VALUING PEOPLE

An Organisational Resource Enabling A Person-Centred Approach

A LITERATURE REVIEW TO SUPPORT THE QUALITY DEMENTIA SUPPORT IN THE COMMUNITY PROJECT

UNDERSTAND ALZHEIMER'S EDUCATE AUSTRALIA

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in the Community project

INTRODUCTION

This literature review was undertaken for the Quality Dementia Support in the Community project. Alzheimer's Australia Vic in collaboration with Alzheimer's Australia identified the need for such a review in order to inform the development of resources that will support community care organisations and their staff to achieve excellence in person-centred care. This document presents the findings of the review.

Funding for the project was provided jointly by the Department of Health and Ageing through the Encouraging Better Practice in Aged Care (EBPAC) initiative, Alzheimer's Australia through the National Quality Dementia Care Initiative and Alzheimer's Australia Vic.

The review adopted a systematic approach to identify, critically evaluate and synthesise relevant published and unpublished (grey) national and international literature. Key funding and service organisation websites were also accessed and a number of key informants were consulted as an additional strategy to elicit information about the main grey material, as well as to identify current issues and key themes in this area.

The review starts by providing an overview of the Australian demographic context and includes Australian and internationally published research relating to the conception and foundation of person-centred approaches to practice. The paper discusses the overarching and interrelated themes that underpin person-centred care and the barriers to the uptake of the approach into everyday practice. It concludes with an overview of the key elements to consider in providing effective person-centred care in the community.

The paper demonstrates that person-centred approaches to care in the community can achieve significant outcomes for individuals. It is an approach that requires changes in the way that services are delivered and a fundamental shift in the way relationships are developed with people, with consumers and those who care for them.

Person-centred care is not a new approach. Its practice can challenges us to consider the ways it can be implemented both on a practical level of service delivery and how it can be embedded in all aspects of an organisation's management and administration.

This report has been developed in recognition of the central importance of person-centred care to people living in the community and the positive differences that can occur in their lives when community organisations are committed to person-centred approaches and thinking.

BACKGROUND AND CONTEXT

The review was undertaken within the context of a significant demographic occurrence, both internationally and within Australia, of population ageing. The ageing of populations has created significant challenges for many countries, including Australia. The significance of this is not just the number of old people but also the ratio of the old to other ages (ABS 2011; Productivity Commission 2005).

In the last 25 years, as a proportion of the population, those aged over 65 and over have increased from 10.5% to 14% and those aged 85 and over from 0.8% to 1.9% (Australian Government 2012a).

While older Australians are living longer than previous generations, it is inevitable that many will require care and support (Productivity Commission 2011). The increase in the number of older people and those aged 85 and above is driving increased demand for health and community care services (Swerissen & Duckett 2007; Productivity Commission 2005; AIHW 2005; AIHW 2004; Hogan 2004; Eloranta, Routasalo & Arve 2008).

In fact ageing of the population is one of the most important issues facing Australia over the coming decades, and responding appropriately to the care needs of older people represents a significant future challenge to health and social care systems (Nolan, Brown et al. 2006; AIHW 2005).

The continued growth and ageing of Australia's population will see an increase in the number of people with dementia (AIHW 2012; Henderson & Caplan 2008; Moise, Schwarzinger & Um 2004). Although dementia primarily affects older people, it is not a natural part of ageing; it also affects some people in their forties, fifties and sixties (Beattie et al. 2004).

Of particular note is the high prevalence rate of dementia amongst Indigenous Australians who are affected in much earlier age groups than the general population (Arkles et al. 2010).

In 2011 it was estimated that 298,000 Australians had dementia, of which 70% were living in the community (AIHW 2012). This number is expected to increase to more than 591,500 by 2030–31 (AIHW 2012). This will see a greater need for care services and a growing need for informal caregiving (Quinn et al. 2012; Access Economics 2009; AIHW 2004). This growth is expected at a time when the relative availability of informal carers is in decline (AIHW 2004; Drame et al. 2012).

The pattern of disease among older Australians is expected to see increases in the proportion of frail older people with more complex care needs and increased prevalence of multi-morbidity (Jeon et al. 2010; Productivity Commission 2008; Henderson & Caplan 2008; Victorian Government 2003).

In addition to being an ageing society, Australia is one of the most culturally diverse nations in the world. People from culturally and linguistically diverse backgrounds are a significant and growing proportion of the Australian population aged over 65 (Australian Government 2012c). They have diverse needs that require diverse responses (Ibrahim et al. 2009; Radermacher, Feldman & Browning 2008; Henderson & Caplan 2008; Productivity Commission 2008).

The community care system is an important and growing element of aged care services in Australia (Wells Foreman & Ryburn 2009). It has been developed to assist older people, people with disabilities and their carers to live independently in their own homes and delay a premature move to residential care (Low, Yap & Brodaty 2011; Quince 2011; Francis & Netten 2006; Australian Government 2004). Community care provides a wide range of services from the provision of domestic and practical support to complex, personal and nursing tasks; it complements the care being provided by family and friends (Swerissen & Duckett 2007; Cobban 2004).

