PIRU POLICY INNOVATION AND EVALUATION RESEARCH UNIT

Personalisation in care homes for older people

Executive summary

Stefanie Ettelt, Jacqueline Damant, Margaret Perkins, Lorraine Williams and Raphael Wittenberg

PIRU Publication 2020-27

For further details, please contact:

Lorraine Williams
Research Fellow
Policy Innovation and Evaluation Research Unit
Department of Health Services Research & Policy
London School of Hygiene and Tropical Medicine
15–17 Tavistock Place
London WC1H 9SH
Email: lorraine.williams@lshtm.ac.uk

Raphael Wittenberg
Deputy Director and Associate Professorial Research Fellow
Care Policy and Evaluation Centre
London School of Economics and Political Science
Houghton Street
London WC2A 2AE
Email: r.wittenberg@lse.ac.uk

piru.lshtm.ac.uk

PIRU POLICY INNOVATION AND EVALUATION RESEARCH UNIT

Personalisation in care homes for older people

Executive summary

Stefanie Ettelt, Jacqueline Damant, Margaret Perkins, Lorraine Williams and Raphael Wittenberg

May 2020

Acknowledgements

We are grateful to Nicholas Mays for his advice throughout this study, to Robyn Polisano and the Clinical Research Network leads for their help in the recruitment of care homes, to Martin Green for his valuable suggestions, and to the care home managers who kindly agreed to be interviewed for this study. We also wish to acknowledge the valuable comments and suggestions received from four anonymous reviewers and from the participants of a workshop we held in November 2019 to discuss our findings.

This report was funded by the NIHR Policy Research Programme through its core support to the Policy Innovation Research Unit (Project No: PR-PRU-102-0001). The views expressed are those of the authors and are not necessarily those of the NIHR or the Department of Health and Social Care.

There are around 350,000 older people living in nursing or residential care homes in England, most of whom have complex needs including some level of cognitive impairment, such as dementia (Laing-Buisson, 2018, Age UK, 2019). It is important for their dignity and well-being, and that of their families, that they receive high quality personalised care rather than just 'warehousing'.

Personalisation, as defined by the Cabinet Office in 2007, is "the process by which services are tailored to the needs and preferences of citizens"(Cabinet Office, 2007: 33). Yet providing personalised care in the collective care setting of a care home presents many challenges. A recent trailblazer programme that enabled local councils to offer direct payments to residents of care homes, proved difficult to implement and much fewer direct payments were taken up by residents and their family members than expected (Ettelt et al., 2017). Factors hindering the use of direct payments in care homes included the substantial level of need for care for many older residents, and difficulties in exercising choice, often in the context of advanced dementia. Other reasons included a dependence on family members to help with decision-making and a lack of resource in care homes to facilitate additional choice.

As a follow-up to the direct payment evaluation, this study aims to better understand how personalisation is conceptualised and promoted in residential care for older people in England.

More specifically, the report addresses the following research questions:

1. How is 'personalisation' conceptualised in residential care?
2. Which approaches are being adopted to promote personalisation in care homes for older people?
3. What are the barriers and facilitators to achieving a higher degree of personalisation in care homes for older people?

Methods

We used several methods of data collection and analysis to investigate these questions.

1. A review of policy documents and guidance relevant to personalisation of care for older people in England;
2. A focused review of concepts relevant to personalisation in the scientific literature, building on previous work on personalisation;
3. A review of studies on approaches to promote personalisation in care homes for older people and the effects of personalisation on care home residents as well as barriers and facilitators (n=77);
4. Interviews with care home managers to explore current approaches to personalisation in care homes for older people, and barriers and facilitators of personalisation in residential care for older people (n=24);
5. An analysis of comments on personalisation in a sample of Care Quality Commission (CQC) inspection reports of care homes for older people (n=50).

