What is person-centred health care?

A literature review

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A report for the Department of Human Services as part of the Best Practice in Person-Centred Health Care for Older Victorians Project

(2004–2007) by Briony Dow, Betty Haralambous, Fiona Bremner and Marcia Fearn, National Ageing Research Institute (NARI), May 2006

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Literature review summary

What is person-centred health care?

There are many definitions of person-centred (patient-or client-centred) health care in the literature. The Victorian Department of Human Services (2003) defines person-centred care as 'treatment and care provided by health services [that] places the person at the centre of their own care and considers the needs of the older person's carers'.

The main features of person-centred health care derived from the literature can be encompassed within the concept of partnership. The overriding message is that person-centred care is about a collaborative and respectful partnership between the service provider and user. The service provider respects the contribution the service user can make to their own health, such as their values, goals, past experience, and knowledge of their own health needs, and the service user respects the contribution the service provider can make, including their professional expertise and knowledge, information about the options available to the service user, and their values and experience. Both the service provider and service user are important as people within the partnership, neither is interchangeable and the experiences of one cannot be generalised to another. The following principles of person-centred care, are all encompassed within the concept of partnership:

1. getting to know the patient or client as a person (holistic approach as well as individual approach)
2. sharing of power and responsibility (patient or client as expert in their own health, sharing of decision making, information, the idea of common ground)
3. accessibility and flexibility (of service provider as a person and of the services provided)
4. coordination and integration (consideration of the whole experience from the point of view of the service user)
5. having an environment that is conducive to person-centred care (supportive of staff working in a person-centred way and easy for service users to navigate).

Does person-centred health care work?

The limited evidence presented in the literature is largely supportive of person-centred approaches to care. Communication between physician and patient, specifically asking questions about the patient's understanding, expectations and feelings and showing support and empathy, can make a positive difference to patient health outcomes. Mental health clients were more satisfied with case management when they had been randomised to client-focused case management interventions. In the literature on chronic illness, education for practitioners in person-centred care and person-centred education for clients were both found to be beneficial for service users. There was also some evidence in the palliative care literature of improved pain management, when working in partnership with clients. There was also evidence of improved patient and carer satisfaction, improved adherence to intervention recommendations and an improved sense of professional worth as outcomes of working in a person-centred way.

What are the things that hinder and the things that help in providing person-centred health care?

The main **barriers** to person-centred health care identified in this review are:

- time. Various studies stated that person-centred approaches to care take more time
- dissolution of professional power; that is, staff experiencing loss of professional status and decision making power
- staff lacking the autonomy to practice in this way
- the lack of clarity about what constitutes person-centred care, making it more difficult to practice and to explain to clients
- clients with communication difficulties
- the constraining nature of institutions, including physically or spiritually impoverished environments of care.

The main **things that help** in person-centred health care are:

- having skilled, knowledgeable and enthusiastic staff, especially with good communication skills
- opportunities for involving the service user, their carers, family and community (for example, volunteers) in health care
- providing the opportunity for staff to reflect on their own values and beliefs and express their concerns
- opportunities for staff training and education, including feedback from service users
- organisational support for this approach to practice
- working in an environment of mutual respect and trust
- physically and emotionally enriched care environments
- being in the client's home.

Gaps in the literature

There was very little literature that included direct client, carer or family perspectives on person-centred health care.

There was limited empirical evidence about the effectiveness or otherwise of these approaches.

Background

This review was conducted for the Best Practice in Person-centred Care for Older Victorians (2004–2007) Project. This project was commissioned by the Victorian Department of Human Services and undertaken by the National Ageing Research Institute as part of the strategy for implementing the *Improving care for older people* policy launched in 2003. A key principle of this policy is 'involving older people and carers'. With this in mind, this review aimed to investigate the following questions:

1. What is person-centred health care?
2. What models of person-centred health care are currently being used?
3. What evidence is there of the effectiveness of these models?
4. What are the documented barriers and enablers for providing a service that is person-centred?
5. What tools are currently being used to assess the extent or adequacy of person-centred practice in health care?
6. What are the concerns of clients and carers in relation to health care?

Appendix A outlines the parameters of the review.

What is person-centred health care?

One of the difficulties identified by health service providers wanting to practice person-centred care is the lack of agreement about what it means. Does it encompass everything you do to improve the service user's experience of care (for example, reducing pressure sores) or does it only include those practices that are designed to directly involve the service user (and their family and carers) in their own health care (for example, goal setting)?

There are numerous definitions of person-centred care outlined in the literature. For example, the following definitions of patient-centred care were identified by Lutz and Bowers (2000):

> A collaborative effort consisting of patients, patients' families, friends, the doctors and other health professionals ... achieved through a comprehensive system of patient education where patients and the health care professionals collaborate as a team, share knowledge and work towards the common goals of optimum healing and recovery (Grin 1994, as cited in Lutz & Bowers 2000, p. 171).
>
> Placing patients at the centre of the system of care and developing good services that revolve around them (Mallet 1996, as cited in Lutz & Bowers 2000, p. 171).
>
> Health care that is closely congruent with and responsive to patients' wants, needs and preferences (Laine & Davidhoff 1996, as cited in Lutz & Bowers 2000, p. 171).

The United States Agency for International Development (USAID 1999, as cited in Harkness 2005) defined patient-centred health care as:

> An approach to care that consciously adopts the patient's perspective. This perspective can be characterized around dimensions such as respect for patients' values, preferences and expressed needs in regard to co-ordination and integration of care, information, communication and education, physical comfort, emotional support and alleviation of fear and anxiety, involvement of family and friends, transition and continuity (p. 9).

The Canadian occupational therapists, Law, Baptiste and Mills (1995) defined client-centred care as an approach to service 'which embraces a philosophy of respect for, and a partnership with people receiving services' (p. 253).

The Registered Nursing Association of Ontario (2002) defined client-centred care as:

> An approach in which clients are viewed as whole persons; it is not merely about delivering services where the client is located. Client centred care involves advocacy, respecting clients' autonomy, voice, self-determination and participation in decision-making (p. 12).

Cribb (1999) identified three components in defining person-centred care:

- person-centredness as a recognition of individuality or specificity
- person-centredness as a recognition of holism, that is, of the range of personal, social and environmental factors that are constitutive of persons
- person-centredness as a recognition of autonomy, that is, a concern to respect people as to some degree self-defining and self-creating and to work with them not just on them (p. 415).

Finally, the Department of Human Services' (2003) policy on improving care for older people calls for greater emphasis on person-centred care, which is defined as, 'treatment and care provided by health services [that] places the person at the centre of their own care and considers the needs of the older person's carers' (p. 18).

All the above definitions place the patient, client or person at the centre of health care and identify the consideration of their needs and wishes as paramount. Some also include the family, carer or health service personnel as important members of the person-centred care team. Some also include notions such as service coordination, location and integration, which relate more to the way in which a service is developed or managed as a whole rather than its responsiveness to individual patients.

In a review of definitions and principles of patient-centred health care, Harkness (2005) concluded that although there were many common themes in the definitions and principles of patient-centred care, there was no globally accepted definition. Further, Harkness argued that perhaps it was more important to focus on promoting the essence of patient-centred health care–that is, the centrality of the patient in the health care system–than on attempts to reach a global definition of patient-centred care.

For the purposes of this review, the Department of Human Services' definition (described earlier) was adopted as a working definition of person-centred care–that is, care that is centred around the service user (and carers as appropriate) and that respects their wishes and needs. However, implicit in this and other definitions is the notion of involvement or active participation. In order to determine what the service user wishes or needs, they (or their representative) will have to be consulted about their health care.

In this report, the term 'person-centred health care' will be used interchangeably with the following terms: person-centred practice, person-centred care, client-centred practice, client-centred care, and patient-centred care.

Theoretical underpinnings of person-centred care

The modern concept of person-centred care is derived from the client-centred counselling approach developed by Carl Rogers in the late 1940s. The Rogerian model was based on the assumption that 'no one can make decisions for another, act for them or solve their problems – because these are matters of personal responsibility and choice' (cited in Lane 2000, p. 311). In client-centred counselling, the therapist was not supposed to give advice, but rather to maintain an attitude of 'unconditional positive regard' (that is positive regard that is not dependent on the client's behaviour) and create an environment in which the client could come to their own resolution of their problems (Lane 2000).

The legacy of Roger's ideas can be found in today's literature about person-centred care. The relationship between the service provider and the service user, incorporating qualities such as mutual respect, equal sharing of power, and active attempts to understand the other's values and history, is fundamental to the concept of person-centred health care outlined in the models described next. More detail about the theoretical underpinnings of person-centred care can be found in Appendix B.

Models of person-centred health care and their effectiveness

Discipline-based models

Most of the disciplines involved in health care have developed models of person-centred care. In this review, literature from medicine, nursing and occupational therapy is described, as well as some aspects of the hospitality industry that are considered applicable to the health care setting. More detail on discipline based models can be found in Appendix C.

Medical (patient-centred medicine)

Mead and Bower (2000) proposed five dimensions to patient-centred medical care, based on a recognition of the limitations of the bio-medical model. These are:

- bio-psycho-social perspective: broadening the focus of the doctor-patient interaction to include psychological and social factors as well as physical symptoms
- patient as a person: exploring the meaning of illness and health to each individual patient
- sharing power and responsibility: including the patient in decision making and considering them to be an expert in their own health
- therapeutic alliance: valuing the relationship between doctor and patient as a means of promoting health
- doctor as a person. Doctors are not interchangeable, the particular qualities, attitudes and values of the doctor are important and will suit one patient better than another.

Similar characteristics are suggested by Stevenson (2002) and Stewart (2001), but both these authors also include health promotion as an aspect of patient-centred medicine.

Stewart also conducted a review of the published literature in 1995 to determine whether the quality of physician-patient communication made a difference to patient health outcomes. Eleven randomised controlled trials and ten analytical studies were included in this review. Sixteen studies reported positive results. The quality of communication in both the history taking and discussion of the management plan was found to effect emotional health, symptom resolution, function, physiologic measures, such as blood pressure and blood glucose levels, and pain control. The elements of history taking identified as effective were:

- asking questions about the patient’s understanding of the problem, their concerns and expectations, and their perception of the effect of the problem on function (impacted on patient anxiety and symptom resolution)
- asking questions about the patient’s feelings (impacted on psychological distress)
- showing support and empathy (impacted on psychological distress and symptom resolution).

In discussing the management plan, the following physician activities were found to be effective:

- encouraging the patient to ask questions (impacted on patient anxiety, role and physical limitation)
- providing patient with information, programs and packages (impacted on pain, function, mood and anxiety)
- providing clear information along with emotional support (impacted on psychological distress, symptom resolution and blood pressure)
- willingness to share decision making (impacted on patient anxiety) (Stewart 1995).

The patient’s success in obtaining information impacted on functional and psychological status and physician and patient agreement about the nature of the problem and the need for follow-up. The patient’s ability to express themself and perception that a full discussion had taken place in the assessment phase also impacted positively on health outcomes (Stewart 1995).

In a review of the literature on patient-centred care, Harkness (2005) concluded that while there was limited evidence of a relationship between patient-centred health care and overall health, there was sufficient evidence from studies of patient satisfaction to conclude that patient-centred care was what most patients wanted. Harkness argued for more research that is designed from the patients’ own perspective and for more patient involvement in the design and planning of health care.

Nursing

There is considerable nursing literature that describes person-centred health care and discusses the barriers and opportunities relating to implementing a person-centred approach. The nursing literature also identifies resources, such as assessment tools, which are designed to facilitate person-centred health care. The following is a sample of the literature and more detail can be found in Table 2, Appendix C.

A paper by Ford and McCormack (2000) explored the philosophical underpinnings of person-centred care and proposed a person-centred approach to assessment. They argued that person-centred assessment should be:

- humanistic (rather than behavioural)
- developed through a relationship of closeness and trust between the nurse and the patient
- approached through biography (understanding the person's history)
- based on the older person's values and the meanings they attribute to health
- take into account the older person's abilities and strengths.

Nolan (2001) argued that concepts of successful ageing, health-related quality of life and person-centred care overvalue autonomy and independence, which are values that can disadvantage the oldest and frailest members of society. He argued for a more inclusive conceptualisation of person-centred care, one that recognises the values of interdependence and reciprocity. In 2004, Nolan and colleagues published a paper that suggested a relationship-centred approach to person-centred care. Nolan developed the senses framework, which consists of senses that all parties (the older person, their carers and staff) involved in caring should experience. These are a sense of:

- security – to feel safe within the relationship
- belonging – to feel part of things
- continuity – to experience links and consistency
- purpose – to have personally valuable goals
- achievement – to make progress towards goals
- significance – to feel you matter.

The emphasis of this model is on all parties to the relationship being important. Thus, staff need to feel these things too. Nolan further outlines what each of these senses might mean for staff, older people and family carers. The framework has been subject to empirical testing (Davies, Nolan, Brown, & Wilson 1999) and although what creates these senses varies across different groups and care contexts, the 'senses' are prerequisites for relationships that are satisfying to all parties involved.

Nolan and colleagues (2004) also identified the characteristics of 'impoverished' and 'enriched' environments of care for older people. Environments could be physically impoverished or they could be impoverished in their attitudes to older people and care practices. These impoverished environments had an adverse affect on nursing students' experience of aged care and their desire to work in this field in the future. By contrast, students experienced enriched environments, where staff actively tried to create the senses described above, much more positively.

Similarly, McCormack (2001) argued that through partnership with nurses, human freedom and autonomy can be retained even in the presence of a debilitating illness if nurses strive to provide care that is consistent with the person's values. In 2001, McCormack conducted a qualitative study using 14 case studies of nurse-patient interactions. He identified a number of issues that were seen as constraints to the older person's autonomy. These were the dynamics of power and control, patient's access to knowledge, the impact of professional authority, the constraining nature of institutions, and the effect of family and carers on decision making.

In the nursing literature on person-centred health care, there is also some discussion about the value of specialised gerontological nursing. McCormack and Ford (1999) argued that gerontological nursing needed to move away from its past history (routinised, institutionalised, low status practice) in order to develop person-centred practice. They presented a model of person-centred gerontological nursing practice that included:

- holistic practice and holistic knowledge

- saliency (seeing the most pertinent issues and appropriate ways of responding to them)
- knowing the patient
- moral agency (a concern for responding to the client as a person, respecting dignity, protecting her personhood in times of vulnerability, helping her feel safe, providing comfort, and maintaining integrity in the relationship)
- skilled know-how.

Some of the identified enablers were:

- the ability to reflect on the effectiveness of practice
- authority in and accountability for practice
- therapeutic interpersonal relationships with team members and patients
- a practice environment that enables a person-centred approach to the organisation of care services (McCormack & Ford 1999).

There is little empirical evidence to support the effectiveness of person-centred approaches to health care in nursing; however, the focus on the environments of care (both physical and experiential), especially for hospital patients or residents in nursing homes, is an important addition to the conceptualisation of person-centred health care.

Occupational Therapy (client-centred practice)

The Canadian Association of Occupational Therapists has spent more than 20 years investigating what is meant by client-centred practice and how to put it into practice among occupational therapists. In 1983, in collaboration with the Department of National Health and Welfare, the Canadian Association of Occupational Therapists introduced national guidelines for occupational therapy practice based on an ideological concept of 'client-centredness' (Townsend, Brintnell, & Staisey 1990a). The guidelines described a seven-stage process for working with clients from referral through to evaluation.

The conceptual framework discussed five key concepts for client-centred practice. These include:

- the need to consider the worth of the individual as an important and active participant
- the need to view man (sic) holistically
- the therapeutic use of activity/occupation
- the need to consider the person's life stage and role demands (Townsend et al. 1990a).

The Canadian guidelines were initially based on the definition of client-centred practice articulated by Carl Rogers in the 1950s and 1960s. Current conceptualisation of client-centredness in Canada is presented in the new Canadian Model of Occupational Performance. This was published in the most recent version of the guideline document, *Enabling occupation: an occupational therapy perspective* (Canadian Association of Occupational Therapists 1997, as cited in Townsend 1998). Client-centred occupational therapy practice is defined in *Enabling occupation* as:

- Collaborative and partnership approaches used in enabling occupation with clients ... therapists demonstrate respect for clients, involve clients in decision making, advocate with and for client's need, and otherwise recognise client's experience and knowledge (Canadian Association of Occupational Therapists 1997, as cited in Falardeau & Durand 2002, p. 136).

Law, Baptiste and Mills (1995) outline seven key concepts of client-centredness, including:

- autonomy and choice – assumes clients' opinions will be sought, values respected and dignity maintained. It refers to a client having the right to receive information in a manner they can understand so they can make choices about their care
- partnership and responsibility – includes the acknowledgement that each person in the partnership brings with them expert knowledge and skills
- responsibility – identifies the goal of a person-centred relationship as being an interdependent partnership with both parties having responsibilities. For example, clients have a responsibility to take on a more active role in defining problems, goals and outcomes. Service providers have a responsibility to act as a facilitator in working with the client to find the means and the options for achieving these goals

- enablement – in the context of the shift from a medical to social model of health, enablement incorporates the change in focus from illness to wellness, the change in outcome measures from acute care outcomes to function and life satisfaction, and the consideration of client's capabilities versus deficiencies
- contextual congruence – the importance of understanding the client's roles, values, interests and the environment and culture in which they live as central to the process of providing client-centred care
- accessibility and flexibility – advocates for equitable service provision that is provided in a timely and accessible manner to meet the needs of the client
- respect for diversity – the need to respect differences in values and beliefs, and being aware of the balance of power within the relationship

There are five volumes of guidelines. Volume 1 presented the generic conceptual framework for client-centred practice and provided specific assessment and program planning guidelines. Volume 2 presented specific guidelines related to intervention as well as discharge, follow-up and evaluation. Volume 3 reviewed issues in outcome measurement related to occupational performance and Volume 4 was the consolidation and brief update of the first three guidelines documents. The Canadian Occupational Performance Measure (Townsend et al. 1990a) was developed in part as a response to the inadequacies of existing outcome measures found in writing Volume 3. The fifth guideline document was the only document that targeted a specific area of practice – mental health. This document was entitled *Occupational therapy guidelines for client-centred mental health practice* (Canadian Association of Occupational Therapists 1997, as cited in Townsend 1998).

The guidelines are well known in Canada (Sumsion 1993) and have been subject to many revisions (McColl & Pranger 1994a; Sumsion 1993; Townsend 1998). The Canadian Association of Occupational Therapists guidelines impact study investigated the use and usefulness of the guidelines for client-centred occupational therapy practice (Blain & Townsend 1993). They identified that between 25 per cent and 50 per cent of respondents used some of the guidelines in most of their work, with 57 per cent of survey respondents finding the guidelines useful overall. Volume 1 was the most frequently referred to document by those directly involved in administering occupational therapy services, particularly those in acute care and rehabilitation settings (as opposed to those working in community settings). Volumes 2 and 3 of the guidelines were identified as more useful to managers or researchers involved in program development and evaluation. Interviewees identified that one of the most useful sections of the guidelines was the generic, conceptual model of occupational performance (Volume 1). Blain and Townsend (1993) found the guidelines had not produced a fundamental shift from traditional practice to a client-centred practice but had encouraged considerable growth by occupational therapists towards such a shift.

Recommendations for updating the guidelines included the need for more examples (74 per cent) and greater clarity of definitions and language used within the document. Some therapists identified that they liked to use the guidelines as a checklist–a reminder of what areas they should consider. Blain and Townsend (1993) noted the tension between the guidelines' authors' desire to define the conceptual framework of practice and the therapists' desire for a practical guide that is simple and easy to access in various clinical, administrative, education and research situations.

Various authors have written about the application of the guidelines for occupational therapists working with clients with depression (Waters 1995, as cited in Blain & Townsend 1993), clients with cognitive impairment (Hobson 1996, as cited in Blain & Townsend 1993), and paediatric clients (Stewart & Harvey 1990, as cited in Corring & Cook 1999).

In 1994, McColl and Pranger evaluated the 'Guidelines Model' for its use conceptually and practically. They concluded the guidelines' use as a conceptual model was sound, but identified various problems when considering its practical applicability.

