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Person-centered dementia care: current perspectives

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Abstract: Person-centered dementia care is widely accepted as a value-based commitment to supporting people with dementia and is a guiding principle in care services. Policy ambitions to put people at the center of their own care are being developed internationally. These may be seen as part of the evolution of person-centered care which has its origins in critical perspectives on practice and social responses to people with dementia. In England, one further development of person-centered care has been personalization – a government policy to extend individuals' choice and control over their social care and, latterly, ways to meet their health care needs. This paper charts the evolution of the concept of person-centered care to the policy of personalization (which has international comparators) and summarizes emerging and conflicting evidence about the implications of personal budgets in England on older people with mental health problems such as dementia and their families. It focuses on the evidence base of personalization and on emerging lessons for practice, drawing from the implementation of personalization and the adoption of personal budgets by this group. While personalization may be one policy initiative, the values and practices of person-centered dementia care remain fundamental to practice and are inspiring new ideas related to rights and justice for people with dementia.

Keywords: person-centered care, personalization, personhood, person-centered planning, dementia

Introduction and background

Person-centered planning, person-centered care, personhood, and personalization

The roots of a person-centered approach lie in the work of Carl Rogers (1958) and his approaches to client-centered psychotherapy.¹ Subsequently, other terms have assumed greater prominence, such as person-centered planning, the origins of which can be traced to changes of the early 1970s in the US and Canada as part of a move to “normalization” or ordinary living to replace long-stay institutions for disabled people. Person-centered planning has become rather an umbrella term when used in professional practice in the English context.² It refers to a variety of approaches to helping people entitled to health and/or care services to plan and express choices about the present and future. It has also been described as a way of enabling people to be involved in planning how the service they currently receive is organized or delivered.³ Initially developed in learning disability services (intellectual impairment), person-centered planning has influenced many social care services in the UK.⁴ However, it is less frequently used in older people's services, although a new variant is emerging with the greater encouragement of advance care planning among health and care services for people with dementia and in end-of-life care.⁵

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Brooker has observed that person-centered care is becoming a more widespread concept:

The term person-centered care has become all-pervasive on the UK dementia care scene. [...] It seems that any new approach in dementia care has to claim to be pc (person-centered) in order to be P.C. (politically correct).¹

Notions of planning, consultation, individualization and deliberation may meet older people's needs effectively, particularly those with dementia, whose needs change frequently and unpredictably.⁶ Experiences of dementia vary and are often affected by other health conditions. Some people with dementia, and many family carers, report that services (such as care at home, day center care, or support in long-term care facilities) are anything but person-centered because they are inflexible, may be too little and too late, reduce rather than promote independence, and may be stigmatizing and reduce community connections. Older people with dementia are also less likely than others to actively participate in assessment so that they are not able to exercise preferences and may underestimate their needs more than other disabled people. The "lottery" of care services reported by older people⁷ means that care systems are criticized for not meeting needs equitably or paying scant attention to individual choices and circumstances. This explains the use of person-centeredness as a "value", signifying attention to the individual. The Alzheimer's Society in England, Wales and Northern Ireland conveys this moral underpinning, here in relation to long-term care:

A good care home will follow the principles of person-centered care. This approach aims to see the person with dementia as an individual, rather than focusing on their illness or on abilities they may have lost. [...] Person-centered care also means treating residents with dementia with dignity and respect.⁸

Wilberforce et al have recently provided a threefold operational definition of person-centeredness, briefly summarized as: first, understanding the person and their unique interpretation and experience of illness or disability is key, requiring a holistic view taking into account the psycho-social not just symptoms; second, service user empowerment in decision-making as the "pinnacle" of person-centeredness, passing control over choices to the service user, guided by an information sharing practitioner; third, the prime importance of relationships in care and treatment.⁹

While person-centered care may be easily (if superficially) linked to good practice or high quality care, or even

synonymous with them, its powerful influence is evident in UK legislation and policy. The Health and Social Care Act 2012¹⁰ imposed a legal duty for National Health Service (NHS) England and local Clinical Commissioning Groups to involve patients in their own care. One reason for the rapid acceptance of the ideas of person-centered care and associated approaches, such as collaborative care, support planning and self-management support, is that they may help society meet the needs of the growing number of people living with long-term conditions in a cost-effective way¹¹ through providing better value for money. Such is the extent of interest in person-centered care that the Picker Institute Europe¹² collated policy initiatives across five European states and the Health Foundation (2015) recently published a guide to person-centered care "around the world".¹³