Conceptualising personalisation in residential care

Personalisation tends to be conceptualised differently in policy documents and care practice guidance. In policy documents, personalisation is mostly associated with the aim of improving the quality of domiciliary care. This aim is closely aligned with the idea of choice and control, self-directed care, and the option of using a direct payment to pay for care, to enable individuals to have control over their budget and choice of service provider. Following the Care Act 2014, policy documents and legislation became more inclusive of residential care, for example by extending personal budgets to residents in care homes and by highlighting the role of person-centred planning and commissioning. However, the approach to personalisation in residential care has not been specified beyond acknowledging that residents of care homes should be included in efforts to personalise care.

In comparison, practice guidance stresses the importance of providing personalised care in care homes, with numerous documents emphasising the role of the care staff and the importance of the care relationship. These often use the term 'person-centred care', which originated from concerns about the quality of care for people with dementia. While person-centred care does not exclude choice and control, its emphasis is on alleviating need and distress, providing comfort and helping individuals to maintain continuity between their lives before and after developing a need for care. There is thus no sharp distinction between 'person-centred care' and the provision of 'good' or 'high quality' care.

In interviews, care home managers used different metaphors to illustrate their understanding and ambition for personalisation in the homes they managed. Many managers evoked the image of the 'institution' to describe the type of depersonalised, routinised care that they wished to distance themselves from. However, some managers conceded that there were elements of task orientation and routinisation that they felt were necessary and defensible, especially perhaps in homes that provided care to a large number of residents with substantial nursing care needs.

In contrast, the 'family' was the most popular image used by managers to describe their ambition for personalised care. This image emphasised close, trusting relationships between staff and residents and an aspiration of treating everyone as equals. Many care home managers spoke about offering activities that are typically associated with the domestic home such as participation in household tasks or the celebration of family occasions. For managers, offering a 'home-like' environment was not incompatible with helping residents to exercise choice, yet these choices tended to be embedded in the communal context of the home (e.g. participation in activities that were available to all).

Other managers tended to liken their home to a 'hotel', emphasising individual choice and a customer service orientation that they tried to instil in their staff. This was expressed, for example, by emulating 'hotel-style' practices, such as presenting the dining room as a restaurant in which residents choose their meals from a menu and referring to residents as 'clients' or 'customers'. It was not always clear whether such renaming made a material difference; the range of choices were unlikely to be much different from the 'family' type homes. In some instances, we noted a tendency to downplay care need, although this may have been rhetorical rather than representing actual levels of need present or different approaches to caring in the home.

We have included a 'co-operative' model as an alternative imaginary that brings together the idea of individual choice and close, more personal, relationships. While no manager directly referred to his or her home as a 'co-operative', arrangements similar to this model can be found in the market for 'extra care' and 'assisted housing' which predominantly provides housing with elements of care that can be scaled up as needed and organised according to people's preferences.

While it can well be argued that it is acceptable, perhaps even desirable, to have different models of personalised care provision existing in the care home market, giving people a choice of approaches they can select according to their preferences, such options are likely to be moderated by availability in local care markets and affordability as some types of care may be more costly than others and thus are unlikely to be available to individuals whose own resources are limited and who rely on (financially constrained) local authority support.

Approaches used to promote personalisation

The literature review identified approaches to promoting personalisation at three levels: the individual, the care relationship, and the care home as an organisation. While we included approaches aimed at promoting personalisation at the level of the wider environment into our analysis, we could not identify any studies that had examined such an approach.

The vast majority of studies identified examined approaches focused on improving the care relationship, typically conceptualising personalisation as the provision of person-centred care in the context of dementia care. Approaches to instilling the principles and techniques of person-centred care in care home staff through training were found to be effective in improving some outcomes for residents with dementia such as reduced agitation and neuropsychiatric symptoms. However, study findings were inconsistent with regard to other types of outcomes (e.g. depression).

There were only a few studies examining approaches aimed at service users directly. Those that were successful addressed the need for stimulation and occupation for people with advanced dementia, which cannot always be promoted simply through improved relationships between staff and residents.