Higher levels of education, increased availability of information and greater access to services are altering community expectations of health care delivery (World Health Organisation [WHO] 2007). Swerissen and Duckett (2007) believe that the 'baby boomer' generation will not be satisfied with current aged care systems and will demand more responsive and higher quality services. In order to meet the changing needs, community aged care services will need to be accessible, responsive and flexible to meet the diverse needs and preferences (Radermacher, Feldman & Browning 2008; Aggarway, Vass, Minardi, Ward, Garfield & Cybyk 2003).

Despite chronic illness or disability (Swerissen & Duckett 2007), most older people prefer to remain in their own homes for as long as possible rather than moving to institutional care (AIHW 2012; Australian Government 2012a; Nolan, Bauer & Nay 2009; Productivity Commission 2008). This has seen a shift in the provision of care away from residential services to services that assist people to stay at home (Australian Government 2012a; Access Economics 2009).

ROLE OF INFORMAL CARERS

To exercise the preference to stay at home, most people who need assistance rely heavily on family and friends (Nolan, Bauer & Nay 2009; AIHW 2004; Productivity Commission 2011; ABS 2004). The need for informal care is expected to rise rapidly over the next two decades (Access Economics 2009; AIHW 2004).

The role of carers in supporting people living with dementia is significant (Eloranta, Routasalo & Arve 2012; McGhee & Atkinson 2010; Tilly 2007; Innes, Macpherson & McCabe 2006). Approximately 88% of people with dementia live in private homes (AIHW 2012) with about 92% receiving care from one or more carers.

Around 42% of primary carers are the spouse or partner of the care recipient (ABS 2010), with about half of those being aged 65 and over (AIHW 2012). Their assistance helps many people to avoid or delay care in a residential setting (Drame et al. 2012; AIHW 2004; Victorian Government 2003).

The role of informal carers in the delivery of aged care services in Australia is regarded as very significant (Hogan 2004). The increased demand for aged care services is expected to coincide with a decline in the relative availability of informal carers in the future (Productivity Commission 2011; Wells, Foreman & Ryburn 2009; AIHW 2004; Hogan 2004). Several factors, including lower marriage rates, smaller families and shifting attitudes towards the role of in-family carers, are contributing to a decline in the availability of informal care; this trend is expected to continue as the population ages over time (Hogan 2004; AIHW 2004).

POLICY CONTEXT

Since the development of the Aged Care Reform Strategy in the mid-1980s, there has been a progressive shift in the emphasis of Australian policy away from institutional to community support. As a consequence, the profile of community-based care of older people and their carers and the range of services that might assist them have increased substantially. The Australian aged care system is funded and managed by a combination of local, state and federal government, and non-government and private agencies.

In April 2012, the Australian Government announced the reform package Living Longer, Living Better which describes a ten-year plan for a flexible system, providing older Australians with more choice and control and easier access to a full range of services (Australian Government 2012a). The Living Longer Living Better reforms passed into legislation on 26 June 2013.

PERSON-CENTRED CARE

The concept of person-centred care has been widely discussed for many years (Sheard 2010) and is becoming more prominent within research literature (McCormack, Karlsson et al. 2010). It was used by Carl Rogers, in the 1940s and 1950s, to describe counselling techniques that recognise individuals have unique values, personal history and personality and that each person has an equal right to dignity, respect, and being able to participate fully in their environment (Rogers 1961).

Developments in dementia care have had a substantial impact on the development of models of person-centred care (McCormack 2004). Tom Kitwood, who applied the Rogers model to caring for people with dementia emphasised a person approach over a medical expert approach, is most notable. His book *Dementia reconsidered*, written in 1997, challenged the way that people with dementia are treated and it provided considerable direction for care providers. He argued that viewing people with dementia in medical terms leads them to be seen as objects and as having no subjectivity or personhood.

Stokes and Goudie (1990) emphasised the importance of using a person's experience within the context of their living situation as a basis for planning care. Dawn Brooker (2007) defined person-centred care as best practice in dementia care that integrates four essential elements, namely valuing people with dementia and those who care for them, treating people as individuals, looking at the world from the perspective of the person with dementia and a positive social environment in which the person living with dementia can experience relative wellbeing (p. 12).

In Australia person-centred care has been emphasised within key policy documents, including the Living Longer Living Better aged care reform package (Australian Government 2012a) and Improving Health Care for Older People (Victorian Government 2003). In their response to the Productivity Commission *Caring for older Australians* report, the Australian Government (2012b) emphasised its support of the concept by asserting that 'all older Australians needing care and support need access to person-centred services that can change as their needs change'(p.3).

The World Health Organization (2007) believes a shift towards people-centred health care promises many potential gains. This is reinforced by Dow and colleagues who are largely supportive of person-centred approaches to care (Dow, Haralambous, Bremner & Fearn 2006).

