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Link to publisher's version: <http://dx.doi.org/10.1017/S1041610214001215>

Citation: Ellis-Gray S, Riley G and Oyebode J (2014) Development and psychometric evaluation of an observational coding system measuring person-centred care in spouses of people with dementia. *International Psychogeriatrics*. 26(11): 1885-1895.

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**Development and Psychometric Evaluation of an Observational Coding System
Measuring Person-Centred Care in Spouses of People with Dementia**

Stephanie L. Ellis-Gray, University of Birmingham, UK

Gerard A. Riley, University of Birmingham, UK

Jan R. Oyebode, University of Bradford, UK

Running title: Coding Person-Centred Care

Professor Jan R. Oyebode (corresponding author), Professor of Dementia Care, University of Bradford, BD7 1DP, U.K. e-mail: J.Oyebode@bradford.ac.uk; tel: +44 (0)1274236330
Dr Stephanie L. Ellis-Gray, Birmingham and Solihull Mental Health NHS Foundation Trust, Juniper Centre, Alcester Road, Moseley, Birmingham, B13 8AQ, U.K.
Dr Gerard A. Riley, School of Psychology, University of Birmingham, Edgbaston, Birmingham, B15 2TT, UK.

Abstract

Background: The notion of person-centred care has been important in investigating relationships between people with dementia and paid carers, and measures are available to assess this. It has been suggested that person-centred care may be a useful construct to apply to understanding family-care relationships. However, no measures of person-centred care in this context exist. The study aimed to develop an observational measure of person-centred care for this purpose.

Method: Firstly, a coding system incorporating a range of behaviours that could be considered person-centred or non-person-centred was constructed. Examples included a code relating to whether the person with dementia was involved in planning a task, and a code relating to how the spouse responded to confusion/distress. Secondly, eleven couples, where one partner had a dementia, were recruited and video-taped co-operating on an everyday task. The system was applied to the care-giving spouse's behaviours, labelling examples of behaviour person-centred or non-person-centred. The final step involved assessing the inter-rater reliability of the system.

Results: The system captured nine categories of behaviour, which were each divided into person-centred and non-person-centred types. The system had good reliability (Cohen's kappa coefficients: 0.65 for category and whether behaviours needed to be placed in a category; 0.81 for category excluding the decision about whether behaviours needed to be placed in a category; and 0.79 in relation to whether behaviours were person-centred or non-person-centred.)

Conclusions: Although the small sample size limits the implications of the results, the system is a promising quantitative measure of spousal person-centred care.

Key words: dementia, spouses, observation, coding system, person-centred care

Introduction

The notion of person-centred care is central to relationships between people with dementia and paid carers. A person-centred approach has been strongly advocated to improve outcomes for people with dementia within a professional, care service context (Brooker, 2007), and is set as a good care standard in the U.K. National Dementia Strategy (Department of Health, 2009). Tom Kitwood's (1990) seminal work pioneering person-centred care in care services was based on the notion that well-being is associated with human interactions that enhance or retain a person's sense of identity and value. Key to providing person-centred care is the idea of enhancing the person with dementia's sense of value as a human being, and their sense of agency, through empathising with their subjective experience, appreciating their individual life history and addressing their basic psychological needs (Downs, 2013). Studying the components of person-centred and non-person-centred care is important to better understand how care impacts upon the person with dementia's well-being. Such understanding can be used to inform national healthcare policies about best practice (de Silva, 2014). Currently, there is a paucity of research exploring the impact of person-centred care on the well-being of people with dementia.

Research into person-centred care has predominantly focused on residential care settings, and measures have been created to assess person-centred care within a care service context (e.g. Dementia Care Mapping (DCM), Brooker and Surr, 2006). By contrast, there has been little research on the applicability of the concept to the provision of care by family members, and no measure of person-centred care within family relationships currently exists. This is surprising given that most care is delivered to people with dementia at home by spouses (Schulz and Martire, 2004), and a plausible case can be made for thinking that the concepts of person-centred care do apply to family-provided care. Person-centredness, for

example, might be demonstrated by a spouse seeking the person with dementia's opinion, empathising with them, or inviting them to contribute to an activity. In contrast, non-person-centred care might include the care-giving spouse being impatient with the person with dementia, blaming them for any mistakes or taking control of an activity.

There is some indication from research that carers' subjective accounts of interaction may differ from their actions. Small *et al.* (2003), for example, found that carers perceived themselves as using simple language when communicating with a spouse with dementia in everyday tasks, but observations of their interactions showed that they overestimated its use. This implies that observation might provide a more accurate way of assessing the quality of interaction between people with dementia and family carers.