A further example of this interest in person-centered care at the level of practice comes from Scotland where it is described as one of three core tenets of care. According to NHS Education for Scotland:

Person-centered care is concerned with empowering staff to cut through the systems and processes and focus on the needs of the patients. It focuses on making the patient experience better-making sure that the patient has everything they need to negotiate their current episode of care.¹⁴

In UK health care there are many claims of the benefits of person-centered approaches to health and care (see National Voices),¹⁵ although Wilberforce et al found it hard to unreservedly recommend any measures of person-centeredness in older people's services because of their multiple methodological limitations.⁹ Engaging people in their own health care is described as a way to improve people's knowledge; enhance people's experience of services; change service use and cost; and positively impact on people's health. Expanding on the core elements of person-centered care, this now encompasses supporting self-management, supporting shared decision-making, enhancing experience of health care, improving information and understanding, promoting prevention and peer support. These may be transferable to dementia services, but it is evident that person-centeredness has an "elastic" quality and gets applied widely. Critiques of person-centered care are infrequent, partly because it is seen as virtuous and possibly because it is so broadly defined. Who, for example, could gainsay the following principles of person-centered care as articulated by the Picker Institute Europe:

- Fast access to reliable health advice
- Effective treatment delivered by trusted professionals

- Continuity of care and smooth transitions
- Involvement of, and support for, family and carers
- Clear, comprehensible information and support for self-care
- Involvement in decisions and respect for preferences
- Emotional support, empathy, and respect
- Attention to physical and environmental needs?¹⁶

Personhood

Specifically, within dementia care a further unfolding of person-centered care has built on the concept of personhood. Most commonly associated with the writing of Tom Kitwood, this has been a powerful underpinning of attempts to provide person-centered dementia care and to improve societal attitudes to people with dementia.¹⁷ Kitwood argued that people with dementia have an enduring sense of self, comprising thoughts, feelings, preferences and personality characteristics and he maintained that attention should be given to their personhood.¹⁷ He defined personhood as the “standing or status that is bestowed upon one human being by others, in the context of relationships and social beings”,¹⁷ proposing that an individual’s personhood should be recognized and emphasized in interactions, providing a safe and nurturing environment in which the person is able to express himself or herself. Personhood reflects every individual’s intrinsic uniqueness, but recognizes the interdependence and interconnectedness of human beings, particularly that of family and professional care staff with people with dementia. By adjusting and negotiating the social context of individuals with dementia and creating a safer, more nurturing environment, cognitive capacity and function may be better maintained and the impact of disability limited.¹⁷ Person-centered care can be seen as the processes that maintain the personhood of people who have dementia and contribute towards their enduring sense of self-worth and well-being. However, while personhood has been a powerful motif, it is less often articulated than person-centered care.

From person centeredness to personalization

One substantial organizational reform of the care and support of older people is that of “cash for care” schemes which are allocations of funding to meet eligible individuals’ care needs.¹⁸ Terms such as consumer-directed care (CDC) are used to cover similar changes in countries such as Australia¹⁹ and the US²⁰ while, in Scotland, the term self-directed support is more commonly used.²¹ These reforms are affecting the lives of many older people with dementia in need of care and

support and the lives of their family carers or caregivers. In England, personalization is the key mechanism to “transform” the care system. Underpinning this are aspirations that it will affect the whole system of care and support by enabling greater numbers of older people to live at home for longer, with tailored support, and that it will be more cost-effective than buildings-based services, such as residential care homes (long-term care facilities) or day care centers. The redirection of resources directly to end users through personalization has been greatly influenced by the disability movement, by consumerism, and by political anxiety about the costs of ageing populations to the public purse. More recently, policymakers have decided to extend the key tenets of personalization to NHS health care²² to meet a similar range of aspirations.