Despite the popularity of the concept there still remains some ambiguity concerning the exact meaning of the term 'patient-centred care' (Kirkley et al. & Bond 2011; Mead & Bower 2000). It is often interchanged with terms such as patient- or client-centred care (Slater 2006). Indeed there is a growing literature on different types of centredness (Hughes, Bamford & May 2008).

The term 'patient-centred care' originated from, and is still widely used by, medical doctors and nurses and has exerted a considerable influence on health care policy, practice and academic literatures (McCormack 2004). The principles of person-centred care are well established and an accepted convention in nursing (McCormack, Karlsson et al. 2010).

In 2004, Nolan and colleagues published a paper that suggested a relationship-centred approach would be more useful than one based on notions of person-centred care, work later supported by Ryan, Nolan, Reid and Enderby (2008). The Victorian Department of Health (2008) contend that 'person-centred', 'patient-centred' and 'client-centred' are synonymous terms describing the practice of taking into account people's personal circumstances.

Notwithstanding the different perspectives, Slater (2006) believes there is some consistency about what constitutes person-centred care, a viewpoint reinforced by Hughes and colleagues (2008), who believe that the many different types of centredness all contain, at a conceptual level, the same underlying themes.

While ideas of person-centred care are many, and the principles widely acclaimed, there has been a hiatus between this and implementation (Sheard 2010; McCormack, Karlsson et al. 2010; Edvardsson, Winblad & Sandman 2008; Dowling, Manthorpe, Cowley et al. 2006; Ericson et al. 2001). In fact there are multiple systemic challenges in providing person-centred approaches which must be addressed before person-centred approaches can be successfully implemented (van Dam, Ellis & Sherwin 2008; Innes, Macpherson & McCabe 2006).

The prevailing culture and a disconnection between beliefs, training and the delivery of support are powerful influences on whether person-centred care can be achieved effectively (Kirkley et al. 2011; Dowling et al. 2006; Patmore & McNulty 2005; Sheard 2004). A lack of clarity about what it is, a belief that it takes more time, a loss of autonomy for staff and a loss of professional status when practising it are reported as barriers to person-centred care (Nay et al. 2009; Dow et al. 2006).

Raising the quality of services in any situation is complicated and requires a clear understanding of the needs and preferences of people who use them with an appreciation of any potential barriers (Moriarty 2008; Francis & Netten 2004). Nay et al. (2009) maintain that the perceived barriers to successful implementation of person-centred care can be worked through. Others report an organisation-wide commitment and culture change is required (Winbolt, Nay & Fetherstonhaugh 2009; Glynn & Beresford 2008; Sheard 2004).

Expectations, policies and rhetoric now demand a very different approach to health care (Nay et al. 2009). It is increasingly expected that those caring for older people base their practice on research evidence, which should be considered in the context of an individual's right to decide on their care needs (Winbolt, Nay & Fetherstonhaugh 2009; Ibrahim et al. 2009).

Sheard (2004) sees person-centred care as a life philosophy. He describes it as 'pursuing the meaning of self, respecting difference, valuing equality, emphasising the strengths in others and celebrating uniqueness' (p.22). The aim should be to acknowledge the personhood of people in all aspects of care (Nowell, Thorton & Simpson 2011; Edvardsson, Winblad & Sandman 2008; Kontos 2005; Nolan et al. 2004). This can be achieved by prioritising the quality of relationships and going beyond people's physical needs to discover more about their experiences, aspirations and the relationships that are important to them (Sanderson & Lewis 2012; Bastiaens et al. 2007; Clarke, Hanson & Ross 2003).

Central to a person-centred approach is support for meeting objectives identified by the person themselves. In the past, health professionals were seen as the expert in a position of power (Ericson et al. 2001) with care focused on people's deficits and problems (Nay et al. 2009). Person-centred care is a shift from this traditional view that sees service users as passive recipients of expert care (Wells, Foreman & Ryburn 2009; Rothera et al. 2008; Morton 2000).

Person-centred care involves putting people and their carers at the centre of planning by considering their needs and involving them in decision-making (Wells, Foreman & Ryburn 2009; Nolan, Bauer & Nay 2009; Nay et al. 2009; Victorian Government 2003). Service users are seen as equal partners in planning and developing support to make sure it is appropriate for their needs (Sanderson & Lewis 2012; Dow et al. 2006; Nolan et al. 2004; Webster 2002). Service providers respect the contribution that service users can make to their own health (Dow et al. 2006).

The term 'dementia care triads' has been used to describe the relationship between service providers, service users and their carers (Quinn et al. 2012; Adams & Gardiner 2007). Ongoing and quality relationships between triad members is an essential feature of good care (McGhee & Atkinson 2010; Nay et al. 2009; Edvardsson, Winblad & Sandman 2008; Nolan et al. 2006; Keady et al. 2004; Webster 2002; Ericson et al. 2001).

McIntyre (2003) believes that practitioners can become role-bound and fail to notice individuals, forgetting that relationships need to be reciprocal. If we are to understand the experience of dementia, we need to access the personal experiences of individuals who are

living with the condition (Hellstrom et al. 2007; Wilkinson 2002). Elaine Robinson (2002) states emphatically that 'no one but us knows what it's really like' (p.107).