In summary, while not all occupational therapists have adopted the Canadian Association of Occupational Therapy guidelines, the occupational therapy profession has contributed a great deal to the development of a client-centred approach to practice, including the development of guidelines to assist with implementing this work across the profession.

Hospitality

One paper argues that in today's competitive health care market, where consumers are knowledgeable about health care choices and costs and are becoming more vocal about their preferences, lessons can be learnt from the hospitality industry. Ford and Fottler (2000) argue that traditionally, health care organisations have focused on the needs and preferences of medical staff and funding bodies. This has led to a system that is fragmented and difficult for service users to understand and navigate. They suggest a new paradigm in which patients are considered as customers in a total health care experience.

Ten principles drawn from the hospitality industry and proposed for hospital care 'guests' are:

1. Service quality and value are always defined by the customer.
2. Customer participation adds value and quality to their service experience.
3. Everyone must believe the customer matters and act that way (customer-focused culture).
4. Find, hire and train competent and caring employees.
5. Customers expect employees who are not only well trained but have good interpersonal skills.
6. Customers expect the service experience to be seamless.
7. Avoid making your customers wait for the service.
8. Create the setting (environment) the customer expects.
9. Measure all aspects of the service experience (what gets measured gets managed). Ask customers about their experience at the time the service is being delivered.
10. Commit to continuous quality improvement (Ford & Fottler 2000).

Aspects of this approach are consistent with the principles outlined in the medical, nursing and allied health models described above. The emphasis on seamless care is an important addition.

Diagnosis/disease-based models of person-centred care

A substantial proportion of the literature on person-centred health care focuses on specific diagnostic groups. Literature about person-centred care with people with chronic illness, dementia and neurological conditions, as well as person-centred care in mental health and palliative care settings, is described below. More detail can be found in Appendix D.

Chronic illness

Renders and colleagues (2000) systematically reviewed 41 studies with the aim of determining the effectiveness of different interventions, targeted at health professionals or organisations, for improving care of patients with diabetes. It was concluded that multifaceted interventions, such as educational interventions combined with auditing and feedback, can enhance the performance of health professionals in caring for patients with diabetes. It was also found that including patient-oriented interventions can improve patient outcomes; however, patient-oriented interventions were not looked at in isolation.

Michie, Miles and Weinman (2003) conducted a review of 30 studies that measured health professional-patient interaction and a physical or psychological outcome for the patient. They divided the studies into two categories: those where the health professionals took the patient's perspective (that is, there is a match between professionals' and patients' perceptions of the illness) and those where health professionals sought to 'activate' the patient (that is, the patient is encouraged to take some control and ask questions). The second group of studies was associated with more positive health outcomes for patients than the first. They concluded that different types of patient-centredness may result in different outcomes for patients.

Some self-management techniques with people with chronic illness have been found to result in improved health outcomes. Three randomised controlled trials involving patients with ulcerative colitis found that providing patients with a self-management guidebook reduced the use of hospital services, decreased the number of disease relapses and improved their knowledge of their disease (Kennedy, Nelson, Reeves, Richardson, Roberts, Robinson, Rogers, Sculpher, & Thompson 2003a; Kennedy, Robinson, Hann, Thompson, & Wilkin 2003b; Kennedy, Nelson, Reeves, Richardson, Roberts, Robinson, Rogers, Sculpher, & Thompson 2004). In another study with patients with ulcerative colitis (Robinson, Thompson, Wilkin, & Roberts 2001), the participants worked with their clinician to develop a personalised guided self-management regimen, which aimed to ensure the patient could recognise a relapse and knew what to do during a relapse. There was no significant difference found in the number of relapses between the intervention and control groups; however, it was found that the patients in the intervention group were more likely to self-treat their relapse and less likely to make appointments with the outpatient clinic or family physician compared with the control group. In all the randomised or cluster-randomised controlled trials with ulcerative colitis patients, the person-centred approach to the management of the disease was favoured by the majority of the patients over the usual care that was provided.

Education and training of health professionals in person-centred care was examined in two randomised controlled trials. Alamo, Moral, and Perula de Torres (2002) found that patients suffering from benign chronic musculoskeletal pain had improvements in measures such as pain and anxiety over a 12-month period when doctors were trained in person-centred consultations. Similarly, Kinmonth and colleagues (1998) found that wellbeing was better in diabetic patients who received a patient-centred approach from health professionals. In addition, the intervention group reported greater satisfaction with their treatment compared with the control group.

In conclusion, it appears that providing health professionals with further training in person-centred approaches to health care management or person-centred approaches that actively involve the patient or providing patients with self-management techniques can improve outcomes for people with chronic illness.

Dementia

Kitwood (1997) is well recognised for his contribution to person-centred care for people with dementia. He argued for a change to the traditional approaches to dementia care, away from one that focuses on the deficits of the person to one that recognises and validates the essential personhood of the older person with dementia. Kitwood developed dementia care mapping, an observation tool designed to examine quality of care from the perspective of the person with dementia. Dementia care mapping is grounded in the philosophy of person-centred care, which promotes the personhood of people with dementia and an holistic approach to their care. It is part of a process of bringing about improvements to care, and is designed to be used only in formal care settings.

Cheston (1998), drawing on Kitwood's (1997) work, identified the following principles of good dementia care:

- regular and structured activity
- activity taking place at the recreational, interpersonal and therapeutic levels
- buttressing the dementia sufferers' sense of themselves as people of worth and value.

Kitwood (1997) focused on the therapeutic interaction (relationship) between clients and carers. He identified ten types of interaction required from the therapist in dementia care:

- recognition – the person with dementia is acknowledged as a person, for example, greeted by name
- negotiation – people with dementia are consulted about their preferences
- collaboration – working together with the person with dementia

- play – where older people with dementia are allowed to be spontaneous and express themselves
- timalation – sensuous or sensual interactions, such as aroma therapy and massage, particularly for those people whose dementia is severe
- celebration – experience of the joy of life by both carer and person with dementia
- relaxation – opportunities for relaxation in solitude or with the help of a carer
- validation – acknowledgment of the person with dementia's emotions and feelings and responding at a feeling level
- holding – to provide a safe psychological space for the expression of frightening or overwhelming feelings, such as grief or anger
- facilitation – enabling the person with dementia to do those things that he or she would otherwise not be able to do.

Kitwood (1997) further identified two types of interaction initiated by the person with dementia: creation, where the person with dementia offers something, such as a song or dance, in a social setting and giving, where the person with dementia offers a gift or another expression of compassion or gratitude.

Kitwood also discussed the organisational characteristics that support and confound good practice. He suggested that the way staff are treated by their organisation will be reflected in the way they treat their older clients. Therefore, staff need to feel respected, valued, free to express their opinions and secure in much the same ways as their older clients do.

Brooker (2004) presents Kitwood's style for representing complex ideas in the form of an equation: PCC (person-centred care) = V+I+P+S. The elements V, I, P and S represent:

- valuing people with dementia and those who care for them (V)
- treating people as individuals (I)
- looking at the world from the perspective of the person with dementia (P)
- a positive social environment in which the person living with dementia can experience relative wellbeing (S).

Other authors have identified various aspects and approaches to care as being important in person-centred care for people with dementia. In the context of a person-centred approach to care, knowing the person's life history and that person's reactions to events and experiences in their life is an extremely important part of any assessment process (Dewing & Garner 1998). It has been reported that it is vital that people with dementia are told of their diagnosis at an early stage so they can make decisions about their future (Jackson 2002). In a review of the literature of the needs of younger people with dementia (under 65 years of age) in residential care, lack of consultation with younger people with dementia about their needs and perceptions was reported (Beattie, Daker-White, Gilliard, & Means 2002). This review also identified good practice examples in working with younger people with dementia, including involving the person, having services to meet needs of the individual, needing a co-ordinated integrated pathway, and providing flexible and responsive person-centred services.

Neal and Briggs (2003) conducted a review of randomised controlled trials examining validation therapy as an intervention for people diagnosed as having dementia of any type or cognitive impairment. They concluded that there was no evidence of the efficacy of validation therapy for people with dementia or cognitive impairment.

Finally, working with family carers has been identified as an important aspect of person-centred care for people with dementia. The family carers' perspective in relation to 'best care' for the person with dementia was explored in a recent study (Ericson, Hellstrom, Lundh, & Nolan 2001). This study explored differences in the family and professional carers' perspectives. Results suggest that professional and family carers are aiming for the same overall goals, at least insofar as the person with dementia is concerned, focusing on the individual needs of the person with dementia, and that a suitable environment was essential to the delivery of good care. There were, however, differences in emphasis concerning both who has the most important type of knowledge and the role and value of institutional care. Although the individual's own home was seen as the environment of choice, professionals, more so than carers, saw the benefits of alternative environments when the need arose.

Neurological conditions

The literature on person-centred health care with people with neurological conditions focuses on care pathways for stroke, rehabilitation (including stroke rehabilitation, rehabilitation in the home versus the hospital, respect for autonomy in neurological rehabilitation, and quality of head injury rehabilitation), collaborations between people with brain injury and treatment teams, experiences with the Canadian Occupational Performance Measure in Taiwan, and goal planning processes with spinal cord injury patients.

Kwan and Sandercock (2004) reviewed three randomised controlled trials and 12 non-randomised studies that compared in-hospital care pathways for stroke with standard medical care. Patients managed with a care pathway were more likely to be functionally dependent on discharge, have lower quality of life scales and be less satisfied with their hospital care but were less likely to have a urinary tract infection or to be readmitted. They concluded that there was insufficient evidence to justify introducing care pathways for the routine care of all patients with stroke.

The following principles were identified as important in considering person-centred care for people with neurological conditions:

- spirituality, especially for stroke patients for whom the stroke may precipitate a reassessment of life priorities and meanings (Watson & Quinn 1998)
- active inclusion of the client (Abreu, Zhang, Seale, Primeau, & Jones 2002) and relevant others (Chan 2002)
- working in partnership (Chan 2002)
- holistic assessment (Chan 2002; Watson & Quinn 1998)
- interdisciplinary model of care (Watson & Quinn 1998)
- sharing power with the client (Chan 2002).

Abreu and colleagues (2002) discussed the active inclusion of clients in their qualitative research observing interdisciplinary team meetings at a post acute brain injury rehabilitation centre. They found that by just including patients in activities such as team meetings, successful collaboration would not automatically occur. In their observational study, the authors identified that teams who said they were interdisciplinary often still worked in a multidisciplinary way and that despite clients attending 'interdisciplinary' meetings, they still often lacked a voice and were dealt with in a patronising and less than equal manner.

Chan (2002) proposed that client-centred practice could be viewed within the context of the International Classification of Function, a view also held by Von Koch, Wottrich, and Widén Holmqvist (1998). Within the International Classification of Function framework, problems and goals set at different levels bring about differences in behaviours, partnerships and responsibilities. For example, an impairment-based goal, such as improving upper limb range of motion, may require more assessment and input from a therapist and could be achieved with less active involvement from the client; however, change at the level of participation can only be achieved with active participation of the client. Chan also argued that while it was necessary to move towards person-centred care in the context of an increasing chronic disease population, questions of how it would be evaluated and whether it was a luxury ideal needed to be debated.

Authors writing about neurological rehabilitation identified a number of enablers for providing person-centred care. Watson and Quinn (1998) identified the following as things that facilitate person-centred care: having access to an interdisciplinary team, having knowledgeable and enthusiastic staff, and working within an organisation that supports the necessary culture change required to achieve it.

Chen, Rodger and Polatjko (2002) found that using the Canadian Occupational Performance Measure in an adult neurological rehabilitation centre in Taiwan assisted in achieving person-centred outcomes. They also noted that skills in reflective listening and experiential learning were crucial for the philosophy of person-centred health care to be translated into practice. Chan (2002) also reinforced that to facilitate autonomy and choice, information and education need to be provided within a framework of trust and respect.

Von Koch and colleagues (1998) reported on the benefit of the home as an opportunity for providing person-centred care. In their qualitative case study, the authors observed therapists and patients treated in two different contexts: the home and the hospital. In hospital, the therapist's role was noted to be that of teacher and expert offering no explanation for the purpose of sessions, providing impairment-based intervention and not seeking client goals. For the patient, the hospital was seen to be an unfamiliar environment, which did not invite them to take initiative or assume responsibility. At home, a different set of behaviours was observed: the therapist was seen as adopting many roles–those of guest ('Can I use the phone?'), friend (sharing a coffee break) and student (listening)–and they used functional activities more for intervention. For the patient, the home was seen to support patient initiative and confidence and seemed to prompt goal setting and execution of choice, including the choice to not participate. Similar findings were reported in the evaluation of home-based rehabilitation undertaken at the National Ageing Research Institute during 2002–04 (Dow, Black, Bremner, & Fearn 2004).

The literature on neurological rehabilitation also identified various barriers to person-centred care, including the shift from multidisciplinary care to interdisciplinary or transdisciplinary care models, which were seen as difficult for staff wanting to protect professional boundaries (Watson & Quinn 1998).

Chen and colleagues (2002), in their research of the Canadian Occupational Performance Measure and person-centred practice, identified increase in time and staff workload as a barrier for some therapists. MacLeod and MacLeod (1996) also identified increased staff workload despite other benefits when implementing a goal setting process for spinal cord clients. Therapists in the Chen study also identified a lack of knowledge of and confidence in implementing a person-centred approach and reported finding it difficult to explain to clients, particularly ones who expected a more traditional paternalistic or medical approach to care. One therapist commented on the fear that therapists could be perceived as being 'less skilled' and 'less professional' when adopting this approach to service provision.

Another identified barrier for staff was that being person-centred required a broader evidence base because staff needed to be able to present all the options in order for clients to be able to execute choice and autonomy. Sim (1998) identified difficulties implementing the approach with a neurological rehabilitation cohort. These difficulties included communication with cognitively impaired patients or patients with a speech and language deficit, issues regarding competence to make decisions, and problems of consensus between patient and professional as well as between patient, professional and families.

Von Koch and colleagues (1998) also identified that the shift in power facilitated by working in the home could be threatening for some therapists; however, they also state that the hospital can be a disempowering context and suggest if working with patients in hospital it is important to encourage them to take on additional roles (from that of patient/student) to help them better deal with the consequences of disease.

Mental health

The person-centred mental health literature covered a range of areas including the introduction of individual-based approaches, factors that promote and prevent partnership between community mental health service users and occupational therapists, nurses' experiences in implementing the Tidal Model (described later), use of participatory action research, and exploring clients' definitions of health. With the exception of the study by O'Donnell and colleagues (1999), most studies used qualitative approaches to explore the experiences of service providers and service users.

The study by O'Donnell and colleagues (1999) aimed to empower clients by establishing parity between clients and staff and involving clients in the rehabilitative process in a way that promoted their respect, dignity and self-determination. The study found that there appeared to be greater satisfaction with case management for clients who were involved in the client-focused case management groups compared with those in the routine case management group; however, case managers commented that time was a barrier to implementing client-centred care.

In a study by Blank, conducted in 2004, seven interviews were conducted with users of mental health services in which they were asked to comment on the factors that assisted or impeded a positive relationship with their occupational therapists. They identified that they felt more positive about therapists who they perceived as being skilled in communication, who were accepting and non-judgemental and able to promote their strengths. The interviewees did not identify their relationships with occupational therapists as partnerships unless prompted. The author concluded that clients with mental health issues may not value the concept of partnership as much as feeling valued, listened to and cared for. However, another study described under the section on service user perspectives (later) found that clients did want a more equal partnership with health professionals (Corring & Cook 1999).

In a study by Fletcher and Stevenson (2001), the Tidal Model was introduced into a pilot ward and data were collected six months prior to implementation and six months after. Their findings suggest that the introduction of this client-centred model of nursing practice might have positive effects on factors such as bed occupancy.

The Tidal Model has three different but related dimensions of care:

1. world dimension – focuses on person's need to be understood
2. self dimension – focuses on person's need for physical and emotional security
3. others' dimension – emphasises the kinds of support the person might need from a wide range of people and agencies to be able to live an ordinary life.

In another qualitative study involving mental health nurses, comparisons were made between hospital and home nursing care. Interviewees identified their role in an institutional setting with patients with mental health issues as care management–the nursing role was linked to an illness perspective, in which the person with mental health problems was viewed as an 'object' of nurse-controlled care. Whereas when the context of care changed to the patient's home, the nurses reported that their professional and moral responsibility became less clear. They began to listen to the needs of their patient in a client-centred manner and their responsibilities were based on a process of negotiation, grounded in mutual trust, and on their assessments of the client's functional resources as opposed to signs of illness (Magnusson, Severinsson, & Lutzen 2003). This study supports the findings of von Koch and colleagues (1998) and Dow and colleagues (2004), described earlier in the neurological rehabilitation section.

A major focus of the mental health literature on person-centred health care is on empowerment, and several studies found that clients with mental health problems had better outcomes if they felt empowered. The focus on empowerment was also evident in the way in which studies obtaining service user perspectives were conducted (Blank 2004; Corring & Cook 1999; Meek 1998; Yurkovich, Smyer, & Dean 1999). However, several studies stressed the importance of the personal qualities of the service provider in working with service users with mental health problems. Service users valued service providers who were able to communicate empathy, respect and an interest in the service user (Blank 2004; Meek 1998; Yurkovich et al. 1999).

Palliative care

The notion of person-centred health care is central to palliative care because in this field there is less of a focus on curative medicine and more of a focus on the person's quality of life, including freedom from pain. It becomes even more important to focus on each person as an individual, to be holistic in approach and to be flexible in service delivery when the service user has a limited life expectancy. Person-centred health care was identified as particularly important in the palliative care literature because of factors such as:

- the practical need to balance quality of life and the management of symptoms (Chaplin 2004)
- the understanding that patients are individuals and their needs and how they perceive and manage situations differ and can be influenced by environmental and personal factors, such as level of social support, individual coping styles and stage of disease (Chaplin 2004; Dowsett, Saul, Butow, Dunn, Boyer, Findlow, & Dunsmore 2000)
- the understanding that individual patient needs, values and priorities may vary over time; for example, as people are dying, various dimensions may acquire new significance, such as spirituality and transcedence (Black 2004; Teno, Byock, & Field 1999).

The palliative care literature focused on the following aspects of person-centred care:

- the need to develop a partnership of care which advocates mutual respect for the role of all parties in the relationship: patient, significant others and health professionals (Ashby & Dowding 2001; Black 2004; Ellis 1999)
- the need to provide accessible services in a flexible manner (Casarett, Karlawish, & Byock 2002) which responds to changing patient needs and priorities (Dowsett et al. 2000).

The personal qualities and skills of service providers, such as having respect for the patient and their values and beliefs, were stressed in the palliative care literature; for example:

- getting close to the patient. Chaplin (2004) described this as 'making real human contact' (also see Dowsett et al. 2000)
- active listening (to better understand the client's understanding of their health condition and their hopes and fears) and avoiding assumptions about what the patient is or is not experiencing (Chaplin 2004)
- involving the patient (and relative/significant others) in decision making (Tobias & Hamilton 2002)
- establishing trust so that information sharing can occur
- providing holistic assessment (Ashby & Dowding 2001) and interdisciplinary care (Black 2004) which is constantly re-evaluating. Falardeau and Durand (2002) write that issues of consent, for example, should be considered as part of an ongoing process rather than a one-off event
- providing information in a manner that can be understood and providing information on consequences if choices are made that conflict with the 'norm' (Tobias & Hamilton 2002)
- identifying goals that are driven by the patient's needs and priorities but that are realistic and quality of life focused (Chaplin 2004).

The literature identified outcomes of implementing person-centred health care behaviours, including improved pain management (Ashby & Dowding 2001), improved patient and relative or friend satisfaction (Dowsett et al. 2000), improved adherence to intervention recommendations (Ashby & Dowding 2001), improved patient empowerment and motivation (Ellis 1999), and improved sense of professional worth (Ashby & Dowding 2001; Ellis 1999; Fraser, Eades, Glackin, & Holmes 2002). There was also some evidence that professional occupation may be a predictor for preferring a person-centred communication style (Dowsett et al. 2000).

