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COMMENTARY

Designing meaningful dementia care

In this issue, Csipke *et al.* (2020) report acceptability and feasibility of the Promoting Independence in Dementia (PRIDE) three-session intervention, delivered to people living with mild dementia together with a family or friend supporter, by facilitators after a short training. The intervention supports participants to increase activities and build on communication skills and plan changes they would like to try out between and after sessions (Lord *et al.*, 2020). The intervention proved acceptable to participants and facilitators, being completed by nearly three-quarters of participants.

These initial feasibility findings from a study evaluating a brief, manualized intervention targeted at people with dementia soon after diagnosis are promising. If the effectiveness of the PRIDE intervention is demonstrated in a future trial, its wide availability might potentially contribute to national priorities to enhance currently available dementia post-diagnostic care. A progress review for the UK Prime Minister's 2020 Dementia Challenge indicated that the UK post-diagnostic care provision was improving, but care standards remained variable and work was needed to ensure consistent, high-quality meaningful care (Department of Health and Social Care, 2019).

NHS England's Well Pathway for Dementia and other national initiatives stress the importance of promoting independence for people living with dementia, and work is ongoing to develop metrics around what constitutes "meaningful care" (Public Health England, 2018). Living well with dementia has been conceptualized as living with quality of life, choice, autonomy, dignity, and as independently as possible. There can be a tension between independence as an expression of full autonomy and the interdependence that can enable people with dementia to live in their own homes for longer. To our knowledge, only two interventions have been associated with longer duration living independently in people with dementia, to date. Both were delivered by clinically trained staff (Lord *et al.*, 2020). Thus, the development of a new intervention to improve post-diagnostic care that promotes independence and could be delivered by a broad range of facilitators (voluntary sector staff, and people with and without clinical training), as in Csipke *et al.* (2020), could potentially be an important advance.

Csipke *et al.* (2020) included a broad range of measures to identify a suitable primary outcome for a future pragmatic trial of PRIDE. They propose a measure of self-management, reflecting findings of many studies, that people with dementia prioritize autonomy and living independently as possible, especially early in their illness (Rapaport *et al.*, 2020). This fits with one of the planned mechanisms of action of PRIDE, to reduce "prescribed disengagement", a term coined by Kate Swaffer to describe post-diagnostic advice which explicitly or implicitly suggests that the person should be slowing down or pulling back from activities. This can result in isolation, loss of hope, self-esteem and self-identity, and threaten social health. This theory posits that a decline in activities and engagement in self-management of care and other activities can be explained by a functional loss related to these social processes, additional to any losses related to the symptoms of the dementia illness itself. Such a decline is potentially reversible with intervention and empowering care (Low *et al.*, 2018; Swaffer, 2015).

PRIDE is an intervention focused on empowering and self-management. If effective and implemented in practice in future, it may benefit people living with dementia with and without regular supporters. As in most previous randomized controlled trials evaluating psychological interventions delivered directly to people living with dementia, the involvement of a family carer (termed a supporter in this study) is a prerequisite of participation. In their paper describing development of the PRIDE intervention, the PRIDE group comment that *"whether those who did not have a supporter could engage with the manual warrant[s] further investigation"* (Yates *et al.*, 2019). As the authors describe in the paper in this issue, the inclusion of supporters in intervention sessions can be key to implementation because *"social factors (such as relationships with family or friends) influence the dynamic balance between opportunities and limitations in dementia"* (Csikpe *et al.*, 2020). In addition, to accurately assess the likely utility of a study, the perspective of family carers/supporters can be critical. The limited opportunities for people living with dementia to participate in intervention studies unless their family carer/supporter is willing and able to do so (Bethell *et al.*, 2018) too are problematic. We cannot assume that interventions that work when delivered to dyads will also be effective when delivered to people with dementia alone. Consequently, the evidence base for

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strategies to support people with dementia without regular family carers remains sparse. In one very small study where people with dementia who were socially isolated and had no regular family carers took part in an arts and cultural intervention, participants enjoyed and engaged with it (Eades *et al.*, 2018).