Most people want to be active partners in their own care by being involved in decision-making (Productivity Commission 2011; Bastiaens et al. 2007; Ottmann, Allen & Feldman 2009; Noel et al. 2005). Their expertise can enrich community organisations (Moriarty 2008). In order to ensure that outcomes are meaningful to service users, it is vital to get their views and the views of those who care for them (van Baalen et al. 2011; Bamford & Bruce 2000; Innes, Macpherson & McCabe 2006; Ericson et al. 2001).

Wallace (2010) believes that those affected by dementia can 'with attention and confidence in the listener, communicate with clarity and insight' (p.24). This view is supported by others (Sanderson & Lewis 2012; Beattie et al. 2004; Gilliard 2001).

People living with dementia are the experts of their own experience, though many believe that their voices have remained largely silent (Mountain 2006; Wilkinson 2002; Reid, Ryan & Enderby 2001). They have important things to say when appropriate strategies for listening are employed (Katz et al. 2011; Allan & Killick 2010; Beattie et al. 2004; Aggarway et al. 2003; Reid, Ryan & Enderby 2001; Bamford & Bruce 2000).

Christine Bryden (2005) states that 'even if we can't say it we know what we want' (p.117). It is up to services to devise ways of actively listening (Reid, Ryan & Enderby 2001). People living with dementia have individual articulate voices that speak of unique life experiences; however, a limited understanding of methods to enable their voices to be heard and understood exists (Wilkinson 2002; Reid, Ryan & Enderby 2001).

Taking the views of people living with dementia seriously can help to redress their frustration and isolation (Quinn et al. 2012; Beattie et al. 2004). It has the potential to enhance autonomy, improve the quality of life and shape services that better meet their needs (van Baalen et al. 2011; Innes, Macpherson & McCabe 2006; Innes & Capstick 2001; Bamford & Bruce 2000).

Person-centred care occurs when staff know how to facilitate support and not just deliver care (Sheard 2010). Adams et al. (2007) describe communication as enabling when staff and carers assist people with dementia to express their feelings and wishes. It is more than just chatting, it is acknowledging individuals as people (Young et al. 2011; Roberts 2011).

The language of care settings can be difficult and cause a loss of self for people living with dementia (George 2010; Reid, Ryan & Enderby 2001; Innes & Capstick 2001). Appropriate communication can effectively improve the lives of people with dementia and those who care for them (Young et al. 2011).

Edvardsson and colleagues (2008) state that person-centred approaches show respectful, humanitarian and ethical values in practice. The principles underpinning a person-centred approach are universally held and enshrined in law, such as human rights and antidiscrimination (WHO 2007). Dow et al. (2006) found the qualities central to person-centred care were 'mutual respect, equal sharing of power, and active attempts to understand the other's values and history' (p.2).

McIntyre (2003) highlights dignity as the most resonant quality in dementia care. It requires practitioners to appreciate the variety of characteristics that make individuals unique (CQL 2009; NHMRC 2007; Clarke, Hanson & Ross 2003) and to understand the distinct values and preferences of people as determined by their life history and experiences, and their likes and dislikes (Pointon 2010; Eloranta, Routasalo & Arve 2008; van Dam, Ellis & Sherwin 2008; Nolan et al. 2006).

Being responsive to cultural, linguistic and spiritual needs and demonstrating a commitment to recognising and appreciating differences including sexual orientation and gender identity

forms the foundation for decision-making within a negotiated approach (Victorian Government 2009; van Dam, Ellis & Sherwin 2008; McCormack 2004).

Kitwood (1997) argues that people with dementia do not lose their personhood, a view point supported by the Nuffield Council (2009) who contend 'the person with dementia remains the same, equally valued, person throughout the course of their illness, regardless of the extent of the changes in their cognitive and other functions' (p.21). Kate Swaffer (2013) implores carers and others to not 'think of us by the symptoms of the disease, think of us as the people we still are'.

Having intimate knowledge of people and their background is essential to quality care (Nowell, Thorton & Simpson 2011; Ericson et al. 2001). Life stories are a potent way of helping staff to see service users as people, to understand them more fully and better develop relationships with them (Clarke, Hanson & Ross 2003). Life stories are a prerequisite of individualised care (Ericson et al. 2001), can nurture personhood and highlight the need to adapt the context of care in order to create a caring environment (McCormack 2004).

Greater wellbeing is associated with people's sense of attachment to place and their local community (Gilleard, Hyde & Higgs 2007). It highlights the importance of seeing people in the context of their community (Quince 2011; van Dam, Ellis & Sherwin 2008; Bamford & Bruce 2000; Stokes & Goudie 1990). The history of the home environment and the emotional connection to home is important (de Jonge et al. 2011; Aminzadeh et al. 2009). It can provide shared memories to motivate conversation or activity (Ericson et al. 2001).