There is small but growing evidence from research findings about the outcomes for people with dementia and their carers of such reforms. Current research findings suggest a dual potential for such changes to be seen either very positively as part of the continuum of person-centered care or for them to be viewed more critically, even as the antithesis of person-centered care. The aims of personalization were initially to broaden choice and control for people needing to use social care services – generally assistance with activities of daily living such as bathing, help with the toilet, meals, and dressing,^{23,24} but also socialization and community connectedness. Overall, in England this was the early genesis of examples of the policy of personalization when its implementation was described as fulfilling the “personalization agenda”. Goals are generally described as being to improve outcomes for people in receipt of local government funded social care (a means tested system with high thresholds for eligibility). Central government in England of both main political parties has adopted the term “personalization” to mandate local government (the funders and arrangers of much social care) to change its assessment, care planning, monitoring, and reviews of people needing care and support.²⁵

In England adults in need of care and support are entitled to assistance from local authorities if they meet eligibility criteria around need, wellbeing and risk although they must pay a means-tested contribution if their income or resources are above a minimum level.²⁶ The level of charge may indeed mean that they pay all the costs. The essence of the changes being made by the policy of personalization is that eligible individuals are encouraged to be more involved in assessing their needs for support; that they are informed how much money they are likely to be allocated to meet these needs, and

that they can choose how to meet their needs (summed up in a support plan), although the support plan must be approved by the local authority. In its early days the sums of money were termed an “individual budget”. Currently, it is referred to as a “personal budget”. In knowledge (to some extent) of the sums available to them, the eligible individual devises a personalized support plan, and can choose to take the money in the form of a direct payment (DP; cash paid to the person or a nominated or appointed proxy). Alternatively, they may combine it with local authority services (managed personal budget), or pass it to an organization or individual to provide the care specified (individual support fund). In some cases, the personal budget is not a regular financial allocation but a one-off payment for equipment such as a washing machine or respite care. However, there are concerns that the benefits for older people may be limited in comparison with other user groups,^{27,28} and that for older people with dementia, there may be particular complexities or reluctance to change the basis of their care.

This paper moves to discuss three research phases that contribute to the evidence base for personalization and personal budgets. They are presented as three stages of evidence building and their implications for older people with dementia and people supporting them are considered. As will be evident from this introduction, the concept of personalization is ill-defined but this may be part of its attraction. In the UK context it has become virtually synonymous with choice and control. At one level this can be seen as explicitly extending person-centered care by stressing that the person at the center has autonomy and is responsible for their own decisions. However, this individualistic focus, with the concept of active citizens taking back power from professionals, has been slow to emerge in dementia services and is regarded as problematic since decision making capacity of people with dementia is increasingly compromised by the progress of the syndrome.²⁹ In dementia care, as many researchers have observed, the focus is on relationships in care and relationship-based autonomy.³⁰

First wave studies

Not surprisingly, interest in the outcomes of personal budgets is high, given the multiple advantages that are claimed for them (choice, care quality, satisfaction, cost savings, empowerment, user control, person-centeredness, and community connectedness). The first wave of studies of cash for care schemes (via DP) were mostly descriptive and high levels of satisfaction among DP users were reported,³¹ particularly among younger disabled people.

However, many older people were initially excluded from DP schemes and people with dementia were not generally eligible because the individual (service user) had to be able to consent to them. It was not possible for others, such as family carers, to take on the DP on someone’s behalf. This was criticized on the grounds of both ageism and on the grounds that such a system might be unfairly being withheld from the people with greatest potential to benefit from it, namely people who need continuity of care and individualized care and support.

Second wave studies

The diversity of experiences and construction of user outcomes as ways to measure impact formed part of the second wave of studies of personal budgets. These studies included national and local evaluations, accompanied by growing numbers of powerful accounts about individual experiences or case studies. A wide-ranging evaluation (using a modified randomized control trial methodology) of the 13 individual budget (IB) pilot projects (the Individual Budgets Evaluation Network [IBSEN])³² was set up in 2005. This government funded independent evaluation collected data on the outcomes, costs, and cost-effectiveness of IBs and compared these to conventional services.

IBSEN’s findings about IBs for older people contrasted to data in respect of other user groups (people under retirement age with learning disabilities; physical disabilities or mental health problems).³³ Social workers reported that older people lack confidence in such new arrangements. Moreover, since many had poor health and progressive disabilities, control or choice could be interpreted as another difficulty to surmount. Practitioners reported that older people often called for help only at a time of crisis when support had to be put in place immediately. Lastly, when the actual amount of money was evident, it appeared that the amounts did not present much opportunity to make choice a reality.