Enablers for adopting person-centred principles identified in the literature include having skilled staff (Chaplin 2004) and having staff who believe in the merit of working in a person-centred way (Ellis 1999). Improving staff members understanding of their own values and beliefs and allowing staff to express their concerns were also identified as being beneficial for effective staff training in a person-centred care approach (Ellis 1999). Skill training was considered necessary, with Chaplin stating that skills of this nature should not be assumed. Ellis wrote about the benefits of staff being trained in the use of reflection and experiential learning.

Barriers identified include the lack of a benchmark about what is good person-centred practice (Casarett et al. 2002), lack of group support for the philosophy (Ellis 1999), and health care professional frustration when patients make decisions that conflict with their own beliefs (Ashby & Dowding 2001). Ellis also wrote about the need for broad philosophical change as opposed to simply implementing forms or practices.

Service user perspectives

In the literature reviewed here, there were few studies that explored what is important to older health service users themselves. As noted earlier, four of the mental health studies canvassed the views of service users and one of the nursing papers included older service users as well as nurses in determining the practices that help to ensure good care from an older person's perspective within an acute hospital environment (Davies et al. 1999).

There is some debate as to whether there is consensus between service users' and providers' perceptions of health care. One study found that there was consensus between health care professionals, managers, patients and relatives in their concept of quality care (Attree 2001). They identified three categories of criteria for identifying quality care: care resources (human and environmental resources); process criteria, including care practices, standards and interpersonal processes; and outcome criteria, including patient satisfaction and health progress. Other research, however, has found that there are differences between the aspects of care that service users and service providers perceive as important (Johnson & Webb 1995) and that discrepancies exist between clients' and professionals' opinions on health service practice (Sullivan & Yudelowitz 1996).

Research previously conducted at the National Ageing Research Institute found that there are differences in the ways older service users and service providers perceive health (Haralambous, Black, Nankervis, & Giummarra 2004) and in their perceptions of what is important in rehabilitation service provision (Dow et al. 2004). In the latter study, service users identified being at home with their family and friends, having friendly and caring staff and follow-up as important aspects of service provision. Service providers also thought the home environment was important, but for different reasons. They believed the home environment enabled a realistic assessment to be conducted and therefore rehabilitation therapy was better tailored to the client's individual needs.

The study by Davies and colleagues (1999), which included older service user and service provider perspectives on acute health care, identified four principles of good care:

- valuing fundamental practice – giving priority to the essential care needs of older people, such as help with personal hygiene, nutrition and going to the toilet
- fostering stability while embracing challenge
- establishing clear and equitable therapeutic goals; for example, older people having the same access to services as younger people; treatment goals set in consultation with older people/family and these being constantly reviewed
- commitment to an explicit and shared set of values.

Corring and Cook (1999) conducted a qualitative research study to gain participants' perspectives about what client-centred care should be, based on their own experiences with health services. They found that clients believed service providers should:

- value and appreciate the life experience of their clients; recognise the client's expert knowledge
- respect different opinions

- ‘get close’; ‘be welcoming’
- take the time to listen; get to know the person
- be person-focused as opposed to paper-focused
- develop a common ground/common respect
- relinquish control and power; facilitate an active client role
- learn from their clients (client role in education)
- advocate for the client
- be flexible
- consider not just the health condition, but the whole person.

Despite the research by Davies and colleagues (1999) indicating discrepancies between client and staff views, the aspects of person-centred care identified in Corring and Cook’s (1999) study are very consistent with the principles of person-centred practice identified in the majority of the literature reviewed in this report.

There is very little published research documenting what service users regard as important in health care generally. Satisfaction surveys are widely used and usually find that service users are highly satisfied with the service, but service users are rarely involved in developing the surveys so they may not reflect what is important to them. Further, the positive responses may be a result of the respondent’s relationship with the staff or program that is being assessed or the social desirability of these responses (Clark, Scott, & Krupa 1993).

In the Victorian Patient Satisfaction Monitor Annual Survey, a survey of patient satisfaction in acute care settings in Victoria, older patients tended to report lower levels of dissatisfaction than their younger counterparts (TQA Research Pty Ltd 2003); however, there were some items with greater than 10 per cent fair or poor ratings overall which had higher proportions of older respondents giving the fair or poor response. These were the quality of the food overall (27 per cent of respondents aged 65 years and over), privacy in the room where a patient spent most time (26 per cent of respondents aged 65 years and over), and the temperature of hot meals (22 per cent of respondents aged 65 years and over).

Despite the extensive literature advocating person-centred approaches to health care, these approaches generally have not been extended to research into the area. Service users generally have not been involved in determining what person-centred health care means. There is therefore insufficient evidence about what older people see as important in health care. More detail about the literature that includes service users’ perspectives can be found in Appendix E.

Carers

Very few papers identified in this review focused on person-centred care with carers, although many of the commentary papers included carers in their discussion of person-centred care. One paper drew together the findings of studies conducted in Sweden and the United Kingdom which examined the impact on practice of various carer assessment tools. Both assessors and carers were interviewed about the experience of using the assessment tools and they were found to be generally effective in improving practice. They found that, used sensitively, carer assessment tools can draw the assessor’s attention to the contribution made by the carer, and give carers status as active partners in the care planning process. The paper concludes that home-care programs should change their mandate to include carers among their clients (Guberman, Nicholas, Nolan, Rembicki, Lundh, & Keefe 2003). The article notes Home and Community Care (HACC) services in Australia already have the mandate to include the carer as a client but there is still a general deficiency in service providers’ understanding of carer issues and inadequate resources to meet their needs. A second paper that focused specifically on carers noted that carer respite services need to be flexible, responsive and person-centred (Longshaw & Perks 2000).

People from culturally and linguistically diverse backgrounds

There is limited evidence available on person-centred care and people from culturally and linguistically diverse backgrounds, particularly older people of culturally and linguistically diverse backgrounds. It has been suggested that person-centred care may be primarily a Western concept, with most research originating from North America and Europe (Harkness

2005). In developing countries where health services are limited, there has been little published on the concept of person-centred care; however, in those countries there may be similar principles of care that are described differently or have not found their way into published literature. Perhaps the concept of person-centred care should start with the individual's right to health care?

It has also been suggested that some cultures value respect for authority over individual self-determination. However, one study conducted in Japan found that respondents preferred a collaborative role in decision making (71 per cent) to an active (12 per cent) or passive (17 per cent) role (Sekimoto, Asai, Ohnishi, Nishigaki, Fukui, Shimbo, & Imanaka 2004). The authors note that other research suggests that Japanese patients generally prefer the physician to make the final decision. If the key principle of person-centred care is to centre health care on the needs, wishes and values of the person receiving care, then their values should be respected (even if it means their respect for the authority overrides their capacity to participate in their own care).

Four studies reviewed here report on the significance of cultural factors in the care of people from culturally and linguistically diverse backgrounds. One study suggests that the principles of person-centred care (for example, goal setting and responding to the individual's specific needs) are the prime factors in the care relationship (Lie & Biswalo 1994). The author argues that cultural factors should be taken into account, but are not the most important features of the care relationship.

However, other research studies have reported that cultural factors are paramount in the care of people from culturally and linguistically diverse backgrounds. Two studies (Dyck 1989; Mitchell, Malak, & Small 1998) focused on the provision of culturally appropriate counselling. Both these studies recognised cultural issues as significant, reporting that service users have preference for counsellors from the same ethnic background (Mitchell et al. 1998) and allowing the client to reflect on cultural factors is critical (Dyck 1989). Similarly, in a study of the experiences of people with dementia and their carers, language, religious belief and observance, cultural factors (including food and personal care practices), and social support and coping mechanisms were identified as important issues for service providers to consider (Iliffe & Manthorpe 2004).

Benchmarking tools

Three main approaches to evaluating person-centred care are described in the literature. The first approach is to evaluate the person-centredness of a single clinical intervention (Stewart 1995) or the work of a single clinician (Salvatori, Baptiste, & Ward 2000) from the point of view of a trained observer or assessor, or through a self-report instrument, usually completed by the patient (Mead & Bower 2000).

The second approach is to assess client satisfaction with the service as a whole, including its person-centredness. An example of this approach is a tool developed to assess client perception of the quality of head injury rehabilitation services (Swaine, Dutil, Demers, & Gervais 2003). After reviewing the literature and existing satisfaction tools, the authors developed a questionnaire that includes five dimensions of care related to patient satisfaction. These are ecological care, including assessment and treatment in real life environments, client-centred care, including individualised care, quality of service providers, including competency of staff, and continuity of care, including transfers from one service to another.

The third approach is to evaluate the extent of person-centred practice within a health setting using a benchmarking tool or observation (Baker, Edwards, & Packer 2003a, 2003b, 2003c; Baker & Edwards 2002; Baker, Edwards, & Packer 2003d; Wellard, Lillibridge, Beanland, & Lewis 2003). An example of this approach is a patient-focused benchmarking tool developed in the United Kingdom by Baker and colleagues (2003a; 2003b; 2003c; 2002; 2003d). The tool was designed to address a gap in the Essence of care document. The *Essence of care* benchmarking for health practitioners has been an integral part of evaluating health services in the United Kingdom since February 2001; however, there was no measure of person-centred care in the *Essence of care* benchmark. Baker and colleages (2003a; 2003b; 2003c; 2002; 2003d) developed and piloted a tool for measuring person-centred care in health settings. It was initially based on the work of Kitwood (1997) with people with dementia, but the authors believe it is applicable across a range of health care settings. The tool asks staff to rate their service on a scale of A to E with A representing best practice and E representing areas that need improvement on six factors. The six factors are:

- assessment of need
- providing person-centred support
- monitoring person-centred care
- reviewing person-centred care
- carer involvement
- organisational strategy.

The tool seems to have been designed for use within an action research approach, where a team discusses their current rating, identifies areas for improvement, then works with another group who can assist them to improve in the areas identified.

In another study that examined the extent of service user involvement on an Australian acute hospital ward, researchers compared the findings of three focus group discussions with observations made in a cardiovascular ward by a trained researcher of nursing practice. They found that there were discrepancies between nurses' espoused beliefs about practice and their conduct on the ward. For example, although participants stated that patients should be fully informed and involved in decision making, those making decisions about patient care were observed as doing so 'away from the bedside and apparently without consultation with patients' (Wellard et al. 2003, p. 258).

More detail about the literature on benchmarking tools can be found in Appendix F.

Summary

There has been a great deal written about person-centred approaches to health care over the past ten years. The key principles of these approaches have been identified independently by various discipline groups, by authors working with people with various diagnostic conditions, and to a lesser extent, by service users. Despite these different perspectives, there is substantial consistency about what constitutes person-centred practice, including client-centred practice and patient-centred care.

From the literature outlined in this report, it seems that the main features of person-centred health care derived from the literature can be encompassed within the concept of partnership. The overriding message is that person-centred care is about a collaborative and respectful partnership between the service provider and user. The service provider respects the contribution the service user can make to their own health, such as their values, goals, past experience, and knowledge of their own health needs, and the service user respects the contribution the service provider can make, including their professional expertise and knowledge, information about the options available to the service user, and their values and experience. Both the service provider and service user are important as people within the partnership, neither is interchangeable and the experiences of one cannot be generalised to another. The following principles of person-centred care, are all encompassed within the concept of partnership:

1. getting to know the patient or client as a person (holistic approach as well as individual approach)
2. sharing of power and responsibility (patient or client as expert in their own health, sharing of decision making, information, the idea of common ground)
3. accessibility and flexibility (of service provider as a person and of the services provided)
4. coordination and integration (consideration of the whole experience from the point of view of the service user)
5. having an environment that is conducive to person-centred care (supportive of staff working in a person-centred way and easy for service users to navigate).

The quality of the service provided (Ford & Fottler 2000) or the skills of the service provider (McCormack & Ford 1999) are also important dimensions of person-centred care, but are not explicit in all the approaches described here. There are other principles that are identified by only one discipline. For example, the medical approach includes health promotion and some of the nursing literature identifies saliency (seeing the most important issues and ways of responding to them) as principles of person-centred care.

Considering the vast amount of published literature on this topic, there is relatively little evidence presented about the effectiveness of practising in a person-centred way. It seems the shift towards person-centred care that is evident in this review is as much due to philosophical considerations (belief in the equality of the service provider-user relationship, belief in the expertise of the client and their rights to make their own decisions about their health care) as it is to evidence-based practice.

The predominance of qualitative and subjective research in this area may be due to the individual nature of person-centred care. The aspects of care that are person-centred for one service user may not suit the needs, wishes and values of another. It is therefore difficult to conduct randomised trials in which groups of people are subject to similar interventions.

However, the evidence that has been presented in the literature is largely supportive of person-centred approaches to care. Stewart (1995) found that the quality of communication between physician and patient, specifically asking questions about the patient's understanding, expectations and feelings and showing support and empathy, made a positive difference to patient health outcomes. O'Donnell and colleagues (1999) found that mental health clients were more satisfied with case management when they had been randomised to client-focused case management interventions (see also Kwan & Sandercock 2004). In the literature on chronic illness, education for practitioners in person-centred care and person-centred education for clients were both found to be beneficial for service users. There was also some evidence in the palliative care literature of improved pain management when working in partnership with clients (Ashby & Dowding 2001), improved patient and carer satisfaction, improved adherence to intervention recommendations, and improved sense of professional worth as outcomes of working in a person-centred way.

Conversely, a study on validation therapy, a person-centred approach to working with people with dementia, found no evidence of its efficacy (Neal & Briggs 2003). A review by Kwan and Sandercock (2004) found no evidence to support the introduction of care pathways for stroke patients, and prompt and reminder care by general practitioners was not found to be effective in improving seizure frequency or satisfaction among epilepsy patients (Thapar, Jacoby, Richens, Russell, Roberts, Porter, Wall, & Roland 2002).

Like the key features of person-centred care, the barriers and enablers to person-centred care are also consistent across the range of disciplines and client groups represented in the literature. The main barriers to person-centred care identified in this review are:

- time. Various studies stated that person-centred approaches to care take more time (Chan 2002; MacLeod & MacLeod 1996; O'Donnell et al. 1999)
- dissolution of professional power; that is, disagreeing with decisions made by the client, loss of professional status and decision making power (Ashby & Dowding 2001; von Koch et al. 1998; Watson & Quinn 1998)
- lack of autonomy to practice in this way (Jewell 1996; McCormack 2003b)
- the lack of clarity about what constitutes person-centred care (Casarett et al. 2002) making it more difficult to explain to clients (Watson & Quinn 1998)
- client communication difficulties (Sim 1998; Stewart 1995)
- the constraining nature of institutions (McCormack 2001), including impoverished environments of care (Nolan et al. 2004).

The enablers or opportunities for client-centred care are:

- skilled, knowledgeable and enthusiastic staff, especially those who have good communication skills with service users and other staff (Chan 2002; Chaplin 2004; Ellis 1999; McCormack & Ford 1999; Watson & Quinn 1998)
- opportunities for involving the service user, their carers, family and community (for example, volunteers) in health care (Chapman, Keating, & Eales 2003; Corring & Cook 1999; Davies et al. 1999; Legault & Ferguson-Pare 1999)
- providing the opportunity for staff to reflect their own values and beliefs and express their concerns (Chan 2002; Ellis 1999; McCormack & Ford 1999)
- opportunities for staff training and education and organisational support for this approach to practice (Chan 2002; Kitwood 1997; Watson & Quinn 1998)
- environment of mutual respect and trust (Chan 2002; Kitwood 1997; Nolan 2001), enriched environments (Nolan et al. 2004)
- being in the client's home (Dow et al. 2004; Magnusson et al. 2003; von Koch et al. 1998).

There were also some criticisms of person-centred approaches to care. These were:

- that the espoused method is not carried out in practice (Hopton 1997; Rycroft-Malone, Latter, Yerrell, & Shaw 2001)
- that person-centred care has not incorporated the views of the patient enough (Corring & Cook 1999)
- that it is too individualistic (Cribb 1999).

Cribb (1999) asks to what extent should we be focussing on individual needs as opposed to the needs of the whole patient population, especially where resources are scarce and what occurs with one patient can alter the availability of services for another. He argues that it is the direct practitioner's job to be somewhat partial to the needs of the individual client, but that the service manager needs to consider the needs of the client group as a whole.

Finally, there were some important gaps in the literature on person-centred health care. The main gaps in the literature identified in this review are:

- older service users' perspectives
- empirical evidence about the effectiveness or otherwise of these approaches.

Concluding remarks

This review does not attempt to provide the ultimate definition of person-centred health care, but presents a range of definitions for consideration. The review outlines and summarises the views of a diverse range of authors about what constitutes person-centred health care in a range of service settings and with a range of service user groups. It highlights the barriers and opportunities for person-centred health care, some criticisms of this approach, and some of the gaps in the literature.

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Appendix A: Parameters of the review

The literature review includes Australian and internationally published (peer reviewed) research relating to person-centred practice within the following parameters.

The following key words were used:

- person-centred practice
- person-centred care
- client-centred practice
- client-centred care
- consumer-focused practice
- consumer-focused care
- patient-centred care
- client goal setting.

The Cochrane Library and the Pubmed and Ovid databases (including Cinahl, Psychlit and Medline) were searched. The following articles were excluded:

- those published in or before 1994
- literature on paediatric clients
- literature that considered adults under the age of 70 unless they had complex care needs (for example, adults post traumatic brain injury or stroke).

Finally, recent Victorian reports that included direct feedback from clients or carers (or both) about their experience of health care, such as the *Evaluation of home-based rehabilitation in Victoria* report and the *Victorian Patient Satisfaction Monitor* report were also included in this review.

All four levels of evidence determined by the National Health and Medical Research Council[1] (1999) and qualitative research reports were included in this review.

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[1] Level One – Evidence obtained from a systematic review of all relevant randomised controlled trials.

Level Two – Evidence from at least one well-designed randomised controlled trial (where participants are randomised to the intervention/non intervention groups; or to different interventions).

Level Three – Evidence from well designed controlled trials without randomisation, or from well designed case controlled analytic studies preferably from more than one centre or research group, or from multiple time series.

Level Four – Opinion of respected authorities, based on clinical experience, descriptive studies, case series (either post-test or pre-test and post-test) or reports of expert committees.

Appendix B: Conceptual and theoretical frameworks

Fourteen articles were reviewed which focused on the conceptual and theoretical frameworks underpinning person-centred care. The study designs included eight discussion papers (including three critical discussion papers), two qualitative studies (one being a qualitative ethnography), a literature/practice review, a policy critique and a policy document, and guidelines for nurses (see Table 1).

The authors focused on the following areas: health promotion and successful ageing, client-centred counselling, the concept of autonomy (incorporating the World Health Organization framework), client/person-centred care and older people, person-centred care and nursing, and the role of doctors in person-centred care.