Activities that enable people to participate in familiar social routines should be promoted (CQL 2009; Themessl-Huber, Hubbard & Munroe 2007). Eloranta and colleagues (2008) and others (Gladman et al. 2007; Qureshi & Henwood 2000) found people's resources were enhanced by providing pleasurable leisure activities and social networks.

Community care makes a tangible difference to the quality of life for many older people, allowing them to maximise their independence and continue living in their own home (Low, Yap & Brodaty 2011; Venables et al. 2006). However, doing so while also safeguarding an acceptable quality of life for older people can represent a significant challenge (Quince 2011).

Genuine choice and control is widely viewed as being key to personalisation (Sanderson & Lewis 2012; Glynn & Beresford 2008). Involvement in decision-making can vary significantly, so individual approaches are essential (Bastiaens et al. 2007). Kate Swaffer (2013), following her diagnosis with dementia was told to give up work and study. The stigma and discrimination she experienced she refers to as 'prescribed disengagement'.

Maximising autonomy in the face of increasing dependency is important to both consumers and carers and it underpins person-centred approaches (Nowell, Thorton & Simpson 2011; CQL 2009; Innes, Macpherson & McCabe 2006; Bamford & Bruce 2000). It requires those involved in care to pay careful attention of people's capacities and choices and focus on what people can do rather than what they cannot do (Sanderson & Lewis; Wallace 2010; Pointon 2010; Allan & Killick 2010; van Dam, Ellis & Sherwin 2008). It also involves supporting and nurturing relationships that are important to the person (Nuffield Council 2009).

Not allowing people to use what abilities they have disempowers them (Brooker 2007). Christine Bryden (2005) asks that people be 'valued for what they can still do and be' (p.127). Risk often becomes the focus when considering people living with dementia because of perceived vulnerability (Waugh 2009; Beattie et al. 2004; Manthorpe 2004; Clarke, Hanson & Ross 2003). It can be one of the biggest barriers to enabling people to have control over their lives (Manthorpe & Moriarty 2010). Minimising risk can lead to controlled freedom, which in turn can be highly detrimental to a person's sense of autonomy and to their wellbeing (Nuffield Council 2009).

The provision of choice requires a balance between the need to protect people from negative outcomes (Manthorpe & Moriarty 2010; Clarke et al. 2009; Beattie et al. 2004) and the need to support them to achieve their goals and build on their strengths and abilities to maximise independence (Quince 2011; Neill et al. 2008; Themessl-Huber, Hubbard & Munroe 2007).

Some people wish to accept risks that may give concern to their relatives or staff providing support; however, care must be taken in making assumptions about what should constitute appropriate activities (Pointon 2010; Qureshi & Henwood 2000). Because risk is individual, plans for managing it need to be as well (Galanttowicz et al. 2005). This requires community care staff to have skills that involve the use of subtle decision-making when engaging with people with dementia and those who care for them (Waugh 2009; Kovach & Krejci 1998).

Both the individual and an organisation's perception of risk are important, and ensuring they are well managed is an essential component of person-centred approaches in community care (de Witt, Ploeg & Black 2010; Ibrahim et al. 2009; Galanttowicz et al. 2005). Discussing risk taking provides the opportunity to develop a shared understanding about the ways risks can be negotiated, particularly with activities that are highly valued and enjoyed (Manthorpe 2004).

The type of choice and control people want should never be presumed (Katz et al. 2011). Each situation requires identification of potential risk with an understanding of consequences to ensure a shared approach to positive risk taking (Manthorpe & Moriarty 2010; Ibrahim et al. 2009). Involving people in service planning is an important dimension of the risk-management conversation (Galanttowicz et al. 2005; Manthorpe 2004).

Neill et al. (2008) believe the best support is what keeps the person healthy and safe in a way that is congruent with how they wish to live now, and what they wish to achieve in the future.

ROLE OF FAMILY AND FRIENDS

The significant role that is offered by family and friends acting as carers has been stated previously. They provide direct care and act as advocates in organising and facilitating formal care provisions (ABS 2010; Wells, Foreman & Ryburn 2009; Productivity Commission 2008). They can provide insights that can support staff to provide appropriate care (William & Sanderson 2006; Manthorpe 2004; Ericson et al. 2001). Many believe that the appropriate attitude of care workers towards families should be that of partners in care (Nuffield Council 2009; Ibrahim et al. 2009; Nolan, Bauer & Nay 2009).

The demands of caring for someone with dementia are known to be stressful (Quince 2011; Moise, Schwarzinger & Um 2004; Parsons 2001). Irene Jacobs (2013) reports the stress and anxiety of being a carer is compounded by the fact that 'everyone expects so much of us as carers'.

Many ageing primary carers are themselves exposed to age-related risk of frailty and disability (AIHW 2004). The quality of support received by carers does affect the care they provide (Aggarway et al. 2003). This highlights the need to support those in caring roles (Quince 2011; Nolan, Bauer & Nay 2009; AIHW 2004).