In a local study, Woolham and Benton found limited benefits and great costs for older people with these new arrangements of personal budgets and that overall there were no savings to the public purse.²⁷ They reported that older people receiving a personal budget were less likely to feel in control than other user groups; or to say that they were getting the right type of support to feel they had the final say about how the money should be spent. These studies need to be set alongside powerful personal accounts of the benefits of personal budgets for some older people.^{6,34}

Overall a systematic review found low quality evidence for CDC (the term used for personal budgets in several countries) but noted an important increase in satisfaction with care and community service use, although little effect on clinical outcomes for older people.³⁵

The implications of these studies for older people with dementia are multilevel. Many people with need for care and support may not have dementia but will develop the syndrome. Early personalized help may provide the in-built flexibility that they will need. Relationships with care workers may have been successfully built up and domestic settings may have been successfully modified so that they are accessible and not disabling. Support plans may have been agreed (they will by definition perhaps be person-centered) and family members may be working well together without placing undue stress on one particular family member. The experiences of managing support may be helpful as circumstances change. Should this happen then the connectivity of person-centered care and personal budgets may be proven.

Third wave

Nonetheless in a context of rising interest in personalizing care, occurring under the banner of personalization with take up of personal budgets being the central mechanism for implementing personalization in care and support, the research and practice evidence about one of the largest groups of care users (people with dementia) has been slow to develop. For older people with dementia needing social care support at home there has surprisingly been little scrutiny or analysis of the changes of personalization, only latterly have the implications for people with dementia begun to be explored in a third wave of studies. In England these took place in a new regulatory context whereby proxies were newly permitted to take on personal budget administration on behalf of people with dementia.³⁶ Other research has also provided evidence from the experiences of people under retirement age with severe or fluctuating mental health problems receiving a personal budget.³⁷ Both these studies found it hard to recruit people receiving personal budgets and suggested that there was some professional reluctance in offering these to people who might not benefit from them. This raises the matter of equalities of access to such opportunities which remains contested.

These third wave studies were accompanied by research that has taken an interest in exploring if there are risks of personalization when implemented as a personal budget.

Personal budgets were described as inherently risky by some professionals who believed that some older people, for example, people with dementia or other cognitive impairments, would be at greater risk of exploitation in the new systems of personalization if monitoring and review were not able to address risks of harm or abuse.³⁸

This third wave of studies took place in the context of greater interest in research about how services and professionals can change their practices:

Implementation of personalization in its broadest sense has proven difficult to measure and record in practice.⁶

This may be applicable to person-centered care overall since, as the introductory section to this article suggested, the positives of person-centeredness have been loudly articulated.

More mixed experiences are emerging in third wave studies. Many older people with dementia first encounter publicly funded social care when affected by depression, crisis, or stress. They will often choose to have their budgets managed by a local authority.⁶ Depending on the local and national context, choice is itself limited; in Australia for example, the prohibition on employing family or friends may minimize role blurring but reduce the individual's choice and decrease continuity of care.³⁹ In the US there is evidence that poor older people may prefer to employ family members^{40,41} but the long-term implications of this are unknown.

Nonetheless older people generally see personal budgets as providing more freedom of choice and control, enabling them to get support when they want it; knowing what there is to "play with", and sometimes making choices about how to spend their money.³³ They also appreciate knowing what sums are available. This may be valuable if dementia syndromes develop, necessitating help with new areas of life or the gradual passing over of responsibilities and roles to family members. However, whatever the positive aspirations of personal budgets, they affect local service configurations and thereby choices. For example, a day center or day services care may now have been replaced by "day opportunities" which are hard to define and assess, or simply smaller in availability and higher in cost.⁴² It is hard in the English context to draw conclusions about service reductions that are attributable to personalization since it was accompanied and linked to public expenditure reductions which, in adult social care, have affected services such as meals on wheels (home delivered food),⁴³ and eligibility thresholds have risen.