There are several potential advantages in developing a measure of family person-centred care. It would provide researchers with a means of investigating the extent of person-centred and non-person-centred care within family settings; and assessing whether person-centred care in this context has benefits for the person with dementia, their family carer and their relationship. If there turns out to be significant variation in the extent to which families provide person-centred care, and such variation is associated with differential outcomes, then the measure could also have clinical application. It could, for example, be used as a way of providing feedback to family carers to help them to understand and enhance person-centred support.

Aims of the current study

The aim of the present study was to develop and evaluate the psychometric properties of a quantitative observational tool that could be used to measure person-centred care in the context of family relationships. Three major steps were followed to achieve this aim. The first step involved constructing a coding system for a range of person-centred and non-person-

centred behaviours that might occur in the context of a couple working together to complete an everyday domestic task. The second step involved recruiting and video-taping couples carrying out such tasks together. The coding system was then applied to the behaviours of the care-giving spouse, labelling examples of behaviour person-centred or non-person-centred. The final step involved assessing the reliability of the coding system.

Method

Development of the coding system

The coding system capturing person-centred behaviours was developed and refined over several stages. The focus was on coding person-centred behaviours during an everyday task of daily living, since it was felt that working together on such a task represents a prime opportunity for person-centred and non-person-centred behaviours to occur, and that its observation would be acceptable to couples without being too intrusive.

The primary basis for the development of the measure was qualitative research investigating interaction between people with dementia and their family members (Clare and Shakespeare, 2004; Hellström *et al.*, 2005, 2007; Perry and O'Connor, 2002; Phinney, 2006; Sanders and Power, 2009; Small *et al.*, 2003; Vikström *et al.*, 2005; Vikström *et al.*, 2008). Papers were chosen if there was a focus on how family members help promote or enhance the person with dementia's sense of agency or personhood in everyday domestic interaction. The 'themes' from these papers were listed and then decided by the first author whether or not they related to components of person-centred or non-person-centred care by using the VIPS framework (Brooker, 2007); V=valuing people with dementia's rights, I=meeting the person with dementia's individual needs, P=understanding the person with dementia's perspective, S=creating a positive social environment. A total of 28 codes were obtained through this process, divided into two broad sets of codes reflecting person-centred and non-person-

centred care. One person-centred code related to whether the spouse involved their partner with dementia in making choices and decisions (Perry and O'Connor, 2002; Vikström *et al.*, 2005). The associated non person-centred code related to whether the spouse was focused on simply getting the task done, either by telling the person with dementia what to do or taking over and completing the task alone (Hellström *et al.*, 2005; Vikström *et al.*, 2008). Another person-centred code related to the spouse avoiding highlighting inadequacies or failures, and avoiding negative criticism of task performance (Perry and O'Connor, 2002; Sanders and Power, 2009). In contrast, a non person-centred code involved the spouse blaming, criticising or finding fault with the person with dementia's task performance. It was considered person-centred when a spouse took into account the cognitive impairments of their partner with dementia and thereby tailoring the way they communicated with them (Phinney, 2006; Small *et al.*, 2003), whereas it was considered non person-centred if they used too complicated language that did not allow the person with dementia the opportunity to understand.

Secondly, other observational measures were consulted including those that have been applied to observe the behaviour with people with dementia in institutional settings, and those used to study marital interaction in 'normal' couples. The former included DCM (Brooker and Surr, 2006) and PIECE-dem (Brooker *et al.*, 2011). Person-centred codes derived from these measures included 'Enabling' and 'Acknowledgment'; non-person-centred codes included 'Ignoring' and 'Mockery'. Their limitations, in the current context, were that they have been developed from observation in institutional care for use in institutional care, not for use in the family home. The nature of interaction in a home setting between relatives is likely to be different from that between staff and people with dementia in care.