Approaches aimed at the organisation of the care home were mostly associated with the 'culture change movement', whose proponents advocate for a holistic approach to improving care for people in care homes. These include promoting individual choice, changing modes of care delivery and management (e.g. by promoting flatter hierarchies and introducing generalist carers) and creating environments similar to people's domestic homes. Such approaches were mostly investigated in studies originating in the United States. We have not identified any studies that suggest such approaches have had an effect on current policy and practice guidance in England (although there are similarities to guidance for dementia friendly environments).

In interviews with care home managers, approaches to promoting personalisation were grouped as follows: approaches used to support people to maintain their identity; share decision-making; and to create a sense of community, both within the care home and by strengthening relationships with the local community. Managers highlighted the value of the care relationship for supporting people to maintain their identity or sense of self within the care home, emphasising trust as essential in building good relationships between staff, residents and their families. Analyses of the CQC reports of care homes rated as 'requires improvement' or 'inadequate' found that positive relationships between residents and care staff did not automatically result in 'good care'. In some instances, particularly amongst care homes rated as inadequate, the reports noted strong, familial bonds between residents and care staff, while simultaneously the quality of care was found to be below expected standards.

In the interviews, examples were provided of managers involving residents and their family members in decisions about their care, illustrating the diversity of situations in which decision-making takes place. Difficulties in sharing decision-making were described by some managers, particularly if it involved residents with variable degrees of cognitive

impairment, which typically required staff to balance the potential benefits of residents' choices with potential risks and concerns about safeguarding. The CQC reports also described instances of shared decision-making between residents, family members and care home practitioners and provided examples of flexible, responsive and adaptable care, suggesting that resident and family involvement is a dynamic and continuous process where risks and daily concerns are openly and frequently considered.

Most managers provided examples of approaches used to build a community for residents and staff, often captured by referring to the care home as a 'family'. Examples included celebrating special occasions and involving residents' relatives into such activities. Managers also emphasised a desire to reduce professional barriers between staff, residents and families, for example by staff not wearing uniforms and by using informal terms of address such as first names (provided this was acceptable to residents).

Managers mentioned that efforts to engage with the local community typically included visits from school children, church groups and people with animals. However, beyond these groups, building relationships with local communities was seen as challenging, requiring effort and persistence. It was also observed that difficulties in engaging with local communities might reflect the negative image of the care home as 'institutions' and 'places of last resort'. Some managers of not-for-profit homes noted that they were successful in building community engagement around fund-raising activities and charitable events. However, it was not always clear whether such events provided much social interaction for residents, although they typically provided financial support to homes that could be used to personalise care and to make the care home 'homelier'.

Care home reports by the CQC highlighted the importance of the role of the care home manager for promoting personalisation by ensuring staff were capable, empowered and enabled to provide personalised care to residents. Reports commented on various forms of decision-making, user led, shared and practitioner led, as an approach to implement personalisation for people with varying levels of cognitive ability. These linked satisfaction of care with shared decision-making, where residents and family members who were involved in decision-making were more likely to be satisfied with their care.

Barriers and facilitators to promoting and providing personalised care

Our study identified a large number of contextual factors that impacted positively or negatively on efforts to promote and provide personalised care in care homes. Using our framework, we identified factors at the individual level, especially the complexity of care needs, often involving dementia; factors at the level of the care relationship, such as attitudes, capacity and competency staff; the organisational context of care including management and leadership in the care home; and the wider societal context in which residential care for older people is provided, organised and funded.

Our analysis of the literature on approaches to promoting personalisation found that studies in dementia care typically explored approaches aimed at improving the care relationship, while approaches aimed at changing the care home organisation were not specifically focused on care provided to people with dementia. This raises the question as to whether some approaches are better suited to people without (and with) cognitive capacity than others.

Analysis of the CQC reports shed light on the endogenous and exogenous barriers to personalisation, where some challenges are related to a specific care home (endogenous), such as poor understanding of care regulations and of the principles of

personalisation amongst staff. Other difficulties result from the economic and political circumstances in which the care home is located (exogenous). Lack of resources, for instance, can be attributed to political prioritisation of social care funding.