Services should help the family and other carers to support the person with dementia; they should not be limited to an exclusive focus on the person with dementia (Drame et al. 2012; Allan & Killick 2010; Nuffield Council 2009; Moise, Schwarzinger & Um 2004; Webster 2002).

The relationship between carer and staff has the potential to create positive care outcomes for people (McGhee & Atkinson 2010; Adams et al. 2007; Innes, Macpherson & McCabe 2006) and must be a part of the care processes when intervention is necessary (Nolan, Bauer & Nay 2009; Dowling et al. 2006). However, dilemmas for practitioners in balancing the needs of both consumers and carers can be present difficulties (Gilliard 2001).

There can be limitations in relying solely on carers as proxy respondents (Wilkinson 2002; Bamford & Bruce 2000) as a carer may not have a complete understanding of how the other person feels (Aggarway et al. 2003). Their perceptions of care provision can be at odds with the way in which practitioners approach tasks (Quinn et al. 2012; Wells, Foreman & Ryburn 2009) so a balance is required where the views of both service users and their carers is sought and used (Aggarway et al. 2003; Ericson et al. 2001).

Many consumers are expecting increased involvement and engagement in their own care and the care of their families (Nay et al. 2009). A partnership approach that includes providers and consumers and their carers is an important component of holistic care (Sanderson & Lewis 2012; Pointon 2010; Ibrahim et al. 2009; WHO 2007). It can enable an accurate assessment of a person's abilities and can maximise the autonomy of people living in the community (Roberts 2011; van Baalen et al. 2011).

WHOLE OF ORGANISATION APPROACH

Each organisation has a unique culture and its own set of circumstances (Frampton et al. 2008). Many believe that personalisation will only occur when person-centred practices are embedded throughout organisations and so change how staff are supported and the way leaders lead (Stirk & Sanderson 2012; McCormack, Dewing, Breslin et al. 2010; Sheard 2004).

Person-centred care requires a whole of organisation approach with shared values (Kirkley et al. 2011; McCormack, Dewing & McCance 2011; Nay et al. 2009). The organisation's vision needs to be communicated by skilled leaders together with fundamental changes to systems, work practices and relationships (Winbolt, Nay & Fetherstonhaugh 2009; Nay et al. 2009; van Dam, Ellis & Sherwin 2008; Frampton et al. 2008; Williams & Sanderson 2006; McCormack 2004; Francis & Netten 2004).

Effective partnerships between people who need care and people who provide it underpin person-centred care (Stirk & Sanderson 2012; van Dam, Ellis & Sherwin 2008; Frampton et al. 2008; WHO 2007; Edelback, Samuelsson & Ingvad 1995). They are needed in any culture-change activity (Scalzi et al. 2006).

Organisational change is not always straightforward and can be a long-term undertaking (Kovach & Krejci 1998; Victorian Government 2008). Participation and collaboration are required from all levels and disciplines of staff for positive changes to occur and be sustained (McCormack, Karlsson et al. 2010; Glynn et al. 2008; Templeton 1996). Teams need to be supported by good leaders with person-centred approaches at the core of professional practice and by appropriate models of care, resources and education (Tinney et al. 2007; Webster 2002; Kovach & Krejci 1998).

Many changes fail because people are not clear about what is supposed to happen (Stirk & Sanderson 2012). Tinney et al. (2007) believe it is unrealistic to expect that increased awareness alone will easily translate into improved practice. Change is more likely to be sustained if the changes are seen as a good fit with the organisational goals and if key staff perceive the benefits of the change (Swerissen & Duckett 2007).

ROLE OF SUPPORT STAFF

People receiving care and support should be treated with dignity and respect (Australian Government 2012b). Kitwood (1997) and others (Brooker 2007; Nolan et al. 2006; Cohen-Mansfield & Bester 2006; Sheard 2004) propose that to provide care that is person-centred, staff need to be afforded the same level of person-centredness within their working environment. This is supported by Frampton et al. (2008) who believe 'the ability and inclination of staff to effectively care for people is unquestionably compromised if they do not feel cared for themselves' (p.4).

Understanding the roles and experiences of frontline workers is crucial to appreciating how support can become more person-centred (Innes, Macpherson & McCabe 2006). The time required to perform tasks and the sensitive work performed by people providing care in the home setting is often undervalued despite service users recognising its importance and staff getting satisfaction from performing caring roles (Innes, Macpherson & McCabe 2006; Cobban 2004).

The provision of care in the home requires skilled practitioners (Keady et al. 2004). It can present isolating and difficult conditions and can touch on the most private and intimate aspects of people lives (Cobban 2004; Ryan et al. 2004). In their study of community-based dementia care workers, Ryan et al. (2004) found that staff liked the autonomous nature of providing care in the home, although their overall satisfaction depended on feeling valued by colleagues and managers.

The emotionally demanding nature of the work requires mechanisms for formal supervision and support to be available for staff (Innes, Macpherson & McCabe 2006; Patmore & McNulty 2005; Cobban 2004; Ericsson et al. 2001). Embracing person-centred approaches to care is only possible when teams are nurtured and supported and staff are valued (Moise, Schwarzinger & Um 2004; Webster 2002).