The couple observational coding systems included the Marital Interaction Coding System (Hops *et al.*, 1972; cited in Heyman, 2004), which was used by Gallagher-Thompson

et al. (2001) to assess spousal interactions in couples where one has dementia during mealtime and future event-planning tasks; the Specific Affect Coding System (Gottman, McCoy, Coan, and Collier, 1996; cited in Shapiro and Gottman, 2004) which was designed to study affect in marital interaction; and the Kategoriensystem für Partnerschaftliche Interaktion (Hahlweg *et al.*, 1984; cited in Hahlweg, 2004), which aims to observe and compare interactions between martially-distressed and non-distressed couples. However these measures were developed using ‘normal’ couples of any age, for the purpose of assessing the quality of interaction in marital relationships but not in a context of caregiving. Many of the codes focus on generic aspects of communication and relationships, such as ‘Agreement’, ‘Justification’ or ‘Dysphoric affect’ rather than on aspects of person-centred behaviour. Despite the fact that these systems were not developed to understand person-centred family care in their context of dementia, their codes were nonetheless examined to see whether they reflected the components of person-centred care generated from family based dementia research. Where this was the case, the code from the marital observation system was merged with the resonant code from the dementia care literature, broadening the code’s definition. For example, a person-centred code relating to ‘Praise’ was incorporated following this process, as was its counterpart non-person-centred code of ‘Fault-find/Criticise’. This process refined the coding system into 13 codes of person-centred and non-person-centred behaviours, merging similar codes together to provide a more comprehensive description.

This version of the coding system was piloted using videos of three couples from the general population working together on an everyday task. The pilot indicated that most of the person-centred codes were appropriate and featured throughout the tasks (for example, ‘Humour’), but which did not have a non-person-centred counterpart; the latter were created following the pilot. Feedback from the two voluntary raters suggested that it was difficult to

distinguish between some codes and further clarity was needed in the form of instructions and examples. Further refinement of the system, including merging of similar codes, resulted in a total of nine broad categories: *Planning, Supporting, Supervising, Asking, Feeding Back, Responding to Communication, Communicating Back, Responding to Confusion/Distress, and Laughing*. Each category included a person-centred code and a contrasting non-person-centred code, creating a total of 18 codes (Table 1). Further feedback from the raters suggested a need for instructions on applying the codes, which provided a definition of person-centred care before giving an explanation of what to look for in terms of identifying the occurrence of a behavioural category. Once the appropriate category was identified, the instructions then provided further descriptions and examples to allow the rater to classify the instance of a behavioural category as person-centred or non-person-centred. An example of instructions for one of the categories is provided in Table 2; full instructions are available upon request.

[Table 1 about here]

[Table 2 about here]

Participants

Ethical approval was obtained from a National Health Service (NHS) Research Ethics Committee. As the system was developed on the basis of qualitative research into spousal interactions, couples were recruited in which one person had dementia and the other was their spouse/partner. A diagnosis of any type of dementia was sufficient; both the person with dementia and their spouse had to have the capacity to consent to take part; the person with

dementia needed to be cared for or supported by their spouse in the home setting; and the couple had to have been together for two years or more. Participants were recruited via NHS staff working with older people in a Mental Health Trust, who informed couples of the research during routine appointments. Voluntary agencies, providing help and advice to people with dementia and their families, were asked to provide contact details for couples who had expressed an interest in taking part in future research. Whilst 25 couples expressed an initial interest in the study, only eleven couples consented to take part. Of the 13 who did not take part, six were not eligible because the person with dementia lacked capacity to consent or they were not living at home, four withdrew their interest because they were reluctant to be videotaped, and three did not have the time. Participation took place between November 2012 and March 2013.

Seven couples were recruited through NHS staff, and four through voluntary agencies. Of the people with dementia, seven were men and four were women, with a mean age of 74 ($SD = 10.90$, range 52-87). Six had a diagnosis of Alzheimer's disease, two had fronto-temporal dementia, one had mixed dementia, one had vascular dementia and one had dementia not otherwise specified. No formal measures were collected regarding severity of dementia, although all participants with dementia required prompts and verbal instructions from their spouse during the task. The average length of time since diagnosis was 47 months ($SD = 29.39$, range four months to eight years). Spousal carers comprised seven women and four men, with a mean age of 72 ($SD = 7.67$, range 62-83). The average length of relationship was 46 years ($SD = 14.56$, range 16-64).

Procedure

Once a couple had expressed interest in taking part and had consented for their information to be passed onto the first author, they were contacted by telephone to confirm

that they were eligible, to provide more information about the study, and to answer questions. If they verbally consented to take part, then a time and date were agreed for a meeting. Couples were informed that their involvement would be kept confidential, and that they could withdraw from the study at any point without repercussion.