Table 1: Conceptual and theoretical frameworks underpinning person-centred care

Authors, date, aim	Study population, background, nature of intervention (including theory/ model of person-centred care)	Evidence of intervention effects/ major findings/comment
Biley 2002 Aim: To review the literature and practice on person-centred care with reference to Wales	In March 2001, the National Service Framework for Older People set out standards for the care and treatment of people over the age of 60 years in England. There are eight standards in the framework, including strategies to reduce falls, strokes and poor mental health and to improve general and intermediate care. Standard two is *'patient-centred care'*. The final standard, *'promoting health and active life in older age'* includes themes such as empowerment and improving quality of life for older people. Patient-centred care and the appointment of older people's champions are possible strategies to achieve this standard. Quality of life fundamental to healthy living for older people as defined by Viverais–Dresler et al. (1995) is *'... the process of enabling people to increase control over and improve their health'.* The article cites Nolan (2001): *'person-centred care must be driven by individual experience and quality of life – the meaning that older people give to their experiences and their description of what health and quality of life means to them is the key to really appreciating person-centred care'.* It also discusses that older people's champions may be important for encouraging older people to be their own champions.	Review of the literature suggests there are limited models of patient-centred health promotion. Themes in the literature on person-centred models are support, education, empowerment and individualised realistic goal setting; however, the evidence is limited. The paper is about health promotion for older people. Links the idea of health promotion to promoting quality of life and empowering older people – person-centred care Discusses the literature, the National Service Framework and some United Kingdom initiatives designed to promote health among older people Interesting conceptual link between health promotion and person-centred care

Table 1 continued

Authors, date, aim	Study population, background, nature of intervention (including theory/model of person-centred care)	Evidence of intervention effects/major findings/comment
Burnard 1995 Aim: To critically discuss client-centred practice and its applicability to nursing	Explores the concept of client-centred counselling and argues the approach is both limited and limiting in nursing practice Philosophical: explores the humanist/existential/individualistic antecedents of the client-centred approach to counselling	Explores the philosophical antecedents of Roger's client-centred approach and argues it is flawed (based on a belief in human 'goodness' and the idea that the client is the only one to have experienced the problem and therefore cannot benefit from the experience or advice of others). Argues that a balance between client-centred approaches, where advice is not offered and the client is seen as the expert on their own life, and some sharing, information and advice giving is required. Also argues there is still a need to get to know the client to determine what is required
Cardol, De Jong and Ward 2002 Aim: To discuss the concept of autonomy and its relationship to client-centred rehabilitation	Discusses handicap or participation (according to the World Health Organization framework) and suggests that the concept of autonomy needs to be considered together with participation: participation can only be assessed in the context of the client's personal preferences and ability to choose to participate or not, rather than by reference to a 'norm'. Makes the distinction between decisional and executional autonomy: the latter often being impossible for people with a disability but the former being dependent on the physical and psychological context Also critiques the liberal–individual notion of autonomy as independence therefore leading to measures of dependence being equated with quality of life. Argues for an extension of the concept to include an 'ethic of care', which incorporates the reality of interdependence as characteristic of human life not just associated with illness or disability. For some communities, interdependence within and between families may be valued more highly than individual autonomy. Raises the important question of individual independence/autonomy/choice being the main aim – perhaps interdependence: an interpersonal perspective is required, entailing responsibilities as well as rights where the views of others, including the therapist, are taken into account	
Corring 1999 Aim: To point out the omission of the client's perspective in the literature on client-centred care	Critiques the omission of the client's perspective in all the writing about client-centred care from Rogers in 1939 to the Canadian Association of Occupational Therapists (CAOT) over the past 15 years	
Cribb 1999 Aim: To discuss the ethical issues associated with client-centred practice within a contracting health service system	The paper discusses the ethical dilemma/conflict between policy and institutional aims of reduction in health care expenditure and the promotion of personal responsibility, private ownership and entrepreneurship and the individual practitioner's aim of promoting person-centred care. The author identifies three components of person-centred care: • person-centredness as a recognition of individuality or specificity • person-centredness as a recognition of holism; that is, of the range of considerations and contexts that are constitutive of persons • person-centredness as a recognition of autonomy; that is, a concern to respect people as to some degree self-defining and self-creating and to work *with* them not just *on* them.	

Table 1 continued

Authors, date, aim	Study population, background, nature of intervention (including theory/ model of person-centred care)	Evidence of intervention effects/ major findings/comment
	Person-centred approaches to health care include those where *'health professional at least take into account and seek to respond to patients' particular personal and social circumstances and considered preferences'* (p. 416). However, Cribb raises the question, 'At what point does person-centred care move from being a necessary feature of tailoring effective care to becoming an illegitimate indulgence of one patient at the expense of others?' (p. 416). The article discusses the personal bonds between health professionals and their patients and argues that there should be some degree of partiality–advocacy of their needs and preferences. However, service managers need to consider service users as a group, not enter the life worlds of individual patients but exercise impartiality and represent the population of patients. Cribb argues that some results–oriented institutional norms can reinforce impersonal rather than person-centred perspectives and that individual practitioners are therefore placed in a position where they have to decide how much they will challenge or stretch those norms on behalf of the needs of those patients to whom they have a particular commitment. The article mainly addresses questions from the point of view of the ethics of 'league tables' where institutions are judged according to certain criteria (perhaps throughput, length of stay, and so on) but does raise an interesting question about the balance of person-centred care–that is, focusing on individual needs as opposed to the needs of the whole group or population of patients. What kinds and degrees of person-centred care are desirable?	
Department of Human Services 2003	Identifies person-centred care as a cornerstone in the delivery of health services to older people in Victoria	
Hopton 1997 Aim: To point out the discrepancy between the espoused philosophy and practice of mental health nursing	Critique of mental health nursing: falsely claiming to be radical and sensitive to users, despite the dissenting voices of the anti-psychiatry movement. Needs to widen its focus from interpersonal to historical, structural and ideological influences on mental health services and the causation of mental distress. Critical theoretical approach	
Johnson and Webb 1995 Aim: To report on a qualitative ethnographic study that identified the power struggles between nurses and patients within a hospital medical ward	Ethnography of a hospital medical ward Nursing Critical	Argues that rather than patients and nurses having mutual goals and a collaborative relationship, nurse-patient relationships are beset by struggle and conflict frequently resulting in patients acquiescing to medical and nursing goals of care
Lutz and Bowers 2000 Aim: 1. To analyse the health care literature around how patient-centred care is defined or implemented in health care 2. To look at issues related to implementing a patient-centred philosophy and to identify the implications for nursing	Review and analysis of the literature	Described the history of providing medical and nursing care. Described the literature on person-centred care as falling into two categories. The first describes person-centred care in terms of the re-organisation of services around patients' needs. The second considers person-centred care in terms of understanding patient-perceived needs, priorities and expectations of health care. The review found that person-centred care is still more often than not implemented from a provider-centred, disease-focused framework resulting in outcomes and care that is not congruent with patient preference. The authors recommend that

Table 1 continued

Authors, date, aim	Study population, background, nature of intervention (including theory/ model of person-centred care)	Evidence of intervention effects/ major findings/comment
		patient-centred care models need to be developed which consider and incorporate patient preferences and that nurses (in developing and implementing these models) need to be mindful of the underlying attitudes and assumptions that they bring to their work and research with patients.
Nelligan, Grinspun, Jonas-Simpson, McConnell, Peter, Pilkington, Balfour, Connolly, Lefebre, Reid-Haughian and Sherry 2002 Aim: To present person-centred care guidelines for nurses (Canada)	The Registered Nurses Association of Ontario's *Client centred care best practice guidelines* recommend that nurses embrace the following values/beliefs: • respect • human dignity • the belief that clients are the experts regarding their own lives. Clients should be given the opportunity to lead their own care as much as they choose and nurses should advocate for clients goals within the health care team. Also recommends continuity and consistency of care and caregiver and discusses the responsibilities of health care practitioners and administrators in working together to ensure these recommendations are incorporated into every aspect of client care and services	
Nolan 2001 Aim: To critique current understandings of person-centred care.	This paper charts the emergence of notions of successful ageing, health-related quality of life and person-centred care. It argues that these developments reflect the importance given to autonomy and independence, values that can disadvantage the oldest and frailest members of society.	Suggests that there is a need for a more inclusive conceptualisation of person-centred care, which recognises the values of interdependence and reciprocity
Rourke 1991 Aim: To explore the relationship between Orem's self-care model of nursing and the challenges it suggests for nursing practice and belief	Early discussion of the shift away from a medical model to an individualistic patient-centred approach. Explores the relationship between Orem's self-care model of nursing and the challenges it suggests for nursing practice and belief	Discusses Orem's model of self-care, which has three levels: universal, developmental and health deviation. At times people may need compensation in self-care (for example, assistance with air intake [universal self-care] during an operation); however, individual patient preferences and beliefs need to be taken into account when deciding on care plans. The article also discusses the role of individual beliefs in self-care (perception of the illness, readiness to undertake action for health and so on).
The Registered Nursing Association of Ontario 2002	Document developed to help articulate and support client-centred nursing practice in Canada. The guideline document has five main recommendations that relate to clinical practice, education and organisation/policy direction. The best practice document aims to help empower the client, improve client satisfaction and enhance quality of care and quality of work life. The guideline development process included an extensive literature review and consultation process.	
Veatch 2000 Aim: To explore the ethical dilemmas faced by doctors in pursuing patient-centred medicine	Ethical discussion about the role of doctors into the next century; how it is unrealistic to expect doctors to know what is of benefit to their patients	*'The result will be a duty to be loyal to the consumer of health care with the recognition that often this will mean that the physician is not permitted to pursue the physician's understanding of the patient's wellbeing'* (p. 701).

Appendix C: Discipline-based models

Thirty-seven documents were located which included discipline-based models of person-centred care. The study designs included discussion papers (one of these citing research into 'senses framework'), qualitative studies (including a qualitative evaluation and qualitative interviews), literature reviews, nursing best practice guidelines, an observational study using questionnaires, a review of randomised controlled trials and analytic studies (level II randomised controlled trial), and a commentary. The articles written by authors from the disciplines of medicine, nursing, psychology, and the hospitality industry are included in Table 2. The substantial body of literature from occupational therapy is included in a separate table (Table 3).

Table 2: Discipline models of person-centred care

Authors, date, aim	Study population, background, nature of intervention (including theory/ model of person-centred care)	Evidence of intervention effects/ major findings/comment
Davies, Nolan, Brown and Wilson 1999 Aim: To identify practices that help to ensure good care from an older person's perspective within an acute hospital environment Discipline: nursing (includes older people's perspectives)	Interviews with nurses and service users at 24 hospitals in England	Four principles identified to underpin good practice are: 1. valuing fundamental practice: giving priority to the essential care needs of older people, such as help with personal hygiene, nutrition and going to the toilet 2. fostering stability while embracing challenge 3. establishing clear and equitable therapeutic goals; for example, older people having the same access to services as younger people, treatment goals set in consultation with older people or their family and these goals being constantly reviewed 4. commitment to an explicit and shared set of values. Ten challenges were identified for improving the care experience: 1. Aim for continuity (staffing, effective interdisciplinary communication, supportive discharge packages). 2. Involve patients and family. 3. Involve local community (for example, volunteers). 4. Meet the needs of older patients with confusion or dementia (admit to ward wherever possible; involve specialist staff and family). 5. Meet the needs of older people from ethnic minorities (staff training; involving community representatives). 6. Help people come to terms with death on the ward (recognise older people form relationships on the ward). 7. Attend to small details for maintaining dignity (use of curtains; help patients dress in day clothes). 8. Demonstrate commitment to developing practice (clear leadership; feedback mechanisms regarding performance/ outcomes; professional development).

Table 2 continued

Authors, date, aim	Study population, background, nature of intervention (including theory/ model of person-centred care)	Evidence of intervention effects/ major findings/comment
		9. Develop specialist roles (expertise). 10. Manage change effectively. Identified the need for staff and older service users to experience a sense of wellbeing; considered in terms of 'six senses' (sense of security, significance, belonging, purpose, continuity, achievement). Various recommendations made to help guide practitioners and managers. For example: • Practitioners should *'try to provide the standard of care which they would like a close relative to receive'.* • Teams should *'take steps to guarantee that every older person has a named key worker…'.* • Managers should *'ensure that systems are in place for supporting staff development including appraisal, mentorship and clinical supervision'.*
Ford and Fottler 2000 Aim: To describe practices of the best guest-service organisations that may be transferable to health services Discipline: hospitality industry	Argues that in today's competitive health care market, where consumers are much more vocal and knowledgeable about health care choices and costs, lessons can be learnt from the hospitality sector Discusses applying the principles of the hospitality industry to health care Need to move away from an organisation that is focused primarily on medical staff and third party payers (old paradigm) to one that considers its patients as customers in a total health care experience	Ford and Fottler propose ten principles drawn from the hospitality industry which compose a new paradigm for hospital care 'guests' and notes the principles are consistent with cost-effectiveness and should not require radical re-organisation. They are: 1. Service quality and value are always defined by the customer. 2. Participation of guests adds value and quality to their service experience (customer participation). 3. Everyone must believe that the customer matters and act that way (customer-focused culture). 4. Find, hire and train competent and caring employees. 5. Customers expect employees who are not only well trained but have good interpersonal skills. 6. Customers expect the service experience to be seamless. 7. Avoid making your customers wait for service. 8. Create the setting (environment) the customer expects. 9. Measure all aspects of the service experience: what gets measured, gets managed. Ask customers about their experiences at the time the service is being delivered. 10.Commit to continuously improve.

Table 2 continued

Authors, date, aim	Study population, background, nature of intervention (including theory/ model of person-centred care)	Evidence of intervention effects/ major findings/comment
Ford and McCormack 2000 Aim: To present an overview of what it means to be a person and how this is articulated in person-centred approaches to nursing practice Discipline: nursing	Discussion of approaches to person-centred assessment Mentions a tool developed for nursing assessment Focus on assessment as the cornerstone of establishing the needs of the older person and attending to those needs in a person-centred way *'Person-centred approaches to practice represent a stage in the development of health care services at which the needs of the individual, rather than the professionals and organisations who meet those needs are held central ... a fundamental shift of philosophy in caring practice'* (p. 40).	Person-centred assessment should: • be humanistic (rather than behavioural) • be developed through a relationship of closeness and trust between the nurse and the patient • be approached through biography (understanding the person's history) • be based on the older person's values and the meanings they attribute to health • take into account the older person's abilities and strengths. The plan of care should be: • individualised • drawn from the user's biography • derived from the aspirations, needs and wants of the user.
Jewell 1996 Aim: To explore patient participation in discharge planning	The study describes two phases. In phase one, a group interview was conducted with nursing staff working in two elderly care units. In phase two, the researchers interviewed five elderly patients during their hospital admission. The data obtained from both phases were analysed using the Ethnograph software package. This paper reviewed the data obtained from interviews with nursing staff.	The first phase of the study, reported in this article, identified that the nurses interviewed recognised the need to involve patients in decisions about their discharge from hospital; however, the nurses viewed elderly patients as being both passive and reluctant to participate in decision making. Patient rather than nursing behaviour was given as reasons for this reluctance to participate.
Legault and Ferguson-Pare 1999 Aim: To evaluate the changes in nursing practice and the patient/family perspectives of nursing care when Parse's theory of human becoming was used as a guide for nursing practice in an acute care setting Discipline: nursing	Evaluation of nursing care in an acute surgical setting when Parse's theory of human becoming was used as a guide for nursing practice A training course in Parse's theory and person-centred care was run over an eight-month period and evaluated using pre and post interviews of participants, patients and their families by an external researcher. The eight dimensions of patient-centred care are: 1. access 2. respect for patients' values, preferences and expressed needs 3. coordination and integration of care 4. information, communication and education 5. physical comfort 6. emotional support and alleviation of fear and anxiety 7. involvement of family and friends 8. transition and continuity of care.	Positive patterns of change in nursing practice and patient and family experiences of care The post-training interviews with patients were subject to a qualitative analysis-synthesis process and reviewed for themes that described changes in patient/family perceptions of nursing care. Participants reported that nursing care was viewed as more individualised and meaningful, and less task-oriented with the nurses taking time to listen. Two issues raised both pre-and post-interview were the need for continuity of nursing care and the problem of sleep disruption at night. Changes identified through pre and post structured interviews with nurses (using open-ended questions) are: • acknowledgement of the importance of 'being with' patients and families throughout the hospital experience • experiencing affirmation and validation of the nurses' values and beliefs • development of more positive nurse-patient relationships • more reflective and meaningful nursing practice

Table 2 continued

Authors, date, aim	Study population, background, nature of intervention (including theory/ model of person-centred care)	Evidence of intervention effects/ major findings/comment
		• personal growth for the nurses • mutual support for nurses • challenging and changing nursing practice traditions (changing visiting hours; documenting patient dissent rather than feeling that they had to convince them) • recognition of ongoing struggles for nurses (for example, understanding theory, conflict with doctors, increasing patient acuity and decreasing lengths of stay). There is some qualitative evidence from this study that training in person-centred practice can lead to changes in nursing practice in an acute care setting. The study canvassed the views of patients and their families and nurses; however, the researcher conducted the training and the evaluation, raising questions about the validity of the research findings.
Little, Everitt, Williamson, Warner, Moore, Gould, Ferrier and Payne 2001 Aim: To measure patients' perceptions of patient-centredness and the relation of these perceptions to outcomes Discipline: medicine	Eight hundred and sixty-five consecutive patients attending three general practices Patients completed a questionnaire before their surgery, consisting of questions about what they wanted the doctor to do. A questionnaire after the consultation asked about their perceptions of their doctor's approach. Both questionnaires were based on the five main domains of the patient-centred model: exploring the disease and illness experience, understanding the whole person, finding common ground, health promotion, and enhancing the doctor-patient relationship (based on Stewart 1995). Patients were followed up after one month with the 'measure yourself' medical outcome profile and their notes were reviewed at two months for re-attendance, investigations and referrals.	Factor analysis revealed five components of patient-centred care: 1. communication and partnership 2. personal relationship 3. health promotion 4. a positive approach 5. an interest in effect on patient's life. Satisfaction was related to communication and partnership and a positive approach. Enablement was greater with interest in the effect on life, health promotion and a positive approach. A positive approach was also associated with reduced symptom burden at one month. Referrals were fewer if patients felt they had a personal relationship with their doctor. Concluded that components of a patient's perceptions can be measured reliably and predict different outcomes. If doctors do not provide a positive patient-centred approach, patients will be less satisfied, less enabled and may have greater symptom burden and higher rates of referral.
McCormack 2001 Aim: To present the findings of a qualitative study of nurse-patient interactions across a number of settings	Four hospital nurses recorded discussions between themselves and their patients and with doctors and members of the health care team for at least three sessions a week over a one-year period, as well as interactions between a community nurse and her clients in the clients' homes and an expert gerontological nurse and patients in a community hospital setting (14 case studies of nurse-patient interactions). Analysed using conversational analysis. Hermeneutic approach of Gadamer (includes active involvement of research participants) Follow-up reflective conversations were held with the nurses and the researcher to clarify and develop the initial descriptions of the data.	

