joint visits with other services.

vacancy rates and limited training all contribute to poor service user experience.

Older people offered care they feel uncomfortable with may express their feelings in different ways. Some reject care outright; others voice frustration, express reluctance through interruptions, physically repel care or more passively avoid it (Choi et al., 2017; Volicer et al., 2017). Within the academic literature, the term 'resistance to care' is commonly used to encapsulate this phenomenon and research suggests it is common. Scandinavian studies report prevalence figures of up to 15% among people receiving care at home, rising to 50% for people with dementia 'at risk' of care home entry (Risco et al., 2015). Such difficulties are associated with a range of poor outcomes, including acute family carer anxiety, the greater use of anti-psychotic medications, self-neglect and hospitalisation (Herron & Rosenberg, 2019; Newbould et al., 2021). Nevertheless, curiously little research has explored how best to support these service users in their own homes, with almost all empirical study devoted to institutional settings. Indeed, a recent review by Newbould et al. (2021) identified just five papers describing interventions for community-dwelling older people who had proved difficult to engage in care and few conclusions could be drawn to improve care delivery.

1.1 | Support work in England

In England, support for older people with mental health and social care needs living at home is shared across multiple organisations. Specialist dementia and mental health support is provided by the National Health Service, while local authorities (units of local government) are responsible for social care. Given the inherent overlap of these functions, many localities coordinate activities

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Two online focus groups were conducted with support workers' supervisors. However, attendance was poor due to the ongoing pandemic.

2.2 | Data analysis

The data were transcribed verbatim and imported into NVivO for thematic analysis. The three academic researchers each reviewed two different support worker transcripts to develop the initial coding framework. One academic researcher (LN) then coded the transcripts. The results were subsequently reviewed by the full team and the coding framework was revised as new themes emerged. The two researchers with lived experience met with the academic researchers to discuss the high-level themes from the service user and family carer interviews and a set of thematic findings were developed through dialogue. Key texts were consulted to provide a presentational frame for the findings. For example, the findings relating to interpersonal trust were reviewed using the seminal text of Lewicki and Bunker (1995).

2.3 | Ethics

The study was approved by the Health Research Authority in England (REC Reference: 19/YH/0418). Participation was voluntary and all participants gave informed consent.

3 | RESULTS

Interviews were conducted with 22 support workers, four homecare workers, three family carers and one service user. Seven supervisors participated in the focus groups.

Eighteen support workers were female and four male. Fifteen had 10 plus years care experience and just four had fewer than 5 years' experience. Three homecare workers were female and one male. All had fewer than 5 years' care experience. The supervisors were nurses, social workers and others with NVQ managerial qualifications. Carers were spouses, siblings or sons/daughters of service users. The primary reason for the service user needing social care was self-described as dementia, bipolar disorder or a 'nervous breakdown'.

Three broad analytical themes were identified: building trusting relationships; reframing care and supportive networks.

via multidisciplinary teams comprising professionally-registered staff (e.g., psychiatrists, social workers, mental health nurses) and assistant-grade workers. The latter have many job titles, but may collectively be termed 'support workers' (Wilberforce, Abendstern, et al., 2017).

Although the role of support workers has been underresearched, one qualitative study suggested they may be particularly effective in helping older people with mental health or memory problems that generic (non-specialist) homecare services have found hard to engage (Wilberforce, Abendstern, et al., 2017). Relative to mental health nurses and social workers, support workers are not encumbered with formal titles and legislative powers that can be viewed as intimidating (Huxley et al., 2009; Manthorpe et al., 2010), while relative to generic homecare workers, they are able to spend more time with service users and have more flexibility in the way that they work (Wilberforce, Abendstern, et al., 2017; Wilberforce et al., 2016). Together with their often extensive experience of working with people with complex mental health needs, it is thus postulated that they may have good insight into engaging this client group-the subject of the study reported here.

2 | METHOD

The study used qualitative methods, encompassing interviews and focus groups.

2.1 | Data collection

Semi-structured interviews were conducted with support workers, homecare workers, family carers and service users. Support workers were non-registered practitioners with mental health specialism, whose remit included working with older people in the community. Participants were recruited from secondary mental health services, local authorities and third-sector services in three localities in England. Sampling sought maximum variation in age, gender, years of experience and ethnicity. Homecare workers were employed by generic domiciliary care agencies and recruited through purposive sampling in agencies in two of the three localities. Service users and family carers were recruited through the same mental health services as the support workers, and were identified by managers as having proved difficult for generic services to engage with social care.