Clear leadership and a shared philosophy are necessary elements of successful teams (Webster 2002). Leaders need to model person-centredness and trust and respect their staff (Pearson et al. 2007; Williams & Sanderson 2006; Sheard 2004). Healthy work environments occur when empowered leaders in turn empower staff (Edvardsson et al. 2009; Pearson et al. 2007; Gladman et al. 2007; Dowling et al. 2006).

Managers play a key role in enabling individuals and teams to adopt person-centred approaches (Dowling et al. 2006). Open communication facilitates the exchange of information and ideas, and opportunities for staff to reflect on their work will help to foster innovations in care (Edvardsson et al. 2009; Ryan et al. 2004; Kovach & Krejci 1998).

As the number of older Australians rises and the demand for aged care services increases, there will be a proportionate growth in demand for a workforce that is well trained (Productivity Commission 2011).

The training and support that staff receive affects the care they provide (Innes, Macpherson & McCabe 2006; Cobban 2004). This is an important factor in job satisfaction and retention (Jeon et al. 2010; Edvardsson et al. 2009; Pearson et al. 2007). Ryan et al. (2004) reported a significant element of job satisfaction was related to the relationships staff had with service users and their families. In fact person-centred approaches to care engender satisfaction among consumers (Noel et al. 2005) and are linked to the wellbeing of staff (Moyle et al. 2011).

Community organisations are responsible for creating a culture that enables services to align with the expectations and needs of consumers and their carers (Themessl-Huber, Hubbard & Munroe 2007). They need to measure in a reliable way people's experiences and the key aspects of quality from their perspective (Quince 2011; Francis & Netten 2004; Qureshi & Henwood 2000; Templeton 1996).

QUALITY

Quality of care is an individual experience and measuring it can be a complex process (Productivity Commission 2011; van Baalen et al. 2011). It can be defined in terms of the distinct perceptions of consumers (Francis & Netten 2004). It requires in-depth forms of feedback to ensure issues and criticisms are identified, as well as positive attitudes towards complaints and criticisms (Quince 2011; Francis & Netten 2004).

Edelback and colleagues (1995) describe 'quality' as those characteristics of a service that consumers evaluate as being good or bad. Others express it as factors that contribute to people's wellbeing (Young et al. 2011; Slagsvold 1997).

Quality of care is influenced by the relationship consumers have with staff providing care (Nolan et al. 2006; Edelbark, Samuelsson & Ingvad 1995). It is dependent on the commitment and capability of staff providing care (Garrat 2009; Qureshi & Henwood 2000; Younger & Martin 2000; Stokes & Goudie 1990).

Dementia is a complex condition, and each experience is an individual one (Roberts 2011; Parsons 2001). Wilkinson (2002) asks 'how can service providers know what people with dementia want and need without being able to gather and include their views and experiences?'(p.12).

Despite progress over recent times, systems that measure process, activity and inputs rather than outcomes continue to dominate. Person-centred care is about more than changing documentation, introducing different processes or changing the names of what is done.

People living with dementia should have the support of people who are confident in supporting them and their carers (Department of Health 2009). Staff must be knowledgeable about the nature and meaning of dementia (Wallace 2010; Pointon 2010; Glynn & Beresford 2008; Gladman et al. 2007; Cobban 2004; Ryan et al. 2001; Stokes & Goudie1990).Training needs to move staff from focusing on physical deficits towards an appreciation of people's abilities (Moyle et al. 2011).

Person-centred organisations ensure a genuine partnership between those providing care and those receiving support (Ibrahim et al. 2009). They are respectful of the relationships between staff and service users and put systems in place to maintain continuity of service provision to facilitate this (Thomas et al. 2007; Patmore 2006).

Kate Swaffer (2011) reports that 'having a new person in our home, a different stranger showering us each day is very invasive and distressing'. People need relationships, not just care. Continuity of staffing is part of building such relationships (Wallace 2010; Patmore & McNulty 2005; Edelback, Samuelsson & Ingvad 1996). This is important to service users and is seen as a key element of good care (Pointon 2010; Patmore 2006; Noel et al. 2005; Francis & Netten 2004; Ericson et al. 2001; Qureshi & Henwood 2000; Edelback, Samuelsson & Ingvad 1996).

A wide variety of support is needed to meet the wishes and goals of people with dementia and their carers (Quince 2011). Care planning and service delivery needs to be flexible and responsive as care needs change over time (Nay et al. 2009; Glynn & Beresford 2008; Rothera et al. 2008; Cohen-Mansfield & Bester 2006; Hogan 2004). People need services to fit in around busy daily routines as not knowing when home visits are due can impose restrictions on important leisure activities (Eloranta, Routasalo & Arve 2012; Themessl-Huber, Hubbard & Munroe 2007; Thomas et al. 2007).