Table 2 continued

Authors, date, aim	Study population, background, nature of intervention (including theory/ model of person-centred care)	Evidence of intervention effects/ major findings/comment
	Findings includ the key issues of the effects of institutional discourse, the dynamics of power and control, patient's access to knowledge, the impact of professional authority, the constraining nature of institutions, and the effect of family and carers on decision making. All seen as constraints on the older person's autonomy. Twenty-three principles for action were identified.	
McCormack, 2003a Aim: To present a conceptual framework for person-centred care of older people	Conceptual framework for person-centred care of older people Respect is central to the idea of person-centredness Respect – based on the Kantian ideal of mutual respect and sympathetic benevolence Rights of individuals as persons is the driving force behind person-centred health care. Represents an attitude of respect for ordinary individuals to make rational decisions and determine their own ends (shift in thinking for health care). Requires health professionals to think beyond scientific facts and technical competence to adopt a more holistic approach which incorporates values. *'Being person-centred requires the formation of a therapeutic narrative between professional and patient that is built on mutual trust, understanding and a sharing of collective knowledge' (p. 203).* Discusses the idea of person-centredness as authentic consciousness. The findings from the study referred to above (McCormack 2001) suggest that nurses need to be able to particularise the person the patient is, the relationship that exists between them and the patient, and the understandings and expectations explicit in this relationship. This is achieved through a process of 'authentic consciousness': *'consideration of the person's life as a whole in order to help sustain meaning in life'* (p. 204).	It is argued that the desires, wishes and needs of the older person can be best understood by having a picture of the person's life as a whole. *'Therefore being person-centred requires getting close to the older person and goes beyond traditional notions of respecting individuality and individualised care, such as choices about food and drink, hygiene, waking and sleeping'* (p. 204). Getting closer to the patient involves consideration of the patient's authenticity ('imperfect duties'). Imperfect duties (derived from Kant) cannot always be applied in the same way to every person and in every context; may also sometimes compete with each other in ethical decision making. Five imperfect duties in person-centred care derived from the study are: 1. informed flexibility. Facilitation of decision making through information sharing and the integration of new information into established perspectives and care practices 2. mutuality. Recognition of others' values as being of equal importance in decision making 3. transparency. Making intentions and motivations for action explicit as well as the boundaries within which care decisions are made 4. negotiation. Patient participation within a care culture that recognises and values the views of patients as legitimate (*'while recognising that being the final arbiter of decisions is of secondary importance'* [p. 205]) 5. sympathetic presence. *'Engagement that recognises the uniqueness and value of the individual by appropriately responding to cues that maximise coping resources through the recognition of important agendas in daily life'* (p. 205). Also notes that there are three important factors for the creation of an environment that facilitates person-centredness: • patient's values. Need to understand the meaning of health for the patient and tailor the intervention accordingly

Table 2 continued

Authors, date, aim	Study population, background, nature of intervention (including theory/model of person-centred care)	Evidence of intervention effects/ major findings/comment
		• nurse's values and expertise. The nurse may need to share his or her values, especially if they differ from the patient's so that he or she understands where the nurse is coming from and the context in which he or she makes care recommendations • context of care Crucial to the practice of person-centred care is that nurses need to have the authority to act autonomously if they are to facilitate the patient's autonomy. Organisational issues include: • the freedom of the nurse • systems of decision making • staff relationships • organisational systems • power differentials • potential of the organisation to tolerate innovative practices and risk taking.
McCormack 2003b	Literature review and discussion paper Author argues that the principles of person-centredness espoused in nursing practice should also underpin research and development practices	Suggests a framework for person-centred research and discusses enabling factors to help implement the principles of the framework into practice. Principles of the framework include: • informed flexibility • sympathetic presence • negotiation • mutuality • transparency.
McCormack 2004 Aim: To explore and clarify the concept of person-centredness and practice in the context of gerontological nursing Discipline: nursing	Literature review of person-centred practice in nursing Discussion of the concept of 'person'. Kant's ideal of person is that persons should always be treated as an end in themselves, not as the means to another's end–does not occur when treatment decisions are based on cost rather than individual quality of life. Kitwood (1997a, p. 8) defines person-centredness as '*... a standing or status that is bestowed upon one human being, by others, in the context of relationship and social being. It implies recognition, respect and trust*'. Four key concepts are extracted from this definition (see next column). Discussion of five models of person-centred practice: 1. McCormack: framework of person-centred practice built on the concept of authenticity; partnership working between older patients and nurses based on a 'negotiated	Many descriptive accounts but few studies that identify the benefits of this approach. Argues that there are four concepts underlying person-centred nursing: • being in relation • being in a social world • being in place • being with self. Articulation of these concepts into current practice raises the recurrent themes of: • knowing the person • the centrality of values • biography • relationships • seeing beyond the immediate needs • authenticity. All models are based on humanistic philosophy, originated by Rogers. Need for further research in gerontological nursing to distinguish between person-centred practice and good quality care for older people, or are these the same thing?

Table 2 continued

Authors, date, aim	Study population, background, nature of intervention (including theory/ model of person-centred care)	Evidence of intervention effects/ major findings/comment
	relationship'. Five caring duties (informed flexibility, mutuality, transparency, sympathetic presence, and negotiation) direct the relationship and three levels of engagement are described (includes 29 principles for action); draws on principles of the 'life plan' 2. Packer (2003): drawing on and further developing Kitwood's 'positive person work'. This model argues for the voice of the person with dementia to be heard and given equal status with professional and lay carers. Twelve core elements (recognition, negotiation, collaboration, play, timalation, relaxation, validation, holding, giving, facilitation, creation and celebration). Relationships, the individual context, the impact of the care setting, and notions of self are all considered in the model. 3. The senses framework (Nolan et al. 2001). Framework consists of six senses that together account for the intersubjective care experiences for both older people and staff. They are a sense of security, continuity, belonging, purpose, fulfilment and significance. Knowing the older person and their carers is central to the successful implementation of the model. 4. Skilled companionship: Titchen (2000, 2001) devised and tested through an empirical study the conceptual framework of 'skilled companionship' for the nurse-patient relationship. Skilled companions take themselves into the relationship with patients and families; emphasises aspects of the relationship. 5. The Burford Nursing Development Unit (Johns 1994): explicit focus on 'the person of the patient'. The assessment process asks the question, 'What do I need to be able to nurse this person?' Nine questions seek to answer this key question with the intention of building the person's biography. The reflective practitioner is a central part of the model.	

Table 2 continued

Authors, date, aim	Study population, background, nature of intervention (including theory/ model of person-centred care)	Evidence of intervention effects/ major findings/comment
McCormack and Ford 1999 Aim: To discuss the nursing contribution to the development of person-centred care services- examples of good practice and new opportunities for the development of good practice Discipline: nursing	Discussion of the nursing contribution to the development of person-centred care services; examples of good practice and new opportunities for the development of good practice	Argues that gerontological nursing has and needs to move away from its historical antecedents (routinised, institutionalised, low status nursing practice) in order to develop person-centred nursing practice. Argues for the specialisation of gerontological nursing, which is holistic in understanding the needs of older people and approaches to planning their care, including interagency work, and demonstrates knowledge of rehabilitation, clinical assessment, health care assessment, and the ageing process. One of the challenges is the demonstration of outcomes for the role because the authors argue 'hard' outcomes of health gain are not always a priority for older people. Presents a model of person-centred gerontological nursing that includes: • holistic practice and holistic knowledge • saliency (seeing the most pertinent issues and appropriate ways of responding to them) • knowing the patient • moral agency (a concern for responding to the client as a person, respecting dignity, protecting her personhood in times of vulnerability, helping her feel safe, providing comfort, and maintaining integrity in the relationship) • skilled know-how. Some enablers (p. 43) are: • the ability to reflect on the effectiveness of practice • authority in and accountability for practice • therapeutic interpersonal relationships with team members and patients • a practice environment that enables a person-centred approach to the organisation of care services.
Mead and Bower 2000 Aim: To review the conceptual and empirical literature on patient-centred medical care Discipline: medicine	Review of the conceptual and empirical literature on patient-centred medical care Two main approaches to measurement identified: self report instruments and external observer method	Good conceptual framework for patient-(person-) centredness based on a recognition of the limitations of the bio-medical model. Main focus is medicine but may be applicable to other health disciplines. Five dimensions: 1. biopsychosocial perspective (that is, broadening the focus of the doctor-patient encounter to include psychological and social factors) 2. patient as person (that is, exploring the meaning of illness or health to that particular patient) 3. sharing power and responsibility (that is, including the patient in decision making; consideration of the patient as an expert on their own health)

Table 2 continued

Authors, date, aim	Study population, background, nature of intervention (including theory/ model of person-centred care)	Evidence of intervention effects/ major findings/comment
		4. therapeutic alliance (that is, consideration of the relationship between the doctor and patient as important) 5. doctor as person; the idea that doctors are not interchangeable and the particular qualities, attitudes and values of the doctor are important. One doctor's style, attitudes, and so on will suit one patient better than another. None of the above has been emphasised in the traditional bio-medical approach, but that is not to say it has been totally absent. Also, a good summary and evaluation of the existing literature on measurement of patient-centredness highlighting some of the conceptual and methodological problems in evaluating this approach to care
Nolan, Davies, Brown, Keady and Nolan 2004 Aim: To provide a framework describing the potential dimensions of person-centred care Discipline: nursing	Takes Nolan's 2001 paper a step further. Suggests a relationship-centred approach and proposes a framework for this approach	The senses framework consists of senses that all parties involved in caring should experience. These are a sense of: • security – to feel safe within the relationship • belonging – to feel part of things • continuity – to experience links and consistency • purpose – to have personally valuable goals • achievement – to make progress towards goals • significance – to feel that you matter. The emphasis of this model is on all parties to the relationship being important. Thus, staff need to feel these things too. Nolan further outlines what each of these senses might mean for staff, older people and family carers. The framework has been subject to empirical testing (Davies et al. 1999) and although what creates a sense of all the above varies across different groups and care contexts, the 'senses' are pre-requisites for relationships that are satisfying to all parties involved.
Rycroft-Malone, Latter, Yerrell and Shaw 2001 Aim: To discuss recent research findings in relation to the health promotion practice of medication delivered by nurses in England to a variety of health care settings Discipline: nursing	Study of nurse-patient interactions in the United Kingdom where consumerist principles were the espoused method The method included non-participant observations and audio-recording of nurse-patient interactions in seven different contexts including older people and mental health.	Espoused theory and practice incongruous Interactions contained simple information, were dominated and led by nurses and offered little opportunity for patient choice Patients expressed satisfaction with minimal information and involvement.

Table 2 continued

Authors, date, aim	Study population, background, nature of intervention (including theory/ model of person-centred care)	Evidence of intervention effects/ major findings/comment
Stevenson 2002 Aim: To discuss the nature of patient-centred care Discipline: medicine	The article discusses patient-centred care from a post-modern perspective. Using a case example, this paper illustrates that patient-centred care is a process of mutual construction of the relationship, of diagnosis goals and treatment between patient and doctor. Suggests six domains in patient-centred care: 1. exploring the illness experience – the agenda 2. understanding the patient as a person – the context 3. management – finding common ground 4. enhancing the patient-doctor relationship 5. health promotion – prevention of suffering 6. the doctor as a person.	Literature review states that patients strongly desire patient-centred care. It has been associated with improved patient and doctor satisfaction; greater compliance; fewer investigations, referrals and malpractice complaints; and no change in consultation time.
Stewart, 1995 Aim: To find out whether the quality of physician-patient communication makes a significant difference to patient health outcomes Discipline: medicine	Review of 21 studies including 11 randomised controlled trials and ten analytical studies (level II evidence)	Sixteen studies reported positive results; four reported non-significant results and one was inconclusive. The quality of communication both in the history taking and the discussion of the management plan was found to effect health outcomes. The outcomes effected in descending order were: 1. emotional health 2. symptom resolution 3. function 4. physiologic measures, such as blood pressure and blood glucose levels 5. pain control. Looks at the elements of the effective history taking Physician: 1. asks many questions about the patient's understanding of the problem, concerns and expectations, and about his or her perception of the impact of the problem on function – impacts on patient anxiety and symptom resolution 2. asks the patient about his or her feelings – impacts on psychologic distress 3. shows support and empathy – impacts on psychologic distress and symptom resolution. Patient: 1. expresses self fully, especially conveying feelings, opinions and information – impacts on role limitation and physical limitation, health status, functional status and blood pressure 2. perceives that full discussion of the problem has taken place – impacts on symptom resolution.

Table 2 continued

Authors, date, aim	Study population, background, nature of intervention (including theory/ model of person-centred care)	Evidence of intervention effects/ major findings/comment
		Effective discussion of the management plan: 1. Patient is encouraged to ask more questions – impacts on patient anxiety, role limitation and physical limitation. 2. Patient is successful at obtaining information – impacts on functional and physiologic status. 3. Patient is provided with information, programs and packages – impacts on pain, function, mood and anxiety. 4. Physician gives clear information along with emotional support – impacts on psychological distress, symptom resolution, blood pressure. 5. Physician is willing to share decision-making – impacts on patient anxiety. 6. Physician and patient agree about the nature of the problem and the need for follow-up– impacts on problem and symptom resolution. Concludes that decision making power should be shared between physician and patient, not totally shifted to the patient, and that medical practitioners and patients should be educated in communication. Further research in both physician and patient education, the association of communication measures with patient outcomes, and qualitative research into patient-physician communication and decision making is recommended.
Stewart 2001 Aim: N/A (commentary) Discipline: medicine	Medical. This paper is a comment on another paper by Little et al. (2001) in the *British Medical Journal*; however, it does briefly outline Stewart's model of patient-centred care (described above). It also talks of the importance of getting patients themselves to measure the extent to which care is patient-centred and cites some research where this has been done.	In the literature review, Stewart found that most educators and researchers focused solely on experts' ratings of observed behaviour in clinical encounters, not the patient's; however, in one study that did both, the patient's perceptions of the interaction were a stronger predictor of health outcomes and the efficiency of health care (fewer diagnostic tests and referrals) (Stewart 1995).
Wilson 1998 Aim: To discuss integrated care management in the United Kingdom and the use of multidisciplinary pathways of care Discipline: multidisciplinary	Discussion of integrated care management in the United Kingdom and the use of multidisciplinary pathways of care	Discusses how multidisciplinary pathways of care should be incorporating clinical guidelines, protocols, interdisciplinary standards, evidence-based practice and clinical outcomes that are monitored across all sectors of care.

Nineteen articles were reviewed which focused on person-centred care and occupational therapy (see Table 3). The study designs included qualitative (interviews, focus groups, workshops), quantitative (surveys), literature reviews and discussion papers (descriptive, commentary and invited commentary). While much work has been undertaken in the Canadian occupational therapy field, there were no level I or II studies located which tested the effects of client-centred practice on client outcomes.

Table 3: Occupational therapy guidelines on person-centred care

Authors, date, aim	Study population, background, nature of intervention (including theory/ model of person-centred care)	Evidence of intervention effects/ major findings/comment
Blain and Townsend 1993 Aim: To investigate: • how the guidelines for client-centred practice produced in the 1980s by the Department of National Health and Welfare and the Canadian Association of Occupational Therapists (CAOT) were being used • the usefulness of various concepts and sections of the guidelines To provide a database for updating the guidelines	Study population: 1. Qualitative interview data from key informants across Canada. Open-ended telephone interview (45-60 minutes) with 21 people. Sample selected from names submitted by CAOT board and executive, and included educators, administrators, researchers and clinicians. Purposive sampling method 2. Quantitative survey completed with random sample of 5 per cent of CAOT members. Stratified by area of practice and region. Interview data (above) provided the basis for the survey questions. Educators and researchers were excluded because they comprised much of the above group. Twenty-nine per cent response rate	Findings: • Variable use of the guidelines • Greatest use in acute care and rehabilitation services • Mixed interpretations of the model of occupational performance, particularly 'environment' and spiritual components Recommendations: • Clarification of purpose and audience of revised guidelines • National consultation during updating to include diverse forms of practice • Rethinking the model of occupational performance as a dynamic model
Clouston 2003 Aims: 1. To explore the concepts of narrative 2. To discuss the use of narrative as one method for exploring the lived experiences of users of occupational therapy, hence encouraging a person-centred approach to care	Explored relevant literature about narrative using a qualitative methodology	Findings: • Described the narrative approach • Identified narrative as a useful tool for clinical and research-based occupational therapy activity • Concluded that occupational therapists can influence the effectiveness of this technique. Techniques such as reflective listening should be used
Corring and Cook 1999 Aim: To explore the opinions and perspectives of individuals with experience of mental illness and the mental health service delivery system. To gain their views on the meaning of client-centred practice. (Prefaced with the idea that the client's views are often neglected.)	Methodology: • Three focus groups • Seventeen individual interviews	Findings • Outlined history of client-centred practice; for example, work of Rogers and the development of the Canadian guidelines • Identified a significant body of literature from professionals about client-centred approach to care and what it means, but few studies from the perspective of the client (identified irony) • Identified inadequacies with the health service relating to client-centred care • Identified the need for individuals with mental illness to be viewed as valuable human beings by service providers and by society

Table 3 continued

Authors, date, aim	Study population, background, nature of intervention (including theory/ model of person-centred care)	Evidence of intervention effects/ major findings/comment
Falardeau and Durand 2002 Aim: To define the concepts of respect and power in the therapist-client relationship. (Prefaced with the idea that a client-centred approach is defined by these two terms as well as by partnership.)	Review of occupational therapy and related health and social sciences literature regarding respect and power	The paper proposes that the term 'negotiation' should be used instead of 'partnership'. Raises the question, 'Who should the power reside with?' Argues that intervention led by the interaction between client and therapist is the best approach compared with a client-led approach whereby the therapist provides the evidence-based options
Lane 2000 Aim: To reflect on whether the principles of client-centred practice are consistent with early discharge from hospital policies	Literature review on: • history of client-centred practice including the Canadian Model of Occupational Performance • opportunities and barriers to providing client-centred care. Discusses: • history/rationale for early discharge strategies • effectiveness of early discharge strategies • barriers to providing client-centred services in the early discharge hospital-at-home setting	Findings: • Principles of client-centred practice are consistent with early discharge home from hospital strategies. • Increased client choice and greater client autonomy and control are inherent principles of client-centred models of care and potential benefits of early discharge hospital-at-home services. • Also discusses history of client-centred approach and barriers and opportunities for implementation
Law, Baptiste, McColl, Opzoomer, Polatajko and Pollock 1990 Aim: 1. To describe the rationale and development of the Canadian Occupational Performance Measure (COPM) 2. To provide information about the COPM's use	Description of testing of psychometric properties of COPM (results of pilot testing and plans for validation). Generally a descriptive paper	Findings: • Describes the rationale and development of the COPM as well as information about its clinical utility • The COPM is an outcome measure designed for use by occupational therapists to assess client outcomes in the areas of self-care, productivity and leisure. • Based on the Canadian Association of Occupational Therapists *Guidelines for the client-centred practice of occupational therapy* (1983), designed to assist occupational therapists in putting the client-centred model into practice • Uses a semi-structured interview, five-step process measuring individual client identified problem areas in daily function • Two scores: performance and satisfaction

Table 3 continued

Authors, date, aim	Study population, background, nature of intervention (including theory/model of person-centred care)	Evidence of intervention effects/major findings/comment
Law, Baptiste and Mills 1995 Aims: 1. To discuss the key concepts of client-centred practice; for example, individual autonomy and choice 2. To provide practice examples illustrating these ideas 3. To raise issues about obstacles to the practice of client-centred occupational therapy 4. To provide research evidence about the effectiveness of client-centred concepts in enhancing client satisfaction, functional outcomes and adherence to health service programs	Literature review	This paper: • discusses concepts of client-centred practice: autonomy and choice, partnership and responsibility, enablement, contextual congruence, accessibility and flexibility, and respect for diversity • defines client-centred practice • identifies opportunities and barriers to implementing client-centred practice at client/therapist/system levels • demonstrates links between client-centred practice and outcome, including client satisfaction, improvement in function, and improved adherence. Provides some resources, including a checklist to be used by occupational therapists, with questions such as, 'How much power does the client have in initial contact?', 'How much time is spent discussing the client's goals and values?'
McColl and Pranger 1994 Aim: 1. To analyse the occupational therapy guidelines to determine the extent to which they can be communicated as a theory and a model of practice 2. To describe the conceptual and the practice model 3. To evaluate both models relative to nine criteria derived from the literature.	Review and analysis of the literature	Findings: • Sufficient information in the Canadian occupational therapy guidelines to outline a conceptual model and a model of practice for Canadian occupational therapists • The conceptual model was found to be largely consistent, supportable, comprehensive and useful • The model of practice proved to be more problematic, with technical, structural and conceptual variances

Table 3 continued

Authors, date, aim	Study population, background, nature of intervention (including theory/ model of person-centred care)	Evidence of intervention effects/ major findings/comment
Pollock, Baptiste, Law, McColl, Opzoomer and Polatajko 1990 Aim: 1. To review outcome measures available in the published literature which assess occupational performance 2. To describe eight assessments that fulfilled many of the review criteria 3. To discuss limitations of these, using the guidelines for the client-centred practice of occupational therapy as the framework 4. To make recommendations for the development of a new outcome measure for use in occupational therapy	Literature review on outcome measures based on a number of key criteria Fifty-four assessments generated, 41 reviewed. Eight found to be closely aligned with occupational performance, including Sickness Impact Profile and the Reintegration to Normal Living Index	Findings: • Majority of occupational therapy outcomes used measure performance components • Of those that measure actual occupational performance, majority self-care. Few consider roles or environment • Shortcomings identified in the eight assessments reviewed • Need for a tool identified • Canadian Occupational Performance Measure developed as a result of this.
Rebeiro 2000 Aim: 1. To describe the experiences of two clients who received a mental health hospital-based occupational therapy service 2. To discuss the implications of these findings for the client-centred practice of occupational therapy 3. To discuss the challenges of providing client-centred services within the current health care environment	Two indepth interviews with clients of mental health services about their experiences with a hospital-based occupational therapy service	Findings: • Clients described their experiences as prescriptive and less than client-centred • Problems included 'prescription' of activity, a lack of choice, a focus upon the illness as opposed to the individual • Problems perceived to diminish the ability to establish a collaborative partnership, eliminating client from any decision making process • Participants recommended a greater focus on occupational choice, consideration of the individual within the client, provision of accepting and supporting environments, using professional expertise on occupation to guide the client towards participation in meaningful occupation

Table 3 continued

Authors, date, aim	Study population, background, nature of intervention (including theory/ model of person-centred care)	Evidence of intervention effects/ major findings/comment
Rebeiro 2001 Aim: To discuss client-centred practice within the framework of body, mind and spirit	Author's perspective of client-centred practice based on her experience as an occupational therapist	Talks about personal beliefs of client-centred practice, framed within a balanced trilogy of body, mind and spirit
Sumison 1993 Aims: 1. To present questions about how the model of client-centred practice is being applied by occupational therapists 2. To question whether occupational therapists clearly understand the implications of the model 3. To discuss the advantages of the model 4. To present the therapeutic challenges of implementing the model 5. To offer author opinion about how a truly client-centred process should be applied	Discussion paper	Findings: • An advantage of the model is applicability to community practice. • An opportunity of the model is the value of team work.
Sumison 2000 Aim: To report on the second phase of a research project to determine a British occupational therapy definition of client-centred practice	Methodology: • Sixty-seven occupational therapist participants • Nine focus groups structured according to the nominal group technique • Groups involved occupational therapists working in social services, mental health, learning disabilities, paediatrics, neurology, women's/children's service, elderly clients, and general medicine • One hundred and sixty-five components of client-centred practice generated and analysed to form themes. Frequencies and means of the components ranked in the top five were also calculated. Additional three questions asked to solicit opinions on the definition. Data used to inform revision of the definition. Revised definition was reviewed by final validating group/council of the college of occupational therapists.	A final definition of client-centred care was established: *'Client-centred occupational therapy is a partnership between the client and the therapist that empowers the client to engage in functional performance and fulfil his or her occupational roles in a variety of environments. The client participates actively in negotiating goals which are given priority and are at the centre of assessment, intervention and evaluation. Throughout the process the therapist listens to and respects the client's values, adopts the interventions to meet the client's needs and enables the client to make informed decisions'* (p. 308).