Interviews took place between March 2020 and March 2021 (during the Covid-19 pandemic). Fieldwork comprised a mix of telephone (n = 14), video-conferencing (n = 17) and face-to-face (n = 3) discussions depending on participant preferences and social distancing laws. Researchers followed a semi-structured topic guide, informed by an earlier workshop with support workers and key stakeholders. Interviews with practitioners lasted

3.1 | Theme 1: Building Trusting Relationships

The receipt of social care was commonly framed as a 'threat' to a person's identity, well-being and/or safety. As above, this is a known phenomenon which, to a degree, exists among other older populations (e.g., Allen & Wiles, 2014). However, the data indicated that the cognitive and emotional difficulties associated with poor mental health manifestly contributed to the sense of fear and confusion this client group experienced, decreasing the likelihood of their accepting social care. In one typical example, a family member described how her 'independently-minded' father would exhaust himself in his attempts to dress and, in not being able to process or control his frustration, forcefully rejected attempts to assist him.

Support workers sought to address this sense of threat using a mix of conversation and behaviours to foster a sense of security and trust in their presence. 'Trust' is a complex concept, characterised as involving 'confident positive expectations about another's motives... in situations entailing risk' (Boon & Holmes, 1991: p190) and our analysis identified three stages in its development (with some parallels to the theoretical work of Lewicki & Bunker, 1995).

First, even before meeting a service user, support workers put considerable time and effort into gathering information (including biographical information, personality attributes and preferences) that could help them understand what might facilitate or hinder the formation of a trusting relationship. For example, one service user, who in her earlier life had held a high-status job, was said not to like being told what to do (especially by younger staff).

Interviewees further described how they deliberately highlighted shared characteristics, interests or experiences in initial conversations to try and connect with service users. These were not necessarily big things. One support worker said it could just be whether they were a smoker: 'oh, do you want a cigarette, or something like this, and that's how you build trust with them'.

Familiarity was also encouraged by referencing key, trusted, individuals in initial conversations: "I go: 'I spoke to [family member name] the other day, she said you were getting on alright". Paradoxically, however, support workers sometimes misled clients in their attempts to gain trust, as they would not necessarily have met or spoken to the family members mentioned. Similar approaches were often used to gain entry to people's homes where urgent risk/ safeguarding assessments were deemed necessary by, for example, saying a visit had been requested by another party (even where this was not so) or faking an urgent need to use the toilet, while in other examples, support workers feigned familiarity with the service user, referencing a fictitious previous meeting or implying they had invited them (and so indicating trust). However, participants stressed that such measures were only ever used where they were in service users' best interests and as a last resort. They were also clear that they should only be employed in the short term to breach initial barriers to engagement and should not act as an ongoing basis for providing support, the implication being that what they were doing was on the borderline of what they considered acceptable.

Where support workers provided continuous, predictable and reliable support, a second level, deeper, sense of trust appeared to emerge over time:

> "Most of them don't understand why I'm going, but they recognise my face. I think it is just that something triggers and sort of says well, if they keep coming then there must be a reason why they keep coming... eventually they will work it out that you're no harm to them." Interview, Support Worker, SW09.

For people with more advanced dementia, emotional memories, such as positive, warm feelings, were seen to substitute for cognitive memories of a support worker's identity. The validation of key worries and past engagement difficulties were also seen as important at this stage, with the establishment of trust dependent on recognising the service user's feelings. One support worker said of an older person:

> "I would say to her, 'it must be awful... yeah, I would feel really crap about that as well' and just validate what she was saying. So, she felt like she was being listened to and heard". Interview, Support Worker, SW14.

Support workers were, however, careful about what narratives they engaged with, noting how important it was to ensure congruence between 'words' and 'deeds'. Trust-building efforts could be undone if expressed views were contradicted by subsequent behaviours. For instance, one support worker explained that she decided not to visit an involuntarily hospitalised service user since that could imply complicit approval and damage their relationship.