The first author visited couples at their home to obtain written consent and demographic information. Couples were asked to think of an everyday, co-operative task that they would be comfortable to do whilst being videoed. It was judged that one task would be sufficient to yield useful data whilst also not taking up too much of the participants' time. The selection of a single task also allowed the chosen activity to be videoed at the time that it usually took place in the participants' routine, in order for their behaviour to remain as natural as possible. Tasks chosen included preparing a meal, raking leaves, getting ready to go out, and preparing medication. The authors considered using the same task for all participants, but decided against this because of the likely variation in the level of impairment across participants; it would have been difficult to find a single task that suited all participants in terms of requiring adequate levels of co-operation and allowing a meaningful contribution from the person with dementia. The first author videoed couples completing their chosen task.

Data analysis

Each video was transcribed by the first author; transcriptions included verbal content as well as non-verbal aspects, such as facial expression, tone of voice, use of gestures, and physical interaction with the person with dementia (e.g. patting them on the back, taking something from them).

The unit of analysis consisted of each behaviour or speech turn produced by the care-giving spouse. The coding involved the first author – the 'primary rater' - identifying each

instance of the care-giving spouse's behaviour by pausing (and, if necessary, replaying) sections of the video. This gave the primary rater time to refer to the instructions and make a decision about whether or not this unit of behaviour could be categorised. If the decision was that the behaviour exemplified one of the nine categories, the relevant part of the transcript was highlighted and assigned one of the 18 codes depending on whether the behaviour was person-centred or non-person-centred. When the behaviour could not be clearly assigned to one of the nine categories, it was assigned to a 'null' category (allocated 0 in the analysis).

The primary rater coded all eleven videos. Each video was also rated by one of two 'secondary raters' (one of whom coded six videos, the other five videos) who were recruited specifically to code the videos for the purposes of evaluating inter-rater reliability. They were given a two-hour tutorial about person-centred care and the coding system, and practised coding using the three pilot videos. The secondary raters coded each instance of behaviour from the care-giving spouse in the participants' videos using the same procedure as the primary rater. Each rater was blind to the primary rater's responses.

SPSS version 20 was used to perform statistical analysis. Cohen's kappa (Cohen, 1960) was used to assess inter-rater reliability. This statistic considers base rates for behaviour, and adjusts for chance agreement. Kappa was used to assess each of two levels of inter-rater agreement, regarding firstly, assignment of instances as person-centred or non-person-centred and secondly, assignment to the categories. A kappa of 0.6 and above was considered an acceptable level of reliability (Landis & Koch, 1977).

Results

Descriptive statistics

The length of the video-recordings, the total number of instances of behaviour that were assigned a category by both raters, and the number of person-centred and non-person-

centred instances of behaviour across the 11 videos are given in Table 3. There was considerable variation between couples in the length of recordings and the number of instances of behaviour coded. A higher percentage of person-centred behaviour than non-person-centred behaviour was observed.

[Insert Table 3 about here]

To demonstrate the difference between person-centred and non-person-centred behaviours, the following are two contrasting examples of the *Communicating back* category, as demonstrated by the same care-giving spouse. A person-centred, tailored way of communicating with the person with dementia: *[Caregiver points to cupboard behind PWD. PWD turns around and puts hand on cupboard door but does not move it, looking around confused] "That's it, push."* In contrast, a non-person-centred, overwhelming way of communicating: *"Shall I do it? Shall I take over?" [PWD doesn't move or answer. Caregiver quickly reaches in front of PWD to take the cup and kettle from PWD]*

Inter-rater reliability

Raters were required to do two things. The first was to identify the occurrence of a behavioural category. Interactive behaviour from the caregiver could be classified as belonging to one of the nine categories or to a null category (i.e. the rater decided it did not fall into any of the nine categories). Examples of interactions falling into the null category included *"It'll take a little while to do this [Caregiver puts soup tin in bin, whilst PWD carries cutlery to table]"* and *"PWD: Gosh that's horrible out there isn't it? Caregiver: [daughter's] gone round to [friend's]. PWD: I know. She only lives round the corner."* Once

a category had been decided, the rater then had to determine whether to rate it as an example of the person-centred or the non-person-centred code.

The kappa in relation to agreement between raters about the category was 0.65, with a 95% confidence interval of 0.60 to 0.70. As shown in Table 4, much of the disagreement came from the fact that one rater often assigned a unit to the null category that the other rater had placed in one of the nine categories. The secondary raters failed to give a category code to 17% of the behaviours given a category code by the primary rater, and the primary rater failed to give a category code to 24% of the behaviours given a category code by the secondary raters. If the null category was excluded from the calculation, the kappa for the level of agreement between raters was 0.81, with a 95% confidence interval of 0.76 to 0.87.