Maximizing the skills of older people to manage their personal budget

One of the problems associated with dementia symptoms is that people, of whatever income level, may find money management increasingly difficult. Different aspects of financial management appear to affect individuals in different ways, affecting skills such as memory, calculation, and estimates of risk.^{38,44}

Third wave studies are now producing findings about people with dementia who have used personal budgets themselves or for whom others have administered them on their behalf. The Dementia Choices study,⁴⁵ for example, set out “to explore, support and promote different forms of self-directed support, including DPs, individual budgets and personal budgets, for people living with dementia and their carers”. These aimed to:

1. Explore and promote what people living with dementia might want from the different forms of self-directed support (personal budgets)
2. Explore and promote the kind of information on self-directed support people living with dementia or their carers need (particularly if the person may lack mental capacity for some decisions, or wish to make plans in case they lose capacity in the future)
3. Explore and identify the appropriate safeguards to ensure that people living with dementia who lack mental capacity can still safely benefit from self-directed support
4. Enable stakeholders to understand the barriers preventing the take up of the different forms of self-directed support
5. Support and promote the development of different ways of delivering support to overcome these barriers.⁴⁵

While these aims may sound remote from practice one example from the Dementia Choices study serves to offer a real world illustration:

A gentleman who used his budget to employ his sister-in-law to support him to get out and about and to his place of worship, and employ a male carer (care worker/aide) to help with his personal needs (eg, hygiene).⁴⁵

Setting up and sustaining a person-centered personal budget seem to demand multiple managerial, administrative, and relationship building skills. Relationships here are multiple, since the carer or caregiver with a personal budget under their control may be at the center of a web of relationships – with their relative but also as an employer, accountable person to the social services authority (funder),

acting under the law as a proxy decision maker, and carrying out consumer functions of purchasing, budgeting, and financial reconciliations.

Not surprisingly, there have been concerns that these are difficult systems, particularly if a person has declining cognitive ability. Evidence from one long-standing US Cash and Counseling Demonstration and Evaluation (Arkansas) program is that support structures, such as representatives, consultants, and fiscal intermediaries, to safeguard consumers and program funding alike are needed.⁴¹ In other contexts we may be talking about the need for support brokers or advocates, but the costs of these services need to be acknowledged.

The development of personalized options for social care presents opportunities but also challenges for older people and carers/caregivers who may face them at times of increasing frailty and cognitive loss. Some will turn to trusted service providers who may also offer person-centered care. For example, the Prime Minister’s Dementia Challenge⁴⁶ provides the following example of a homecare agency in which person-centeredness features as descriptor of its inherent quality:

Homecare provider Somerset Care has spent a number of years developing a service, known as PETALS. This service focuses on six key features: Person-centered, Empowerment, Trust, Activities, Life History and Stimulation. The service places the individual and their family at the center of the support package.⁴⁶

As this extract illustrates, personalization has no copyright on the notion of person-centeredness. It will be important to consider ways in which people with dementia may develop understanding, skills, and confidence in consumer activity prior to dementia, illness, or disability and practitioners and advisers will need to explain that they will also have the option of less individualistic transactions.

Conclusion

Discussions of person-centered care tend to veer to the abstract or are somewhat circular. Wilberforce et al found that person-centeredness was hard to define or conceptualise.⁴⁷ As noted, the prefixes to “centeredness” can sometimes express different emphases; and these are newly joined by references to micro-level financial transactions, the management of money, and day-to-day decisions which are so prominent in discussions of personalization. A disability such as dementia that affects memory and calculations, the

understanding of money and risk, relationship building and sustaining, or non-financial transactions may necessitate a reworking of personalization. There is a risk that, in focusing on the micro-level or interpersonal transactions, the wider opportunities for personalizing care and support relationships may be overlooked.

There is a risk that personal budgets may be seen as the only way of enabling older people and their carers to explore their preferences over their care and to realize the ambitions of person-centered care. There are many elements of person-centered care that do not have choice and control as key values. These include relationships that enable care to flourish, respecting dignity, negotiating over unwelcome alternatives, and behaving with compassion.³⁰ Person-centered care might also be seen as a right rather than a service value, stressing the human rights of people with dementia. The use of person-centered terminology in legal challenges could be a new development.

This conceptual and policy review has chartered the links between personhood, person-centered care and planning, and later ideas of personalization, using England as a case example. Care is needed in using them and presuming that definitions are necessarily shared or that they can be conventionally measured as processes or outcomes. The fundamental values behind them may need to be highlighted and critical perspectives should not be muted just because they seem to be implicitly positive.

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