Community care staff need be aware of, and understand, the specific care issues for older people and how to manage these issues in accordance with practice based on best evidence. Diverse and complex health and social profiles require care and support to be developed and delivered by the underpinning principles of person-centred approaches.

CONCLUSION

Organisations where both consumers and frontline staff are included and valued in the development of service provision are well positioned to deliver person-centred approaches (Frampton et al. 2008; WHO 2007; Dowling et al. 2006).

> Holistic supportive care, given by properly trained family carers and staff with ready access to informed professional advice and offered with love, creates quality of life for both people with dementia and their carers. (Pointon 2010, p. 32).

Across Australia more than 210,000 people with dementia are living in the community with the number projected to triple by 2050 (AIHW 2012). The aged care sector in Australia, like others throughout the world, is navigating significant challenges to meet the increasing needs of an ageing population. Higher life expectancy in an ageing population brings greater demands on services and makes the establishment of a sustainable care system a significant issue (Venables et al. 2006).

For over 20 years, successive reforms in aged care have responded to the key policy objective of enabling older people to stay at home and to have greater choice in services. Funding is more flexible, information is more readily available and a new generation of people and services are coming through to offer good leadership for the future.

The community care system makes a tangible difference to the quality of life for many older people; however, raising the quality of care is far from straightforward. The challenge is to make sure that people continue to lead happy, healthy and connected lives by strengthening and reorienting community care systems to provide person-centred care.

Traditionally, people have been expected to fit into existing services with little input into the design or delivery of the service they receive. The increasing focus on consumer-directed care and the introduction of national quality standards means the time is right for person-centred care to become a genuine part of the fabric of how we support people in Australia by refocusing how we go about delivering care.

There are many fine examples of person-centred care being delivered in the community, particularly at the staff level. Regrettably for many it is seen only as a tool to aid quality improvement or fulfil business requirements. Ambitious plans are drawn up, new templates developed and elaborate training programs introduced. However, any plan that does not see service users and those who care for them as integral partners belies the necessary changes in culture and attitude that are required to see person-centred care successfully implemented.

In order to deliver tailored responses to meet an individual's needs, systems must respond to the fact that not everyone is the same. An organisational culture that is open to the possibilities of person-centred approaches by thinking creatively and strategically, adapting to changing demands and collaborating with all stakeholders and staff can achieve positive outcomes for both service users and staff.

Change is an ever-present feature of organisational life. While many organisations appreciate the need for change, many change programs do not achieve their intended outcomes. In order to respond to change, leaders need a full understanding of their organisation and its structures, people and culture. They must then choose the most appropriate approach and identify the factors that might act as facilitators or barriers to change.

Through self-assessment, an organisation can discover its strengths, identify gaps, and make plans for addressing priority areas in the future. The evidence generated can help to explain where operational decisions come from and help broker agreement and recognition of the need for change.

Personally held beliefs come from seeing something work; consequently, person-centred care can only succeed if it is modelled by leaders and supported by real change in the culture of an organisation. Despite the progress over recent times, systems that measure process, activity and inputs rather than outcomes continue to dominate.

Supporting people to make choices and to be included has been labelled many different things over the years including 'independent living', 'consumer-directed', 'self-directed' and 'person-centred' care. All value people by ensuring those who depend on services are at the heart of decisions about the design and delivery of services and by recognising the important role of family carers and the significance of the relationship between service users and those managing and providing services.

What is evident from this review of the literature is that a commitment to valuing people involves:

- treating people with dignity and respect by being aware of and supporting personal perspectives, values, beliefs and preferences
- the provision of choice and subsequent respect for choices made
- optimising a person's control through the sharing of power and decision-making
- maximising independence by building on individual strengths, interest and abilities
- balancing rights, risks and responsibilities
- listening to each other and working in partnership to design and deliver services
- supporting the sense of self by understanding the importance of a person's past, their present-day experience, and their hopes for the future
- collaborative relationships between the service provider and service user and their carers and between staffing levels
- organisational values underpinned by person-centred principles
- support that is responsive to individual needs
- planned, organisation-wide effort to individual and organisational learning.

The evidence presented here has led to the development of a model of care that sees person-centred practice defined by all involved in care delivery – consumers and their carers, staff at different levels and organisational leaders.

Capturing these perspectives is important to ensure person-centred practice is what consumers, their carers and staff experience.

The model is supported by a framework of person-centred principles that supports an organisation self-assessment process. The framework consists of guiding values that describe the features of person-centred care that are important for people living in the community.

The self-assessment process enables the systematic identification of successful person-centred care and areas in need of improvement by capturing the views of those involved in care – service users and their carers, staff at different levels and organisational leaders. It will help community organisations to prioritise issues and identify enablers to change. The report provides guidance to community aged care providers that are looking to become more person-centred and to provide extra evidence for those already committed to person-centred approaches to care.

The idea of older people living well and having a good quality of life is attainable in Australia. Change is underway, and across communities changes are occurring that have the potential to transform how people are supported. Ways of delivering services that allow people and those who care for them to have greater control allow them to make choices about the types of services they access, how they are delivered and when.

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