The third stage of trust-building concerned the internalisation of mutual aims and goals. That is, support workers sought to reach a position where the two parties' goals overlapped and could be reached by working together. In the following quote, for example, the support worker matched their own goal (to promote self-care) with that of the service user (to manage without home care):

> Let's me and you do this, and we'll show them that we don't need it [home care]... Interview, Support Worker, SW17.

A sense of being on the same journey could also be achieved by sharing positive experiences / 'good times', as highlighted in the following account:

> There was a time we went to the pictures, and it took me a while to get her there, but she always remembered it, because it was quite a strong emotional memory... I would always bounce back to that if she was starting to get upset with me. Interview, Support Worker, SW01.

The lengths support workers went to establish trusting relationships were noted in the focus groups. In one group, the supervisors stated that support workers did not always ask for permission to engage in some activities 'knowing full well we wouldn't have said yes'. Examples ranged from accessing properties with dangerous pets to giving the service user some of their own money. That said, supervisors stressed that support workers thought creatively and came up with 'new, ingenious ways of working nearly every day' indicating that the risks of such approaches outweighed the benefits. They also emphasised that it was not always possible to establish trusting relationships and that support workers could only go so far.

3.2 | Theme 2: Re-framing Care

The second theme referred to how the provision of care and support was framed within a narrative that made this easier to accept. This interpretation of the data was informed by Positioning Theory, which seeks to examine how people attach 'storylines' to their part in an interpersonal exchange (Harré & Van Langenhove, 1991; Jones, 2006) Positioning Theory focuses on the iterative process by which people use narratives to furnish their claims for a desired role (or to avoid being positioned in a feared one). As such, it can help to understand how care can be 'reframed' over time.

Within this context, interviewees referred to the importance of accommodating the way in which service users/families viewed their own needs. It was evident that being direct about care needs sometimes backfired, as exemplified by one homecare worker:

> "Oh gosh, I've just thought of one really resistant person. Oh, this one lady, she definitely doesn't like me...I think it's because I'm one of these people that - when I know somebody needs the care - I will say: 'you really need to do this'... And, she does not like that at all". Interview, Homecare Worker, HCW01.

Support workers appeared alive to the need for less direct approaches—'I would never go in with my marigolds [gloves]'—and the importance of taking time /being patient:

I think most people, even in their darkest moments, can see that things aren't right, but they do not always have the wherewithal to know how to put it right, or the motivation or the willingness or the understanding...you know what you want them to do, but you have to go about it in a bit of a long way round, to get them to come to the decision that they want that to happen. Interview, Support Worker, SW02.

Indeed, conversations around care needs were recognised as sensitive areas, to be approached cautiously, with support workers wary of imposing decisions. As an example, one support worker described how they had sought to encourage a visit to a day centre by framing it as going for a free cup of coffee, while another spoke of 'planting the seeds' of an idea for something they might do later, in the knowledge that changing attitudes takes time:

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"So, what I try and do is almost make them think that it's their idea rather than me telling them what to do. So, giving enough to tease them and say 'what do you think about this', but always let it be that it's them that's making the decision..." Interview, Support Worker, SW17.

For some service users, care was more acceptable if the relationship was viewed as reciprocal—'I sort of make out that I enjoy it as well, so I'm not taking him out for his...benefit'—while humour was also regularly used to alter the threatening positioning of intimate personal care:

> And then I'd make her laugh, I'd say: "come on then, let's get them out!". Again, it would be going from how she responds to things: she'd be a bit cheeky and she was a bit of a character, so she would not mind me shaking my boobs in front of her and she'd do the same. Interview, Support Worker, SW01.

Framing care in a manner acceptable to family carers was also important, so as not to suggest that they had failed their loved one. One support worker, for example, discussing her approach to a service user's wife stressed that they were not there to take over: 'You've been doing fantastic all this time, it's just a bit of support, that's all, that will help you look after him'.

Despite support workers' best efforts to engage older people with mental health problems with social care, however, they were not always successful, particularly with individuals with functional mental health problems and long histories of contact with mental health services. In one instance, for example, a support worker talked about working with people who had spent long periods of their younger adult life in hospital concluding:

> "I'm just thankful that things have moved on, but now it's about getting this older generation to accept that we're not there to harm them, we're not there to hurt them, we only want to help anyway we can". Interview, Support Worker, SW08.