Table 3 continued

Authors, date, aim	Study population, background, nature of intervention (including theory/ model of person-centred care)	Evidence of intervention effects/ major findings/comment
Sumison and Smyth 2000 Aims: 1. To determine which therapist barriers prevent client-centred practice 2. To determine which methods are perceived as being most effective in resolving therapist barriers	Literature review to: • identify therapist barriers • identify methods to resolve therapist barriers Literature review informed a postal questionnaire which was sent out to 60 occupational therapists in the United Kingdom (40 per cent rejection rate)	Main results: • Therapist and client having different goals was identified as the main barrier preventing client-centred practice. • The values, beliefs and attitudes of therapists and of the employment culture were also identified as barriers to implementing client-centred practice. • Case examples showing how to practice in a client-centred fashion were rated as the most effective method of barrier removal.
Townsend 1998 Aim: • To discuss Canada's guidelines for client-centred practice • To consider possibilities for enabling occupation in Australia	Invited commentary	Describes the development of the guidelines/ history of client-centred practice. Describes development of the Canadian Occupational Performance Measure. Introduces the Canadian Model of Occupational Performance and the Occupational Performance process. Difficulties were encountered with enabling occupation and providing client-centred care for children, people with dementia and people from culturally and linguistically diverse backgrounds. Australians are likely to use enabling occupation for guiding practice with clients, documentation, guiding program and policy development, explaining occupational therapy to others, advocating with and for clients, and focusing research. All of this may help Australian occupational therapists to articulate a social vision, gain visibility and demonstrate holistic versus technical approaches to situations.
Townsend 2003 Aim: To discuss the issues of power and justice related to client-centred practice in occupational therapy: • How do power and justice work in occupational therapy today? • What vision of power and justice guides the profession in implementing the client-centred practice of enabling occupation?	Power and justice reflected on using occupational therapy guidelines. Clients' perspectives and occupational therapists' comments on the guidelines	Two dimensions of power and justice reviewed: power relation between clients and occupational therapists, and occupational therapists' own empowerment to do work Offers practical insights and strategies for addressing power and justice as issues in implementing client-centred practice. Offers a methodology to guide strategic development for implementing a service that fosters client-centred practice

Table 3 continued

Authors, date, aim	Study population, background, nature of intervention (including theory/model of person-centred care)	Evidence of intervention effects/major findings/comment
Townsend, Brintnell and Staisey 1990 Aim: To provide an overview of the development of the Canadian guidelines for the client-centred practice of occupational therapy	Discussion paper, using case examples	Outlines development and content of the Canadian client-centred guidelines Identifies need for review with questions including, 'How do therapists interpret guidelines for use in a broadening range of institutional and community practices?'
Townsend, Ryan and Law 1990 Aim: • To summarise the World Health Organization International Classification of Impairment, Disability and Handicap (ICIDH) and the Model of Occupational Performance in the guidelines for the client-centred practice of occupational therapy. • To consider the similarities and to provide case examples for how to use the ICIDH in occupational therapy for communicating with other health professionals, program planning and management, and clinical evaluation and research	Discussion paper on the models and their compatibility for providing occupational therapy services	Findings: • ICIDH conceptually compatible with the generic Model of Occupational Performance • ICIDH has a variety of communication, planning, management, evaluation and research uses for occupational therapy • Helpful in articulating roles to clients examples for how to use the ICIDH in occupational therapy for communicating with other health professionals, program planning and management, and clinical evaluation and research
Townsend and Wilcock 2004 Aim: • To describe the relationship between occupation, justice and client-centred practice • To consider how occupational therapists work for justice	Authors reflection on their own practice. Workshop with participants. Literature review	Four cases of occupational injustice are proposed: occupational alienation, deprivation, marginalization, and imbalance. Four rights thus identified: right to experience meaning and enrichment in one's occupations, right to participate in a range of occupations for health and social inclusion, right to make choices and share decision making power in everyday life, and right to receive equal privileges for diverse participation in occupation Authors encourage open dialogue about occupational injustices

Table 3 continued

Authors, date, aim	Study population, background, nature of intervention (including theory/ model of person-centred care)	Evidence of intervention effects/ major findings/comment
Unsworth 2004 Aims: 1. To examine the relationship between client-centred practice and clinical reasoning 2. To explore the concept of pragmatic reasoning 3. To present a diagrammatic conceptualisation of knowledge of clinical reasoning in occupational therapy	Methodology: • Review of clinical reasoning literature 1982–2001, combined with data from a study which explored the clinical reasoning of 13 experienced occupational therapists • Data collected and analysed within a focused ethnographic framework	Findings: • Clinical reasoning occurs in the context of client-centred practice. • A reciprocal relationship exists between client-centred practice and interactive reasoning. • Pragmatic reasoning is related only to the therapist's practice context. • All forms of reasoning are influenced by the therapist's world view. Development of a diagram to depict the current understanding of the models of clinical reasoning.
Wilkins, Pollock, Rochon and Law 2001 Aim: To explore the challenges of implementing client-centred occupational therapy practice	Review of findings from three qualitative studies with three different populations (family-centred care for children and their families, community-based home care, and facility-based care for older adults)	Challenges of implementing client-centred practice are divided into three categories: challenges at the level of the system, the therapist, and the client. Occupational therapy services should be respectful, supportive, coordinated, flexible and individualised.

Appendix D: Diagnosis based models

Eleven articles were reviewed which focused on person-centred care and mental health (see Table 4). The study designs were mainly qualitative, including narrative approaches, testing a service model, literature reviews, action research, interviews (including pre and post) and one level II randomised controlled trial.

Table 4: Literature on person-centred care within mental health settings

Authors, date, aim	Study population, background, nature of intervention (including theory/ model of person-centred care)	Evidence of intervention effects/ major findings/comment
Blank 2004 Aim: To identify the factors that promote partnership and the barriers to partnership between occupational therapists and their clients	Semi-structured indepth interviews with seven community mental health service users (three men, four women, aged between 35 and 65 years). Interviews went for up to an hour. Much has been done regarding client-centred care in the area of occupational therapy; however, there has been little that has actually looked at it from the client's viewpoint. Data were analysed by inductive coding.	Four factors were identified as contributing to a positive relationship between occupational therapist and client: 1. therapist's personality: a therapist who is calm, gentle, soothing, appears to enjoy job, approachable, not intimidating 2. behaviour of therapist: verbal (giving reassurance, showing interest in client, welcoming, friendly, hard working, well organised, helpful, accessible, showing concern), non-verbal (listening to whole group and not just focussing on one person [*'Eyes look at everyone'*]), skilled communicators, empowering and enabling, skilled at building client's self-esteem, knowledgeable, challenging 3. client-centred skills: showed acceptance, non-judgmental, showed respect, trust, empathy, prepared to proceed with intervention at client's pace 4. boundary issues. Five factors were identified as barriers to a positive relationship: 1. lack of individual approach: lack of time, being just one of number of other demands, lack of anticipation of individual's needs 2. lack of communication and knowledge; for example, if therapist is new or just qualified or if there is a lack of feedback on progress 3. lack of confidentiality 4. a directive therapist, includes bossy, authoritative attitude, direct questioning, being told what to do, client feeling need to please therapist, criticism of lack of progress 5. inequality. Findings: • Clients did not identify the relationship between them and the occupational therapist as a partnership without being prompted. • These findings support those of other authors, including original writing on client-centred care (for example, Rogers). • Findings suggest that clients need to first feel valued, listened to and cared for prior to being a partner in the health care.

Table 4 continued

Authors, date, aim	Study population, background, nature of intervention (including theory/ model of person-centred care)	Evidence of intervention effects/ major findings/comment
		• Findings also suggest that clients are keen to receive opinions and information from the health professional involved in their care. • Participants frequently referred to feeling understood, cared for and valued by therapists. This is consistent with Corring and Cook (1999), who wrote about clients with mental illness. In conclusion, it appears that clients appreciate a person-centred approach but may not need to be in a partnership with their health professional. They liked to be valued, listened to and cared for by warm, accepting and non-judgemental therapists.
Cockburn and Trentham 2002 Aim: To provide a summary of participatory action research and how it provides a framework for research for the discipline of occupational therapy	This paper discusses how participatory action research provides a framework for engaging clients and community members in research, which is compatible with occupational science and occupational therapy perspectives.	
Fletcher and Stevenson 2001 Aim: To implement a new model of psychiatric nursing which uses person-centred care to empower people with acute mental health problems	It was felt that there was a need for an alternative model of mental health nursing practice which acknowledges the relationship of the nurse's role with other disciplines and the nurse's power relationship with the person in care. The result was the Tidal Model. The Tidal Model represents a multidimensional approach to the provision of quality psychiatric and mental health care. This model acknowledges the complementary standing of nursing in relation to care and treatment offered by other health and social care disciplines. In the Tidal Model the nurse has two discrete role relationships: their therapeutic relationship with the person (and family) and their professional relationship with other members of the care and treatment team. The Tidal Model has three different but related dimensions of care: 1. world dimension – focuses on the person's need to be understood 2. self dimension – focuses on the person's need for physical and emotional security 3. others' dimension – emphasises the kind of support the person might need from a wide range of people and agencies to be able to live an ordinary life.	The Tidal Model was introduced into a pilot ward (data were collected six months prior to implementation and six months after). Preliminary findings indicate: • an increase in the number of people admitted on informal status • a doubling in the number of admissions for post-test period • a decrease of 24 per cent in length of stay • a decrease of 40 per cent in number of violent incidents • a decrease of 6 per cent in episodes of self harm • a decrease of 67 per cent in use of restraint • a reduction in the interval between admission and full initial assessment from three days to average of 1.3 days. Findings suggest that introduction of client-centred model of nursing practice might have positive effects on factors such as bed occupancy and economics of care provision. The Tidal Model appears to be useful to nurses and seems to bring positive benefits for patients and the organisation when judged by both quantitative and qualitative outcome measures.

Table 4 continued

Authors, date, aim	Study population, background, nature of intervention (including theory/ model of person-centred care)	Evidence of intervention effects/ major findings/comment
	The Tidal Model recognises that people's need for nursing flows across artificial boundaries as the nature of the person's needs shifts. The model embraces the concept of a care continuum.	The Tidal Model seems to be a good method for implementing person-centred care in acute mental health services. The specific assessment employed in the Tidal Model places patient and patient's story at the centre of the decision making process.
Magnusson, Severinsson and Lutzen 2003 Aim: To explore and describe mental health nurses' experiences of how structural changes in mental health nursing influence interaction when providing home care to patients with long term mental health problems	Interviews with 11 mental health nurses (four men, seven women) with experience in both institutional and community mental health nursing Used a qualitative approach, based on the main tenets of grounded theory	Interviewees identified their role in an institutional setting with mental health patients as *care management*. Nursing role was linked to an illness perspective, in which the person with mental health problems was viewed as an 'object' of nurse-controlled care. On the other hand, when the context of care changed to the patient's home, the nurses reported that their professional and moral responsibility became less clear. They began to listen to the needs of their patient in a client-centred manner and their responsibilities were based on a process of negotiation grounded in mutual trust and on their assessments of the client's functional resources as opposed to signs of illness.
Meek 1998 Aim: To determine service users' evaluation of the role of health care assistants (unqualified mental health staff) within a community mental health intensive care team	Kelly's repertory grid technique and theoretical sampling Rich descriptions from service users.	Client-centred approach was apparent. Emphasis was placed on the personal qualities of the care provider, supporting Rogers' view (1961) that healing comes as much from the therapist's personality as techniques Results argue against the professional ideology of nursing
O'Donnell, Parker, Proberts, Matthews, Fisher, Johnson and Hadzi-Pavlovic 1999 Aim: To empower clients by establishing parity between client and staff without legal imposition, and by involving clients in their rehabilitative process in a consensual manner that promoted their respect, dignity and self-determination Objectives: To provide client-focused services, thereby empowering clients to participate as equal in management of illness and	Case managers underwent training in use of Rose's Advocacy Empowerment Model. Three random groups used: 1. control group (standard case management as it is routinely practised by community mental health staff), n=20 2. client-focussed case management group (case management by project staff), n=32 3. client-focussed case management plus consumer advocate (case management by project staff plus assignment of project community consumer advocate, n=27. Intervention = 12 months Mean (SD)age (of total group) = 36 years(9.8); 68 male and 51 female; mean number of education years = 11.6 No significant differences between three groups	Findings: • Significant difference between groups regarding case manager's satisfaction in working with their clients (specifically between control and client-focused case management and consumer advocate group ($F_{2,74} = 3.4$, $p = 0.04$), with the latter group being more satisfied) • Significant differences between groups regarding the size of the case manager's case loads. Experimental groups had smaller loads ($p<0.01$) • Significant differences between groups on total severity of burden scores (Family Burden of Care). Families of client-focused case management groups reported less severe burden than control ($F_{2,25} = 4.36$, $p = 0.02$) • Seventy-five per cent of client-focused case management groups reported feeling that

Table 4 continued

Authors, date, aim	Study population, background, nature of intervention (including theory/model of person-centred care)	Evidence of intervention effects/major findings/comment
increase compliance and service satisfaction; to reduce disability and increase client functioning; to reduce re-hospitalisation; deliver goal-orientated outcomes through development of structured client-focused recovery agreements		participation in project had made their lives 'better', whereas all control group participants reported things being the same (_^{2}=27.9, $p<0.01$). • Client-focused case management clients more frequently reported that their case managers seemed *'to understand my problems'* (p = 0.04), *'listen to me'* (p = 0.03), 'help me reach my goals' (p = 0.07) and *'be available when I needed them'* (p = 0.01), compared with standard community case managers. There appeared to be greater satisfaction with the case management for those in client-centred groups; however, this satisfaction did not translate into greater improvements in compliance-related variables (functioning, quality of life and so on). Limitations of the study include sample size and short timeframe. Concepts of empowerment, partnership with health professionals and consumer participation in the delivery of services were new to the clients. Case managers commented on how much of their time was spent validating and supporting clients' capacity to make their own choices about treatment, indicating that they were provided with insufficient time. Time is essential when implementing client-centred care because it is new to both staff and the clients.
Place 2003 Aim: To explain coping strategies for people who hear voices and what the mental health nurse's role is in these coping strategies	Article suggests coping strategies that could be used to help patients who hear voices. It suggests approaches that could be used which are person-centred because they are introduced on an individual basis and it is the patient who takes the leading role in deciding which techniques to try.	
Roth and Crane-Ross 2002 Aim: To test a model of the effects of service amount, service empowerment, and met needs on mental health outcomes	Participants with severe mental disabilities; in total 457 adult consumers and their case managers (in this paper between 213 and 248 consumer-case manager dyads) Demographic and clinical characteristics similar to those of whole adult population with severe mental disabilities A financial incentive given to consumers and case managers Undertaken in the community setting	Findings: • Met needs predicted lower levels of symptomatology and higher quality of life. Consumers' perceptions that their needs were met with regard to mental health, social support and daily living needs were associated with better symptomatology and quality of life outcomes. • Consumers' perceptions of met needs were not related to level of functioning outcomes.

Table 4 continued

Authors, date, aim	Study population, background, nature of intervention (including theory/ model of person-centred care)	Evidence of intervention effects/ major findings/comment
	The proposed model stipulated that mental health outcomes would be predicted by the amounts of services received and consumers' perceptions about their level of empowerment with regard to services. It was expected that these factors would be mediated by consumers' perceptions that their needs were met. Thus, service amount and service empowerment would have indirect effects on consumers' outcomes by meeting consumers' needs. Greater amounts of mental health service were expected to predict better symptomatology, functioning and quality of life if they were responsive to consumers' individual needs. Similarly, consumer empowerment with regard to services was expected to predict better outcomes by increasing the likelihood that consumers would be able to seek and obtain needed services. No relationship was expected between service empowerment and service amount. The proposed model has three yearly measurement points to account for auto-regressive effects.	• Findings suggest (even though there were limited measures of empowerment) that the feeling that one has a say or control over their service decisions and the feeling that service providers are responsive to one's requests for contact were strong predictors of consumers' perceptions of their needs being met. • Service empowerment had indirect effect on outcomes through consumers' met needs. • Consumers' level or service empowerment was unrelated to service amount. • Service amount did not predict mental health outcomes or consumers' perceptions of met needs. Consumers who received relatively high levels of service were no more likely than others to report that their needs were met. • Results suggest that for individuals receiving long term treatment, outcomes may be improved by collaborating with consumers to identify services that will address their self-perceived needs and including them in service decisions.

Solomon and Draine 2001
Aim:
To examine three types of consumer-provided services, consumer-operated services, consumer-partnership services and consumers as employees
	It is argued that employing consumers as providers can facilitate cultural change in the mental health system.
	This review focuses on those services that are provided by consumers working in a professional or paraprofessional role and that are intentionally designated to be consumer-delivered.
	Consumers, in this paper, are described as individuals with serious mental illness who have been users of mental health services.
		Consumer-run or operated mental health service:
		• High turnover of consumer staff or difficulty finding individuals with qualifications (for example, owning a car) cause problems for implementation.
		• Consumers generally report satisfaction with these services.
		• A randomised controlled trial showed that consumer Assertive Community Treatment services are equally as effective as non-consumer services.
		Consumer partnership services:
		• A randomised designed project that compared a consumer self-help employment program in partnership with professionals with services for those who were provided information about local vocational services while continuing with their customary services found that the consumer self-help partnership was more effective in terms of a higher proportion of recipients:
		  • gaining employment
		  • receiving a higher average hourly wage for those employed (but not statistically significant)
		  • having a higher vocational rehabilitation status.