[Insert Table 4 about here]

Kappa was also calculated in relation to the level of agreement between raters on whether the behaviours classified as belonging to one of the nine categories were person-centred or non-person-centred (see Table 5). For the purpose of this analysis, the type of category was not taken into account. The kappa was 0.79, with a 95% confidence interval of 0.71 to 0.87.

[Insert Table 5 about here]

The frequency of use of each of the 18 codes, and the percentage level of agreement between raters, is shown in Table 6. All 18 types of behaviour were observed in the sample and, within each of the nine categories, person-centred behaviours were seen more frequently

than non-person-centred behaviours. Four person-centred codes were the most frequently assigned by the primary rater: *Enabling*, *polite request*, *facilitating* and *active listening*. The level of agreement about identifying a behavioural category (Table 6, column B) was generally good, but was lower for the *Supporting* and *Communicating back* categories, suggesting the need for a refinement of the instructions relating to the identification of these two categories. When both raters identified the same category, the level of agreement about whether to use the person-centred or non-person-centred code (Table 6, column C) was generally excellent. *Fault finding* and *Laughing at* were exceptions, but these were both based on only four instances and so it is unclear how reliable this finding is.

[Insert Table 6 about here]

Discussion

An 18-code observational coding system was developed as a means of capturing a range of person-centred and non-person-centred behaviours shown by spouses towards their partner with dementia whilst collaboratively completing an everyday task. The coding system comprised nine categories: *Planning*, *Supporting*, *Supervising*, *Asking/ordering*, *Feeding back*, *Responding to communication*, *Communicating back*, *Responding to confusion or distress*, and *Laughing*. These categories were created from themes found in previous research findings, marital observational coding systems, and refined through analysing three pilot videos of couples interacting on an everyday task; followed by testing on 11 video recordings of couples completing an everyday task. The results suggested that the coding system has good inter-rater reliability for identifying which category (including the null category) a particular instance of behaviour should be placed ($\kappa = 0.65$). This improved to an

excellent level (0.81, as defined by Landis & Koch, 1977) when the null category was excluded. Agreement between raters was near excellent ($\kappa = 0.79$) for whether behaviour was person-centred or not. This was particularly important, given that the coding system was designed to measure this construct.

Weaknesses of the coding system

The key drawback of the coding system was highlighted in the level of disagreement between raters as to when a spouse's behaviour could be classified as falling into one of the nine categories (as opposed to the null category). This suggests that the instructions for the application of the coding system needed to be clearer, i.e. regarding what types of behaviours the raters are expected to code. After obtaining feedback from the secondary raters, it was clear that some codes needed further refinement in the form of clearer, more distinct descriptions. These could be accompanied by further examples of behaviours that might be appropriately assigned to each code.

Strengths of the coding system

A good level of inter-rater reliability was achieved on the novel instrument developed for this study, supporting the notion that the coding system is a reliable tool for the purpose of observing and identifying person-centred spousal behaviours within an everyday task. The coding system has a clear theoretical basis, as the codes were carefully grounded in Kitwood's (1990) theory of person-centred care. The descriptions given to the raters were detailed and the provision of examples aimed to enhance understanding of the codes. The high level of agreement between raters, regarding person-centred and non-person-centred instances supports that this was effective. Although validity was not formally evaluated, it can be argued that the coding system has good ecological validity as it was applied in a naturalistic setting (the couples' own home) and with a familiar, everyday activity.

Further strengths were that coder training was not a time-consuming process, and its application to the data was relatively quick. Coding software was originally intended to be used to analyse the video-tapes. However, this study has demonstrated that no specialist equipment or resources are required to produce good, reliable results. In light of the above, the coding system could be deemed to have good practical utility, although further studies would be needed to support this statement.

Weaknesses of the evaluation

The main limitation of the study was the small sample size, largely due to recruitment difficulties. As mentioned in the Method, some couples who were initially interested in the study withdrew their interest because they did not wish to be on video-tape. Furthermore, there was no formal assessment of validity.

It is possible that participants' behaviour was influenced by the presence of the first author, in that couples may have behaved in a way that they thought the first author wanted to see. This could have led to more person-centred behaviour, and less non-person-centred behaviour, than would have been the case if social demand characteristics had not been present. Nevertheless, it shows that spouses are able to provide person-centred support. It is also possible that there was some sample bias, in that those who volunteered to take part may have been confident in the positive nature of their relationship, which may correlate with being more person-centred in approach. A larger, more diverse sample would reduce the sample biases that may have occurred in this study.