3.3 | Theme 3: Building Supportive Networks

Although interviewees commonly referred to the shrinking worlds of the older people they supported, there were marked differences in the perceived cause. Family members typically saw loneliness and isolation as resulting from a steady decline in people's networks, as mental health or dementia impaired the ability to socialise. Related changes in functioning (e.g., losing the ability to drive, to navigate public transport or to shop) also reduced social skills and decreased motivation to maintain community networks.

In contrast, support workers instead linked isolation to societal stigma associated with dementia and mental health. For example, one talked about an older person with a long-standing mental health need having been 'left alone' by local people and viewed as a 'strange old woman'. Another potential interpretation was offered by a homecare worker who attributed loss of social connections to a service user's strong desire to remain independent in the face of growing mental health needs, pushing-away people who might support their social as well as functional needs.

Regardless of the cause of isolation, however, it was clear that the support workers saw the building of connections with wider community and social resources as one of their key roles, in keeping with modern 'assets-based' approaches to care (Munford et al. 2020). The staging of activities, facilitating the building of confidence, appeared central to their approach, with the first step often being to engage the service user in a relatively non-threatening external activity, such as going to the shops or for a drive. Even then, however, support workers were vigilant to potential risks and negative reactions. For example, one support worker avoided outings in the mid-afternoon, when crowds of high school children could provoke anxiety.

Attendance at more formal social events, including day services, necessitated sensitive communication, with graduated visits facilitated by the often good relationships support workers had established with day service managers.

> "So, it was more about introducing him in a roundabout way, "oh, we'll stay for a coffee", and then next time we'll go for a coffee and have a game of bingo, and to lunch. And at the initial stages I would stay with him. ... And then gradually, I would disappear in the next room, or go and talk to somebody and leave him talking to whoever else was at the table". Interview, Support Worker, SW05.

Nevertheless, it was apparent that these were fine judgements and not all worked out:

> "So, we went and it absolutely frightened him to death. There was people there who were more impaired than he was, there was people there who had other mental health conditions, not necessarily dementia... it just completely backfired on me...". Interview, Support Worker, SW02.

Transferring care to generic homecare organisations, which often involved joint visits, could also be difficult. Many support workers spoke of carefully selecting agencies with more reliable staff, to whom they provided comprehensive advice prior to meeting the service user. For example, one support worker said they gave new staff a 'pep-talk' so that they were prepared for comments that might appear hurtful if the associated mental health need was not considered. Commonly, homecare workers were initially introduced as simply another helper, they then gradually taking on a more prominent care role.

The most prominent barrier to the successful transfer of care, however, appeared to be the high rate of home agency staff turnover, with the resultant loss of knowledge and continuity often prompting care crises. That said, the gulf between the time allowed for support worker and homecare worker visits was also frequently cited as contributing to care breakdown, with the homecare workers, for example, providing a meal for the older person, but not having time to sit and prompt them to eat it.

4 | DISCUSSION

International policy on community long-term care typically focuses on eligibility criteria and funding (e.g., Gori et al., 2016). Where questions of 'access' are considered, debates tend to centre on the difficulties of navigating complex systems or expanding support for under-recognised groups such as family carers or minority ethnic groups. Indeed, the implicit assumption is that any proffered service is simply accepted. However, for many older people living at home with mental health needs, this is not so. While the literature on 'resistance' offers explanatory factors (Newbould et al., 2021), it defines the phenomenon as a 'symptom' of psychiatric disorder and locates the difficulty with the individual. It does not accommodate Volicer et al. (2017)'s observation that care 'resistance' is distinct in occurring only in the context of care delivery. Further, it ignores the contribution of poor service design and delivery, as well as the societal stigma linked to social care and mental health. Against this background, the present study highlights the ways in which specialist mental health support workers (under supervision from mental health professionals) adapt their support using a wide range of skills and approaches to engage this client group and offers a promising account of how people labelled 'resistive' can be maintained at home.

This study illustrates the importance of framing care in a way acceptable to older people with dual mental health and social care needs. Through the lens of Positioning Theory, support workers were found to present care activities in a non-threatening manner. The use of non-directive language, for example, enabled service users to be involved in making decisions and choices, even if following a broad course of action initiated by a support worker. Positioning the user as 'leading' rather than 'following' is arguably a defining feature of person-centred care which helps older people counter the narrative of decline, helplessness and incapability associated with care receipt (Wilberforce, Challis, et al., 2017) and other gerontological research using Positional Theory has reported similarly encouraging results (Allen & Wiles, 2014; Jones, 2006). For example, Allen and Wiles (2014) found childless older people viewed assistance as acceptable within specific storylines, such as where the older person perceived themselves as giving advice and guidance to (often young and inexperienced) care workers, with the implication being that

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support workers (and other caregivers) should pay attention to the narratives older people use in interpreting their needs.