Table 4 continued

Authors, date, aim	Study population, background, nature of intervention (including theory/ model of person-centred care)	Evidence of intervention effects/ major findings/comment
		• A randomised designed trial (but with relatively weak power and no control group) compared consumer case management to non-consumer case management. At two years, both services were found to be equally effective on behavioural symptomatology, a variety of clinical and social outcomes and quality of life of service recipients. • A quasi-experimental study (with ten experimental participants and 51 comparisons) that evaluated a consumer provided service that offers peer social support to people with both mental illness and substance use disorders found: – A significant decrease in the number of crisis events and hospitalisations – improved social functioning – reduction in substance abuse – improvement in some aspects of quality of life for those in the experimental group – Participants were not randomly assigned. Consumers as employees: • A project that randomly assigned 80 participants to one of two groups (a Community Network Development program that employed a consumer as manager in addition to professional staff to maintain contact with members, and a control group that did not receive network services) found: – Community Network Development participants had fewer and shorter hospitalisations than control group participants – a significantly higher proportion of Community Network Development members were able to function in the community without mental health system contact. • Quasi-experimental project compared whether employing consumers as peer specialists as an adjunct to a team of intensive case managers, as opposed to a case manager with a non-consumer assistant or case manager with no assistant, enhanced outcomes for people. The study found that participants in the experimental group had greater gains in some aspects of quality of life, fewer major life problems, and greater gains in positive self-image, outlook and social support. There is insufficient evidence to make conclusions about the effectiveness of consumer-provided services, but it does appear that consumer-provided services may be as effective as non-consumer-provided services.

Table 4 continued

Authors, date, aim	Study population, background, nature of intervention (including theory/ model of person-centred care)	Evidence of intervention effects/ major findings/comment
Thomas, Corring and Cook 1993	This paper reports that the views of patients and clients in psychiatry should be sought and they should be encouraged to speak out and complain if services do not meet their expectations. The importance of involving people in their own mental health services has become more widely recognised. The paper also states that the interests of clients should be paramount and there should be a closer collaboration between all those involved, which would foster openness and a sense of mutual understanding.	
Yurkovich, Smyer and Dean 1999 Aims: • To compare the definitions of health held by clients of two rural mental health day treatment centres • To validate and test the 'fit' of the findings of an original grounded theory study of seven patients with chronic mental illness or disability	Grounded theory design Semi-structured interviews. Open-ended questions were used to stimulate free response about the participants' views on the meaning of health and their health-seeking behaviour. Participant observation of the participant's appearance, ease with answering questions, non-verbal communication, and observation of the environment in each of the centres. Site one: seven clients with a mean age of 38 years (range 25-54); 43 per cent male; mean educational level of 12.5 years (range eight to 14years); all met criteria for chronic or persistently mentally ill Site two: nine clients with a mean age of 39 years (range 25-62); 44 per cent male; same educational range as site one; all met criteria for chronic or persistently mentally ill	Preventing loss of control was a core variable which all clients defined as their perception of health. Informants viewed 'healthy' as effectively using internal and external controls to maintain a balance that prevents loss of control. Differences between the two settings: • External support systems were different. – Site two participants were not building external support systems that were cost-effective. • Physical environment was different. (Better in site one: more open, well lit, clean, comfortable, greater ambience). • Site one had lowest admission rate to acute and chronic treatment settings in state. Site one: • Clients demonstrated positive outcomes (enhanced social resources: supportive use of peers; enhanced personal resources, such as insight and self-reliance (ability to assist self and other); development of problem solving skills (ability to identify need and access appropriate resources). • Care providers empowered clients. Site two: • Clients only used staff during adversity and did not expand social support to include peers. • There was no empowerment from care providers. It was felt that the clients in site one were able to achieve these positive outcomes because their environment and care providers consistently communicated respectfulness, a desire to have them involved in their treatment, and the importance of the treatment meeting their needs. In conclusion, the authors stated *'the person with chronic mental illness seeks to gain and maintain balance, and needs to be surrounded by a socially oriented, aesthetic environment which supports the development of belongingness. The environment must reflect active involvement of the professional care providers and a peer group that fosters a prosocial attitude. Care providers need to gain an understanding of their clients and their ability to maintain balance by using internal and external controls'* (p. 68).

Eighteen articles were reviewed which focused on person-centred care and chronic illness (see Table 5). The study designs included seven studies that were of a qualitative nature (such as an evaluation, or descriptive or expert opinion), six randomised or cluster-randomised controlled trials, two quasi-experimental studies, two literature reviews, and one systematic review.

Table 5: Literature on person-centred care and chronic illness

Authors, date, aim	Study population, background, nature of intervention (including theory/ model of person-centred care)	Evidence of intervention effects/ major findings/comment
Alamo, Moral and Perula de Torres 2002 Aim: To assess whether patient-centred consultations are more effective than the usual style of consultations used by general practitioners with patients suffering from benign chronic musculoskeletal pain and fibromyalgia	The patient-centred approach evaluated in this study is based on mutual discussion and partnership, clear information provided by the doctor and a search for common ground, along with the doctor offering support and being friendly, approachable and empathetic. Cluster-randomised, single blind trial Twenty general practitioners were randomised to either the intervention group (IG) or the control group (CG). IG: • Sixty-three patients were recruited. • Doctors in this group were trained in the application of the communication skills necessary to undertake a patient-centred approach. The doctors were provided with a prompt card which contained the main features of the patient-centred approach. CG: • Forty-six patients were recruited. • These doctors were asked to carry out the same treatment as usual. Follow-up at one year The degree of patient-centred care was evaluated: 1. A blind observer to the experimental status of the doctors evaluated, with a 13-item questionnaire, the interaction of each doctor with a standardised patient. 2. A researcher blinded to the experimental status contacted patients by telephone two to three months after the visit and asked them *'Have you had the opportunity to openly discuss the problem with your doctor?', 'How clearly has he or she explained the cause of your pain?'*, and *'Do you believe that your doctor has taken your opinions and suggestions into account concerning the management plan?'*	Findings: • Doctors in the IG showed better scores in relation to the evaluation of patient-centredness than the doctors in the CG. • IG patients registered reduction of one-point on average according to their perception of pain intensity (through a visual analogue scale); however, this was not significantly different from the CG patients. • The number of reduced tender points and anxiety level improved significantly in the IG patients compared with the CG patients. • The majority of variables (for example, pain intensity, number of associated symptoms, subjective health status, existence of psychological disturbance) showed positive tendencies in the IG compared with the CG. It was concluded that the patient-centred approach trialled in this study is effective in improving measures, such as pain and anxiety, in patients suffering from benign chronic musculoskeletal pain and fibromyalgia over the course of 12 months.

Table 5 continued

Authors, date, aim	Study population, background, nature of intervention (including theory/ model of person-centred care)	Evidence of intervention effects/ major findings/comment
Barnett 2004 Aim: To describe how an existing chronic obstructive pulmonary disease outreach service, which manages patients at home and attempts to avoid inappropriate hospital admission, could be improved by implementing an early supported discharge scheme	This paper describes how a five-step (preparation, movement, team creativity, new reality, and integration) change management model, developed by Post in 1989, could be used to implement an early supported discharge scheme for an existing chronic obstructive pulmonary disease outreach service. The anticipated benefits of implementing this early supported discharge scheme are: • reduced pressure on acute medical beds • reduction in medical 'out-liers' on surgical wards • empowerment for patients to make choices about management of their care and to return home to their own surroundings and family sooner.	
Bauman, Fardy and Harris 2003 Aim: To describe the rationale and methods of patient-centred care, with using two examples (one older patient with diabetes and one younger patient with asthma)	This study reports that three elements that are important to patient-centred care are: 1. communication with patients 2. partnerships 3. focus beyond specific conditions: more on health promotion and healthy lifestyles. Findings: • *'Patient-centred care requires a thorough explanation of disease to patients and exploration of their feelings, beliefs and expectations (patients "affect and cognition")'* (p. 253). • Patient-centred care also relies on increased teamwork. • The goal of patient-centred care is to *'form a partnership with patients allowing them to express their individual problems, fears and frustrations with having a chronic disease'* (p. 253). • The amount that a patient contributes to the decision making related to their disease can depend on factors such as age and cultural background. • There is some evidence that patient-centred approaches can increase patient satisfaction, engagement and task orientation, reduce anxiety and improve quality of life, as well as increase doctor satisfaction. • There is also some evidence that patient-centred care is more efficient, even requiring fewer diagnostic tests and unnecessary referrals. • Patient education programs that are integrated into patient-centred care are likely to be more effective than those delivered independently (according to a Cochrane review of diabetes management). • Simply providing information to patients has been recognised as ineffective: it needs to be incorporated into a more systematic and comprehensive patient-centred approach. • Patient-centred care needs to be for preventive care as well (for example, providing advice about reducing smoking increasing physical activity). Four principles of patient-centred care are: 1. Explore patient 'cognitions' (what they think, believe and expect, and their confidence about their disease management). 2. Explore the social supports, social and family influences and physical environment in which people live, which may influence their health and illness. 3. Apply the principles of behaviour change: discuss the disease management plan, individualise patient education and plan for change to occur in stages. 4. Work with teams of health care providers, community agencies and support groups.	

Table 5 continued

Authors, date, aim	Study population, background, nature of intervention (including theory/ model of person-centred care)	Evidence of intervention effects/ major findings/comment
Chapman, Keating and Eales, 2003 Aim: To consider how care in residential care might be provided in a manner that remains focused on the care recipient, has the benefits of living in a community context and is economical for the public purse	Evaluation study of three residential care facilities with different care models: • assisted living • dementia care • adult family living. Participants were two key stakeholder groups consisting of staff members who provided direct services to residents and family members of residents who had some experience with the program. Focus groups were used to obtain opinions and experiences surrounding the implementation of client-centred care: six with staff and four with family (as well as some individual and small group interviews with family members due to their schedules). Participants were asked open-ended questions about carer roles, care resources, the management of interpersonal dynamics, support for resident decision making and challenges for carers.	Both staff and family endorsed a client-centred approach, but found the implementation very challenging. Three key themes emerged from the focus groups, illustrating why the implementation of person-centred care in the residential care models was challenging: • engaging with others in a care partnership • responding to residents' preferences and care needs within limited resources • maintaining residents' connections with the community. The main features of successful person-centred care identified were: • including family members in care team • shifting staff assignments to a generalist, family-like style of care • having physical settings that support residents and their connections to the community. The article states that it is important to note that there are other key players whose needs also must be met in person-centred care. Barriers to client-centred practice identified in this study are: • values and preferences of staff members • high levels of frailty of residents • time • financial issues • the requirement for training.
Evans, Street and Lynch 1996 Aim: To promote positive lifestyle changes which foster improved health, better quality of life and increased independence for older people experiencing alcohol withdrawal, by using a client-centred, non-judgmental, and non-confrontational model known as Victoria Innovative Seniors Treatment Agency or VISTA	VISTA is based on the Community Older Persons Alcohol Program, which was developed in 1983 by Saunders and which recognised that building a relationship with a counsellor is fundamental to successful treatment. Four alcohol-dependent clients (two men and two women), aged between 66 and 77 years and all living at home alone, received services at home for alcohol withdrawal. During the assessment, the following items were monitored: • alcohol withdrawal • benzodiazepine use • cognitive function • overall function and recovery. The program was developed through a committee, which was made up of health professionals and acted as a partnership (that is, nothing could go ahead until all committee members were in agreement).	It was found that the program provided safe, effective, client-valued alcohol withdrawal services to older people; however, the program was developed by a partnership of service providers and there did not appear to be any input from service users about what would be best for the older person.

Table 5 continued

Authors, date, aim	Study population, background, nature of intervention (including theory/ model of person-centred care)	Evidence of intervention effects/ major findings/comment
Fuller, Harvey and Misan 2004 Aim: To discuss the sustainability of client-centred care planning based on the evaluation of a chronic disease self-management project in rural South Australia	The project discussed in this paper recruits clients who have a chronic disease and helps them to learn more about their disease and to understand how to better manage their symptoms. The approach used for the project is the client-centred 'partners in health' approach, which establishes client-determined problems and goals as the starting point for care planning. In addition to this approach, clients are offered the opportunity to participate in a chronic disease self-management course and contact with and involvement in a community-based health information and resource centre. Data were collected by interviews and focus groups from five key stakeholder groups-clients, carers, health service providers, community members and project staff–at the beginning and middle stages of the project. Clients and carers were randomly selected from the project database, all health service providers involved were invited to participate, and community members were drawn from advisory committees. Total participants = 40 at the beginning stage and 39 at the middle stage	Findings: • All informant types were positive that the care planning and self-management used in the project facilitated clients' and carers access to information and learning about living with chronic disease. • Clients indicated that the approach used in the project helped them to learn more about their condition, provided mutual support for setting and attaining goals, helped them to accept their disability and gave them the trust and confidence to talk about their illness. • Clients and carers described this approach as *'more personal', 'not hurried',* and *'more complete discussion'* than simply a focus of medical matters. This approach is more like a friendship between the client or carer and health professional. Barriers (issues that made it hard for health professional): • Because this approach is a *'more complete'* way of dealing with the client it requires more time. • More time per client means greater costs (especially in the short term). • Because this approach is *'more complete'* the client tells the health professional more and therefore the health professional has more to deal with: they have to take on a number of roles (for example, social worker, counsellor, rehabilitation officer). • Dealing with more issues also means that the care planner is required to know more (for example, what community services are available). • The approach also requires greater teamwork between health professionals and this sometimes is not always suitable or practical (for example, different funding arrangements for different health professionals, different attitudes between health professionals).

Table 5 continued

Authors, date, aim	Study population, background, nature of intervention (including theory/ model of person-centred care)	Evidence of intervention effects/ major findings/comment
Gordon 1998 Aim: To discuss person-centred care in relation to patients with human immunodeficiency virus (HIV) and challenging behaviour	Carl Rogers believed that if you can create a safe therapeutic environment in which to counsel, educate or care for a person, the person will develop in that environment. Therefore this paper argues that when a person comes into a unit for assessment and treatment, it should be individualised, person-centred care. The article says the barrier to implementing person-centred care is that it can be difficult to adopt a humanistic, person-centred approach when your own rights are being violated or you are being compelled to compromise required care. This article identifies the essential traits of person-centred care as including personal warmth, empathy, sincerity, honesty, knowledge, ability to be non-judgemental, to understand and to be sensitive to the person-centred approach, to be able to acquire information in a non-judgmental way, and to be able to turn assessment documentation into a plan for individual multi-disciplinary care. Person-centred care requires all service providers to have the necessary skills, attitudes, knowledge and practice; therefore training should be provided.	
Harkness 2005 Aims: • To provide useful reference material on patient-centred health care • To assist in identifying and promoting the principles of patient-centred health care	Literature review by International Alliance of Patients' Organizations exploring a wide range of literature (not just patients with chronic conditions) to address the questions: • What is patient-centred health care? • What effect does the practice of aspects of patient-centred health care have on outcomes?	Main conclusions of review: • There are numerous proposed definitions of patient-centred care with many of the same core principles but no accepted definition. • Evidence base is not comprehensive. • There are numerous barriers, including: – lack of definition – focus on costs and outcomes not quality of care – structure of health care system (belief that it will take longer in an already stretched system) – dissociation between health care and other aspects of the patient's life – lack of communication skills and desire for partnership with patients – need for attitudinal change – difficulties involving patients (and their families) in the development of services • There is a need to design health care systems around the patient and to formulate tools and targets to achieve this rather than focusing on defining patient-centred health care.
Kennedy, Nelson, Reeves, Richardson, Roberts, Robinson, Rogers, Sculpher, and Thompson 2003 Aim: To determine whether a whole systems approach to self-management, using a guidebook developed with patients combined with physicians trained in patient-centred care, improves clinical outcomes.	Cluster-randomised controlled trial Control group (CG): • Ten hospitals • 403 patients with ulcerative colitis or Crohn's disease Intervention group (IG) • Nine hospitals • 297 patients with ulcerative colitis or Crohn's disease • Intervention included training consultants to provide a patient-centred approach to care, provision of guidebook to patients, negotiation of written self-management plan, and improving access to services.	Findings: • Fewer hospital visits after 12 months for IG compared with CG (1.9 versus three, $p<0.001$). • Patients in IG felt they were more able to cope with their condition compared with those in the CG ($p<0.05$). • The IG patients reported fewer symptom relapses than the CG patients (1.8 versus 2.2, $p<0.01$). • Cost-effectiveness analyses favoured the person-centred approach over standard care.

Table 5 continued

Authors, date, aim	Study population, background, nature of intervention (including theory/ model of person-centred care)	Evidence of intervention effects/ major findings/comment
	Main outcomes: • Rates of hospital outpatient consultation • Quality of life • Acceptability to patients Other outcomes: • Anxiety and depression • Patient enablement • Patient satisfaction • Relapse duration • Interval between relapse and treatment Also involved an economic evaluation Data obtained through interviews at baseline and patient diaries, postal questionnaires and hospital records at 12-month follow-up	
Kennedy, Nelson, Reeves, Richardson, Roberts, Robinson, Rogers, Sculpher and Thompson 2004 Aim: To determine whether a self-management package could lead to a more appropriate use of health service resources and improve symptoms	Cluster-randomisation. This was chosen to avoid the risks of contamination within centres because staff training (which was an important part of the intervention) could only be delivered to entire clinical teams. Nineteen hospitals in total Control group (CG): ten hospitals, continued to provide treatment as usual Intervention group (IG): nine hospitals, delivered the self-management program to eligible patients Intervention involved: • clinicians receiving a two-hour training session in 'patient-centred consultations in gastroenterology'. This encompassed principles of patient-centred medicine advocated by Stewart • patients being given a guidebook that contained a negotiated self-management plan and phone number to make unscheduled appointments. Thirteen month recruitment and 12-month follow-up Three outcome measures: number of appointments kept during trial year, number of made appointments not attended, and percentage of patients who failed to attend at least once Qualitative interviews: 28 patients based on responses to exit questionnaire to represent success or failure of intervention	Findings: • Number of kept appointments reduced by one third in the IG compared with the CG (difference = -1.04 [95 per cent confidence interval -1.43 to -0.65]; p<0.001). • Mean number of clinic non-attendances per person was lower for IG (difference = -0.08 [95 per cent confidence interval -0.15 to -0.01]; p = 0.034), even after adjustment for number of non-attendances in pre-trial year. • No significant difference between groups for quality of life or health related anxiety and depression. • No significant difference between groups regarding satisfaction with consultation but IG reported higher enablement score (difference = 0.90 [95 per cent confidence interval 0.12 to 1.68]; p = 0.026). • The IG reported on average 16 per cent fewer disease relapses compared with the CG (difference = -0.36 [95 per cent confidence interval -0.63 to -0.09]; p = 0.013); • More patients in the IG than in the CG self-referred for at least one appointment (43 per cent versus 22 per cent) (p<0.001). • There was no difference between groups for general practitioner appointments. • There was no difference between groups for corticosteroid treatment. Sub-group analyses: • In the IG, feelings of enablement were related to being female (p = 0.005), older people (p = 0.006), more recently diagnosed patients (p = 0.045) and those with higher initial quality of life scores (p = 0.026). • Guidebooks were well received by both patients and clinicians.

Table 5 continued

Authors, date, aim	Study population, background, nature of intervention (including theory/ model of person-centred care)	Evidence of intervention effects/ major findings/comment
		• The approach used in this study may not be suitable for those with multiple social problems. In conclusion, the adoption of guided self-management was generally popular with both patients and clinicians, reduced the use of hospital services, increased quality of care without adverse effect on disease control and reduced cost.
Kennedy, Robinson, Hann, Thompson and Wilkin 2003 Aim: To evaluate the impact of a patient-centred, evidence-based guidebook on knowledge, quality of life, anxiety and depression on patients with ulcerative colitis	Cluster-randomised controlled trial. Six hospitals were chosen at random and invited to participate in the trial; these were then randomised to either the intervention group (IG) or the control group (CG). IG: patients were given the guidebook and were asked to read it. CG: patients were told they were participating in a study evaluating a guidebook, which would be given to them at the end of the study. Guidebook: • Content was based on information provided at a series of meetings with patients, who shared their experiences of living with ulcerative colitis and identified their information requirements, as well as medical information. • Pharmacists, gastroenterologists and dieticians reviewed final drafts. • The final product was full-colour and contained eight chapters, a section for personal details and guided self-management, including a series of pages highlighting areas of patient choice. Patients completed questionnaires at recruitment, one month and nine months after entry: • Anxiety and depression were measured by the Hospital Anxiety and Depression Scale (HADS). • Quality of life was measured using the Inflammatory Bowel Disease Questionnaire. • Knowledge was measured by a knowledge questionnaire developed for use with the guidebook.	Findings: • There were significantly higher knowledge scores in the IG at both one month and nine months compared with the CG, with the biggest improvement occurring between baseline and one month. • Therre were no significant differences between groups for quality of life; however, there was an indication that these were improving over time for the IG compared with the CG. • There were no significant difference between groups for health related anxiety and depression, indicating that provision of detailed information did not increase anxiety or depression. Findings from qualitative studies (not reported in this paper) indicate that reading the guidebook acted to negate feelings of isolation and uncertainty common in people with ulcerative colitis, and increased people's ability to manage problems and initiate self-care. It has been suggested that all patients with ulcerative colitis be provided with appropriate patient-centred information, and also that similar guidebooks for other chronic disorders would be warranted.