It is also recommended that raters using the coding system should achieve a minimum percentage agreement with each other before proceeding to analyse participant data. Higher levels of agreement might have been obtained in this study if the secondary raters had worked through more pilot data.

Strengths of the evaluation

The present study allowed couples to choose their own everyday task, leading to variety in the nature and duration of tasks. The average duration of tasks was just under ten minutes, but some recordings were shorter than this. The shortest task allowed capture of only 10 instances of person-centred or non-person-centred behaviour, which is unlikely to be a representative sample. In the context of coding couple interactions, Heyman *et al.* (2001) reported that a 10-minute task is long enough to elicit a sufficient number of behaviours to produce reliable results. The authors felt that giving couples the freedom to choose the task enhanced participation, and also demonstrated that the coding system was not limited to one type of task. We would therefore advocate retaining the element of choice to make the interaction meaningful and the recording acceptable. However, a minimum of 10 minutes of recording is recommended.

Potential value and development of the coding system

Further work in developing and evaluating the system is recommended. As noted earlier, clearer instructions are required to enable raters to more reliably identify incidents of behaviour that require rating (particularly the categories of *Supporting* and *Communicating back*). Most disagreements between raters centred on whether a behaviour belonged to one of the nine categories or to the null category. Post-rating discussions between raters suggested that this occurred often because the behaviour had simply not registered to one of the raters as something that may belong to a category; once the behaviour was pointed out, there was agreement that it should have been placed into one of the nine categories). To address this, additional instructions may be required about how to partition the video-tapes into instances of behaviour in which the family member interacts with the person with dementia, and about what should be classified as behaviours belonging to the null category (e.g. task-irrelevant

conversation). A larger scale study would provide more robust evidence about the reliability of the system. Its validity also needs to be evaluated. Construct validity, for example, could be evaluated by using the coding system to test hypotheses and by correlating the degree of person-centredness with other measures investigating the same construct (e.g. asking spousal carers to complete a questionnaire about empathy, which is a component of person-centred care). Studies are also required to evaluate the extent to which the system can be applied to interactions between the person with dementia and family members other than spouses. The present study focused on developing a measure of spousal interactions because qualitative research about couple interactions in dementia, on which the system was based, focused on spousal interaction, but interactions within other types of family relationship (e.g. daughter/sons caring for a parent) are also likely to be important in promoting good outcomes for the person with dementia. If necessary, the system could be further developed to encompass these other types of family relationship. Further work is also required to establish the stability of the construct across different tasks within the same couple, i.e. whether the spouse shows very similar levels of the observed behaviours in different tasks. The results of this would be of theoretical interest, but also provide justification for applying the system to a task chosen by the participants rather than imposed by the researcher.

This coding system offers a promising means of quantifying person-centred care-giving behaviour in couple relationships, and thereby a method of studying quantitatively how this relates to other aspects of the relationship and other outcomes. For example, a comparison of gender could contribute to a wider understanding of whether the level or nature of person-centred care differs between male and female carers. The system could allow researchers to test some of the suggestions about relationships derived from qualitative research, for example, the importance of person-centred support for how well the family and the person

with dementia cope with the challenges of dementia, as well as how well the person with dementia retains their self-esteem and sense of agency.

Understanding more about approaches that promote good outcomes will eventually help clinicians provide more effective support for families and people with dementia. For example, informing care-givers about the types of communication strategies that they use, and whether these are helpful or unhelpful in the context of person-centred care, may help promote and maintain a good relationship. Reflective coaching using video-feedback could provide an intervention to teach person-centred skills and responses.

The approach developed in this study builds on previous, largely qualitative work, by providing a systematic coding system for observation of spousal person-centred care in domestic settings. Further development and application of this system may allow hypothesis-driven exploration of relationships in dementia care and inform dyadic interventions that could support and enhance couple relationships in the context of dementia care.

Conflict of Interest

None.

Description of author's roles

S. Ellis-Gray recruited participants, collected the data, performed statistical analysis of the data and wrote the paper.

J. Oyebode assisted with the design of the study, supervised the first author and contributed to the writing of the paper.

G. Riley assisted with the design of the study, statistical analysis, supervised the first author, and contributed to the writing of the paper.

Acknowledgements

The authors wish to acknowledge and thanks Bradley Crook and Lauren Albrecht for their assistance with coding the videos.

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