Nevertheless, the challenges of support work with this client group are also apparent. Attempts to reframe care, for example, need grounding in trusting relationships which demand specific conditions to grow. Two in particular have implications for service design. First, it is clear that trusting relationships often take time to build, requiring service providers to grant care staff sufficient latitude for this. However, ageing populations, growing needs and the straitened fiscal climate mean pressure on services is likely to rise. Indeed, in this situation, it may be tempting for services to discharge or reduce support to people seen as 'not engaging'. Second, the findings demonstrate the fine judgements made by support workers, with individual casework often iterative and nonlinear. This requires staff capable of implementing complex strategies, confidence in which only develops through experience and learning. Previous research, however, suggests that opportunities for support workers to engage in learning are severely constrained (McCrae et al., 2008; Sarre et al., 2018), with most of the available training too elementary or targeted at gualified practitioners. Moreover, as support workers are not a formally recognised practitioner group with clear job descriptions or occupational structures, there are few opportunities for peer support or the propagation of good practice (Wilberforce, Abendstern, et al., 2017). Further work to formally recognise support work in England and provide adequate training is thus recommended, echoing calls elsewhere (e.g., Tudor et al., 2018).

One final noteworthy finding relates to the ethical dilemmas described by participants. While support workers argued that the use of simple 'untruths' were in service users' best interests, the reality is that such practice is fraught with complexity and controversy (James & Caiazza, 2018). The concept of therapeutic lies, whereby practitioners accept and 'go along with' a person's altered perceptions or reality, is well-established in both the literature and in practice. Therapeutic lies are used to address avoidable harm and are generally supported by samples of people living with dementia (May et al 2011). For example, to avoid repeated grieving over the death of loved one, a practitioner may act as though they are still alive if that is congruent with the older person's perception of reality. However, this was not the context in which support workers tended to tell untruths in this study: instead, they were used to gain access to a property, or to (paradoxically) counter initial doubts or suspicions of their trustworthiness. Coupled with an (albeit, singular) observation from a focus group that support workers may not always highlight certain practices to managers, a framework or standard to help support workers navigate these complexities would be welcome.

Lastly, it is important to acknowledge the limitations of this study. First, although the research explored the work of support workers with older people from multiple vantage points (the support workers themselves, supervisors, homecare staff and family carers/service users), the sample sizes for the latter groups were small and cannot be presented as comprehensive. Homecare workers were also relatively inexperienced and it is unlikely saturation was reached on all likely themes. Second, and relatedly, the organisational and geographic contexts in which support workers work undoubtedly vary across England and the way these interact with support workers' activities is relatively unexplored. This study can only hint at some of the complexities involved. Third, while the Covid pandemic undoubtedly impacted this study (support workers undertook fewer home visits and wore masks, while several research interviews were conducted online), its effect is difficult to assess. However, discussions about isolation will undoubtedly have been influenced by the legal restrictions on social gatherings in place during the research.

5 | CONCLUSIONS

This study found that support workers utilise a range of different strategies to engage older people with mental health needs with social care. Key themes included building trusting relationships, reframing how care was provided and forming bridges to a wider network of community support. The authors recommend more attention is paid to support worker training, including options for peer-support, to allow the sharing of good practice across team boundaries. A framework offering guidance on ethical practice and the telling of untruths are also required.

AUTHORS CONTRIBUTION

MW oversaw the study as a whole, from conception to analysis, and drafted the manuscript; LN led interviewing of staff and coding/analysis of qualitative data; ST supported all aspects of the study including analysis and drafting of the manuscript; WM and DM supported ethical aspects of the research, supported topic guide design; led interviewing with service users and family members, supported interpretation of results and contributed to the broad thrust of the discussion section, but did not contribute to writing.

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CONFLICT OF INTEREST

The authors declare they have no conflicts of interest.

DATA AVAILABILITY STATEMENT

Research data are not available as this was not a feature of the participant consent process.

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