Unfortunately, this trial fell short of its recruitment target. The authors' description of the challenges contributing to this is useful for those planning future dementia trials. Over half of the eligible participants approached consented to take part, but identifying eligible participants to approach was challenging. One explanation for this is that the team experienced unanticipated national research governance changes. They planned three recruitment pathways: self-referral, Join Dementia Research (JDR), and NHS recruitment (Shafayat *et al.*, 2019). NHS recruitment was by far the most successful one. JDR is a key national infrastructure supporting recruitment to dementia trials. Set up in 2015 (it celebrated its fifth birthday in February 2020), it matches people with dementia interested in taking part in research to studies for which they are eligible. One percent of people living with dementia in the UK have now signed up. JDR's objective is that everyone living with dementia has an opportunity to take part in studies (Department of Health and Social Care, 2019). This broadening of opportunity would especially benefit groups who are currently underrepresented in dementia research, including people from Black and Minority Ethnic groups (Cooper *et al.*, 2014).

Unfortunately, JDR was not a successful recruitment route in the PRIDE trial (Csikpe *et al.*, 2020). Most of those approached were not in the catchment areas of participating NHS sites who were delivering the intervention or were uncontactable. In a previous trial recruiting in 2016–17, the yield for participation from JDR (2 randomized from 140 initial contacts) was similarly low (Livingston *et al.*, 2019). JDR enables all people interested in taking part in dementia studies to register, and people remain registered until they request removal from the register or pass away. It is inevitable that the yield will be lower than in memory services, where at least some information about eligibility is known before any approach; and catchment area issues would not apply. Hopefully as JDR membership continues to grow, the number of people the register can match with studies will also increase (currently over 30,000 people have been recruited to studies through JDR) (Department of Health and Social Care, 2019). In our dementia psychological intervention study (recruiting in March 2020), which has broad inclusion criteria, we approached 132 participants via JDR over 4 months, of whom 12 have been randomized (Cooper, 2020). Perhaps this reflects the growth of the database, with the passage of time, among other factors. JDR has enabled many studies to continue recruiting during the recent pandemic. Most psychological interventions (NHS and research) for people with dementia are being delivered remotely at the time of writing due to the needs for social distancing during the COVID-19 pandemic. This has illustrated the possibilities of remote delivery as well as challenges. Interventions can be potentially delivered in people's homes very cost-effectively through video calling, and catchment areas can potentially be widened to national boundaries. Not all family carers and people with dementia will find video call interventions possible or acceptable. In our current trial, 77% of dyads are currently taking part by video call and 23% by telephone ($n = 22$) (Cooper, 2020).

Although the PRIDE intervention study trained 26 facilitators, only 14 (54%) delivered PRIDE in practice. The broad range of facilitators trained and involved (clinical and nonclinical; NHS and voluntary sector employees) indicates the intervention's potential flexibility. While the study offered advice by telephone and email, and one site took up the offer of an additional site visit, delivery and supervision was largely delegated to sites. Of 19 participants in whom self-reported enactment (doing what was planned in the session) of the intervention was reported, 10 (53%) scored as 76% + on this measure of fidelity. There is always a trade-off between a high level of oversight and centralized supervision than may increase fidelity and a more pragmatic, disseminated approach which reflected realities of practice. The included quote from one facilitator "On one occasion I had to scrap everything and pull it right back, because we thought too big" illustrates the difficulties of running a pragmatic psychological intervention trial, where facilitator supervision is not standardized. In the PRIDE study, measures were taken to maximize fidelity to the intervention, including all facilitators attending the same training but nonetheless for 47% of deliveries for which fidelity was recorded, and it was below 75% (Shafayat *et al.*, 2019).

The authors now plan a large, pragmatic trial of this intervention to evaluate if it is a useful tool to deliver consistent, good quality post-diagnostic care to people living with dementia. While this feasibility trial met with some recruitment challenges, the intervention was well received and acceptability and adherence were good. The trial also provided valuable experience to inform future dementia trial designs.

Conflict of interest

Claudia Cooper is the Chief Investigator and Jessica Budgett is the Programme Manager of the

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Alzheimer's Society-funded NIDUS trial, which is referenced in the paper and is also developing and testing a manualized intervention for support for people living with dementia.

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