Concerns about the level and quality of staffing in residential care also featured prominently, in our analysis of the literature, interviews with managers, and CQC reports. Factors such as heavy workloads and inflexible staff rotas were identified in the literature as contributors to pressures on staff which undermined their ability to provide personalise care. Studies also highlighted that training in person-centred care was more successful if staff recognised the importance of personalisation, the programme was supported by the leadership of the home and staff had sufficient time and resource to implement behaviour change. Questions emerged about the weight that should be given to recruiting the 'right' type of staff, e.g. those whose attitudes and behaviours support the type of care and caring required for personalised care versus the importance of training, supporting and supervising staff to encourage, regulate or demand such behaviours in themselves and others.

Studies also identified a number of factors relating to the organisation of the care home as potential barriers and facilitators of approaches to promoting personalisation, including: staffing and staff time; the role of managers and their type of leadership; and the design and physical layout of the home. Some studies also acknowledged the wider societal context of residential care, including policies that promote (or hinder) personalisation, such as potential tensions between the requirement of homes to protect the health and safety of residents while accommodating the wishes of their residents which may involve a degree of risk. This observation was seconded by many accounts provided by managers in interviews who stated that they felt they often had to balance individual preferences with regulatory requirements and professional standards. Few studies also discussed the cost implications of personalisation, both with regard to the cost of changing to a more personalised approach to care (e.g. such as investments into training or changes to the physical layout of the home) and the continuous cost implications of providing individualised care, which requires care homes to move away from approaches aimed at increasing economies of scale.

References

AGE UK 2019. Later life in the United Kingdom 2019. Factsheet. www.ageuk.org.uk/globalassets/age-uk/documents/reports-and-publications/later_life_uk_factsheet.pdf. Accessed 19 July 2019.

CABINET OFFICE 2007. HM Government Policy Review. Building on Progress: Public Services. London: Cabinet Office.

ETTELT, S., WITTENBERG, R., WILLIAMS, L., DAMANT, J., LOMBARD, D., PERKINS, M. & MAYS, N. 2017. Evaluation of Direct Payments in Residential Care Trailblazers. Final report. London: Policy Innovation Research Unit.

LAING-BUISSON 2018. Care homes for older people – Market report.

OWEN, T. & MEYER, J. 2012. My home life: Promoting quality of life in care homes. York: Joseph Rowntree Foundation.

WILBERFORCE, M., CHALLIS, D., DAVIES, L., KELLY, M. P., ROBERTS, C. & CLARKSON, P. 2017. Person-centredness in the community care of older people: A literature-based concept synthesis. International Journal of Social Welfare, 26, 86-98.

PIRU POLICY INNOVATION AND EVALUATION RESEARCH UNIT

The Policy Innovation and Evaluation Research Unit (PIRU) brings together leading health and social care expertise to improve evidence-based policy-making and its implementation across the National Health Service, social care and public health.

We strengthen early policy development by exploiting the best routine data and by subjecting initiatives to speedy, thorough evaluation. We also help to optimise policy implementation across the Department of Health and Social Care's responsibilities.

Our partners

PIRU is a collaboration between the London School of Hygiene & Tropical Medicine (LSHTM), the Care Policy & Evaluation Centre (CPEC, formerly PSSRU) at the London School of Economics and Political Science (LSE), and Imperial College London Business School.

The Unit is funded by the National Institute for Health Research (NIHR) Policy Research Programme.

LONDON SCHOOL of HYGIENE &TROPICAL MEDICINE

CPEC CARE POLICY AND EVALUATION CENTRE Research at LSE

Imperial College Business School

Policy Innovation and Evaluation Research Unit
Department of Health Services Research & Policy
London School of Hygiene & Tropical Medicine
15–17 Tavistock Place, London WC1H 9SH

Tel: +44 (0)20 7927 2784
piru.lshtm.ac.uk