Table 5 continued

Authors, date, aim	Study population, background, nature of intervention (including theory/ model of person-centred care)	Evidence of intervention effects/ major findings/comment
Kinmonth, Woodcock, Griffin, Spiegal and Campbell 1998 Hypothesis: Additional training for practitioners in a patient-centred approach would lead to better communication between the patient and practitioner, healthier lifestyle choices, and improved clinical, social and psychological outcomes among patients in their first year of diabetes compared with routine care	Cluster-randomised controlled trial Intervention group (IG): • Trained to give patient-centred care. Nurses offered half-day training to review evidence for patient-centred consulting and full day in which to practice skills learned. Doctors offered the half-day only and had an experienced facilitator assisting • Skills learnt include active listening and negotiation of behavioural change • Materials also provided to the patients in this group • Nurses received follow-up training • Twenty-one practices (142 patients) (complete data set). Comparison group (CG) • Routine care, which was based on national guidelines and materials for patients • Nurses received follow-up training focusing on use of guidelines and materials • Twenty practices (108 patients) (complete data set) Inclusion criteria (of practice): greater than or equal to four medical partners, list size greater than 7,000, diabetes register with greater than 1 per cent of practice population, diabetes service registered with health authority Recruitment of patients: • Aged between 30 and 70 years. • All new cases of diabetes within 12-month period were identified and approached Data collected at baseline and 12 months	Findings: • Patients in the IG were significantly more likely to report excellent communication with doctors and great satisfaction with treatment compared with those in the CG. • Knowledge scores were significantly lower in the IG patients compared with those in the CG. • Both groups had similar diet and exercise scores. • Functional and psychological measures favoured the IG; however, wellbeing scores were the only ones that were significantly different. • Wellbeing scores were significantly higher in the IG than in the CG ($p = 0.03$). This was reported to be the first randomised controlled trial in primary care to show that training in patient-centred care, with a focus mainly on nurses, can significantly improve communication, wellbeing and satisfaction among patients with newly diagnosed diabetes. However, it was concluded that professionals committed to achieving patient-centred care should be careful not to lose focus on the disease while paying attention to the unique experience of each patient.
Michie, Miles and Weinman 2003 Aim: To review published research on health care communication in chronic illness	Thirty studies were identified which measured health professional-patient interaction and a physical or psychological outcome for the patient.	Two types of studies were identified: 1. Health professionals took the patient's perspective (that is, there is a match between professional's and patient's perceptions of the illness) 2. Health professionals sought to 'activate' the patient (that is, the patient is encouraged to take some control, ask questions, and so on). The second group of studies was associated with more positive health outcomes for patients than the first.

Table 5 continued

Authors, date, aim	Study population, background, nature of intervention (including theory/ model of person-centred care)	Evidence of intervention effects/ major findings/comment
Mills, Harvey and Council of Australian Governments 2003 Aim: To describe the patient management processes and use of health outcome measures to monitor changes in utilisation patterns and patient wellbeing over time for type 2 diabetes patients	Intervention group (IG): 398 participants Control group (CG): 111 participants Patients were assigned to service coordinators who were trained in goal setting. The patients' 'problems and goals' were defined and a care plan prepared for 12 months, in consultation with their relevant general practitioner. This process involved an assessment of a patient's problems using a behavioural assessment and functional analysis. This translated a patient's emotions, thoughts and behaviours into patient-specific problem statements. Designated service coordinators recorded problem and goal scores on a linear analogue scale. Patients also recorded their own 'self-reported' scores. Goals were then tallied according to improvement (at least one point between first and final rating), no change, or deterioration (of at least one point). Participants also undertook the Work and Social Adjustment Scale (WASAS) and the SF36, a quality of life scale.	Findings: • Between 40 and 60 per cent of patients made some progress towards achieving their first goal over the trial • Up to 60 per cent of patients felt their main problem improved by the end of the trial. • There was no significant difference in the SF36 quality of life assessment between the IG and the CG. • WASAS scores between the two groups were statistically significant ($p<0.01$) over time, with mean scores improving by 10 per cent. • The percentage of patients requiring at least one hospital admission in the IG fell by 18.2 per cent compared with the CG. The conclusions suggested that a structured patient-centred care planning process can improve patient knowledge of their condition and increase motivation for sustainable behaviour change to assist in managing their illness.
Renders, Valk, Griffin, Wagner, van Eijk and Assendelft 2000 Aim: To determine the effectiveness of different interventions, targeted at health care professionals or the wider organisation, to improve the care for patients with diabetes	Systematic review methodology to look at studies that have intervention strategies to improve the care for patients with diabetes Forty-one studies met all the criteria: 27 randomised or quasi-randomised controlled trials, 12 controlled before and after studies, and two interrupted time series trials Studies that only evaluated patient-oriented interventions were excluded; however if they were combined with professional or oganisational interventions they were included. Two reviewers independently reviewed all studies.	The systematic review found: • education, in combination with other interventions, such as reminders, audit and feedback, andeducational outreach visits, improved the diabetes care; however, the effect that these have on patient outcomes is unclear • strategies that improve recall of visits and review of patients (for example, central computerised tracking, telephone call follow-up, nurses regularly contacting the patients) can improve diabetes management • including patient-oriented interventions along with health professional or organisational interventions also appears to also be effective in improving patient outcomes.

Table 5 continued

Authors, date, aim	Study population, background, nature of intervention (including theory/ model of person-centred care)	Evidence of intervention effects/ major findings/comment
Robinson, Thompson, Wilkin and Roberts 2001 Aim: To assess the effectiveness of a patient-centred approach to management of ulcerative colitis. It was hypothesised that the new approach to management would: • be acceptable to patients • result in a clinically worthwhile reduction in the delay between onset of symptoms and treatment • reduce outpatient attendances without a concomitant decline in health-related quality of life	Randomised controlled trial Intervention group (IG): • A personalised guided self-management regimen for every patient was developed by the clinician, in collaboration with the patient, during a 15-30 minute consultation. The aim of this was to ensure patients could recognise a relapse and knew what to do during a relapse. • Patients were given a helpline number. • Eighty-eight patients had completed exit questionnaires. • Seventy-five returned diaries (which were used to record relapse, time to treatment, medication, length of relapse, visit to practitioner and so on) suitable for analysis. Control group (CG): • Patients were told they would be offered the new regimen at the end of the study. • Eighty-six completed exit questionnaires. • Sixty-three diaries were available.	Findings: • There was no difference between groups in the use of medications. • There was no significant difference between groups in the number of relapses (61 per cent in the IG and 49 per cent in the CG: more in the IG). • Relapses were treated significantly earlier in the IG compared with the CG (14.8 hours versus 49.6 hours respectively, $p<0.0001$). • For those patients who began their relapse treatment within 24 hours, there was a trend towards shorter relapses compared with those who waited longer than 24 hours; however this difference was not significant. • Significantly more relapses in the IG were self-treated compared with the CG (96 per cent versus 50 per cent respectively; $p<0.0001$). • CG patients self-treated more relapses incorrectly compared with IG patients (30 per cent versus 5 per cent respectively; $p<0.0001$). • IG patients made significantly fewer outpatient visits per year compared with the CG patients (0.9 vs 2.9 respectively; $p<0.0001$). • IG patients also made significantly fewer family practitioner visits compared with the CG patients (0.3 vs 0.9 respectively; $p = 0.0006$). • There was no significant difference between groups for quality of life scores. • The majority of patients in the IG preferred the new patient-centred approach to the management of ulcerative colitis over the usual care.
Shellman 2000 Aim: To describe how blood pressure clinics (elder wellness program) can provide opportunities for health care professionals to promote elder wellness in an atmosphere that encourages nurse-client interactions.	The elder wellness program was developed using Anderson and McFarlane's Community-as-Partner model, which was based on Meumann's total-person framework. There are two central components to the model: 1. a focus on the community represented by the assessment wheel; includes assessment parameters such as the demographics of the community as well as the beliefs, values and history of the people who are central to the structure of this model 2. use of the nursing process. Establishing a partnership between the members of the community and the community	On evaluation of the elder wellness program it was found that older people living in isolated areas of the town had inadequate access to the senior centre developed through the program. Results of the evaluation indicate that the blood pressure screening clinic fostered an atmosphere for the sharing of health concerns and clients felt they could have a private conversation with the nurse. The findings suggest that a community-focused blood pressure screening clinic can provide opportunities for health promotion by using the Community-as-Partner model as a guide for the development of the overall program, developing

Table 5 continued

Authors, date, aim	Study population, background, nature of intervention (including theory/ model of person-centred care)	Evidence of intervention effects/ major findings/comment
	health nurse serves as the basis for the Community-as-Partner process. According to Anderson and McFarlane: • Residents have the right to identify their own health needs and then negotiate with the community health nurse about interventions and specific programs that they want in their elder wellness program. • Walking into a community requires having an attitude of 'doing with' the people instead of an attitude of 'doing for' the people. At the beginning of the elder wellness program, a partnership was established between health care providers and community residents to determine the health needs of the seniors. • Assessment is the act of becoming acquainted with a community and, according to their Community-as-Partner model, the first step of the community assessment is to become familiar with the people.	a community partnership between the health professionals and the older people at the start, and fostering a trusting nurse-client relationship.
Zernike and Henderson 1998 Aim: To determine whether the implementation of a structured patient-centred education program, which systematically deals with risk factors for the hypertensive patient, is more effective in improving knowledge of hypertension than the normal ad hoc information	Quasi-experimental design. Forty participants (20 in each group) with an average age 67 years. Nineteen males. Control group (CG) received ad hoc information Intervention group (IG) received patient-centred structured education (a learning program conducted through an interactive process between the patient and research nurse) and written material The study tested whether there were differences between groups regarding changes in knowledge about lifestyle management of patients on anti-hypertensive medications. Testing was conducted at: • Pre-test – 24 hours after admission to hospital • post-test – at discharge • post-test – eight weeks after discharge. The IG patients were also followed up one year after the second post-test.	Findings: • There was no significant difference for the CG between its participants pre-and post-tests. • There was a significant difference for the IG participants between pre-test and discharge ($p = 0.0035$), eight weeks after discharge ($p = 0.0013$) and one year after discharge ($p = 0.04$). • Patients in the IG were more likely than those in the CG to retain knowledge about lifestyle risk factors that have been implicated in hypertension. This study has shown that a structured approach to health education is more effective in improving patients' knowledge about their condition than relying on the ad hoc information they would generally receive during hospitalisation. Further, this type of structured education program is sufficiently easy and can be performed within the everyday interaction that occurs between a nurse and a patient. Therefore, it has been suggested that it is an education program that can be implemented by nurses working in the acute care setting.

Eighteen articles were reviewed which focused on person-centred care and people with dementia (see Table 6). The studies were predominantly discussion papers (including resource guides for nurses and reporting on a case study). In addition to discussion papers, the study designs included literature reviews (one of these using a systematic review methodology), reporting on interviews and reporting on an audit using the non-participatory observation method. One of the references cited was a book and another was information from a website. Only one level I study was reviewed (Neal & Briggs 2003).

Table 6: Literature on person-centred care with people with dementia

Authors, date, aim	Study population, background, nature of intervention (including theory/model of person-centred care)	Evidence of intervention effects/major findings/comment
Beattie, Daker-White, Gilliard and Means 2002 Aim: To examine research concerning the needs, care and current service provisions for younger people with dementia	This paper reviews the literature on younger people (under 65 years of age) with dementia who are in dementia care. The main research questions to be answered were: • Is there a need for services for younger people with dementia? • What are those needs? • How are services provided? • Are there services specifically designated for younger people? • Can we identify any styles of service provision that constitute best practice? (pp. 205-6). This review was undertaken in tandem with a review of the dementia care literature concerning minority ethnic groups. Systematic review methodology was used to identify and assess relevant articles.	Seventy-four relevant papers were identified using a search strategy derived from the methodology of systematic reviews, the majority of which originated in the United Kingdom (69 or 93.2 per cent). Response to research questions: • A central theme emerging from the literature surrounding younger people with dementia was the necessity for specific assessments of need in this group (p. 206). • It was suggested that the social and psychological context of younger people with dementia was different from that of older people; however, due to lack of consultation with younger people, perceptions tend to be those of professionals (pp. 207-8). • A side effect of arguing for the special case of younger people is various assumptions: older people are not physically fit; older people do not have sexuality; their carers do not work; and so on. • Suggestions for good practice were recommended (p. 209); for example, involving the person, having services to meet the needs of the individual rather than categories (such as age) of people, the need for a coordinated integrated pathway, and having flexible and responsive person-centred services. Overall, the literature argues that the needs of younger people with dementia are best served by interagency collaboration, early assessment, and an awareness of individual needs. Clearly, these proposals could usefully serve anybody with dementia, irrespective of age. However, aside from a few prevalence studies, and some exploratory work with small numbers of service users, little in the way of empirical work is available. The recommendations that have been made about dementia services for younger people are based largely on the practical experience of professional and paid carers, rather than scientific evidence (p. 205).

Table 6 continued

Authors, date, aim	Study population, background, nature of intervention (including theory/model of person-centred care)	Evidence of intervention effects/major findings/comment
Bradford Dementia Care Group, School of Health Sciences, University of Bradford 2004 Background: Dementia Care Mapping or DCM is a tool developed by the late Professor Tom Kitwood and Kathleen Bredin in the late 1980s. It was designed to assess quality of care from the perspective of the person with dementia. In 1992 the Bradford Dementia Group began delivering training courses in using the method and since then undertaking training in the method has become increasingly popular with those working with people with dementia from many professional backgrounds.	Dementia Care Mapping is an observation tool designed to examine quality of care from the perspective of the person with dementia. It is part of a process of bringing about improvements to care and is designed to be used only in formal care settings. It is grounded in the philosophy of person-centred care, which promotes the personhood of people with dementia and an holistic approach to their care. *The DCM process involves briefing staff who work in the areas to be 'mapped' about the method, observation of participants with dementia within the setting, processing the analysed data, feeding back this information to staff, and using this to draw up an action plan for change. Therefore it is a means for bringing about change and improvements based on direct observations of the care being delivered.*	This is from the Bradford Dementia Care Group, School of Health Sciences, University of Bradford web site.
Brooker 2002 Aim: To provide a channel of two-way communication between researchers and practitioners in the expanding field of social, psychological and nursing research in dementia care, including all aspects of nursing care practice, communication and the environment. The focus is on Dementia Care Mapping, provided by Tom Kitwood.	The article takes stock of DCM: what has been achieved and what else it can be used for.	The article outlines the multiplicity of uses for DCM, arguing that in the absence of other tools, DCM has been used for: • improving person-centred care • staff training • assessment • outcome measurement • evaluating the effect of therapeutic interventions • assessing general quality of a service (p. 34).
Brooker 2004 Aim: Not stated	The paper presents Kitwood's style for representing complex ideas in the form of an equation: PCC (person-centred care)=V+I+P+S	The elements V, I, P and S represent: • valuing people with dementia and those who care for them (V) • treating people as individuals (I) • looking at the world from the perspective of the person with dementia (P) • a positive social environment in which the person living with dementia can experience relative wellbeing (S).

Table 6 continued

Authors, date, aim	**Study population, background, nature of intervention (including theory/ model of person-centred care)**	**Evidence of intervention effects/ major findings/comment**
Cheston 1998 Aim: To examine the published literature in this area (psychotherapy and counselling techniques and person-centred care with people with dementia) which beares on psychotherapy assessment, intervention and evaluation	Although there is a developing clinical literature on intervention techniques drawn from all the main psychotherapeutic approaches, there has been little research into the effectiveness of this work and the research that does exist often uses methodologies that are inappropriate for such an early stage of clinical development. While the last ten years or so have seen a consistent increase in the number of reports of psychotherapeutic interventions with people with dementia, there have been comparatively few attempts at evaluating this work. Even validation therapy, the most extensively reported of all psychotherapeutic interventions with people with dementia, has a limited evaluative basis (p. 219).	It is argued that clinical research should adopt case study or single-case designs which are more appropriate than group designs for evaluating new clinical developments.
Clare 2004 Aim: To consider the concepts and models that, often implicitly, underlie accounts and studies of variations in awareness of difficulties in people with early stage Alzheimer's disease.	This study critically reviews a range of literature relating to concepts and models of awareness, drawn from different disciplines and published during the past 30 years (p. 155).	There is a need for a comprehensive biopsychological model of awareness in early stage Alzheimer's disease which is compatible with person-centred approaches to research and clinical practice (p. 167). Further work is needed to develop a model that can incorporate all relevant factors and offer a comprehensive explanatory framework to serve both as a basis for sensitive, person-centred intervention and a stimulus for future research (p. 170). This paper does not provide strategies for how person-centred approaches will assist in early stage Alzheimer's disease.
Dewing 1999 Aim: Not stated	This study discusses old culture and new culture of dementia and personhood in the context of the new culture (referencing Kitwood and others). Also discusses person-centred nursing in dementia care *'The primary purpose of person-centred dementia care is to maintain personhood in the face of failing mental powers'* (p. 587).	The article acknowledges that, *'some of the ideas in this article have yet to be proven by large-scale research or practice-development studies'* (p. 588).
Dewing 2000 Aim: To discuss critically, within a person-centred framework, the nature of wellbeing for older people who are cognitively challenged through the processes of dementia, and to consider how nurses can make a difference through their practice	This article is targeted at nurses working with people with dementia, presenting exercises (including case studies) to guide professional development. The article draws on Kitwood's model of dementia care.	This article is useful as a staff guide for working with people with dementia.

Table 6 continued

Authors, date, aim	Study population, background, nature of intervention (including theory/ model of person-centred care)	Evidence of intervention effects/ major findings/comment
Dewing 2003 Aim: To help nurses and other members of the rehabilitation team understand more about older people with dementia so that they might maximise their potential for rehabilitation. It also discusses the principles and practice of person-centred rehabilitation and suggests it is especially appropriate for patients with dementia.	This paper is structured as a guide for nurses in their practice with people with dementia. Tasks are provided throughout the paper to assist nurses in practice change. The paper discusses the following areas: • re-enablement • quality of life • behavioural changes. It is important that the prevailing view in rehabilitation (that patients must have goals and be an active and informed partner) is amended to accommodate those with dementia (p. 44) • the best environment • dementia-sensitive communication, The Essence of care benchmarks set out several tools for patient-focused ways of working and communication features in all of them; however, a specific tool on communication was published recently which makes it clear that particular attention needs to be paid to each person's cognitive abilities. Establishing communication that patients and supporters experience as effective and sensitive to their needs and preferences is fundamental to the success of rehabilitation. This paper also outlines some useful and simple methods of communicating with an older person with dementia (p. 47).	The author suggests that, 'person-centred rehabilitation with this patient group [dementia] can enhance their abilities and help them to acquire new ones' (p. 42). *'There are different models and methods contained in [person-centred dementia care]. However, person-centred models and methods usually share the same global concerns and aims of maintenance, and nurture the four subjective states that underpin wellbeing and personhood: personal worth, agency, social confidence and hope. That is the promotion of:* • *Personal worth – where older people with dementia feel that they are of value to others;* • *A sense of agency – where the older person knows that he or she has the freedom to make things happen;* • *Social confidence – where the person knows he or she will be socially accepted; and* • *Hope – where the person has a fundamental feeling of trust and safety'* (p. 43).
Dewing and Garner 1998 Aim: To demonstrate how one person with dementia (Enid) was listened to and how her behaviour was interpreted within the context of her life and experiences. It also shows how the insights and information gained were shared with staff and used in care records.	In the context of a person-centred approach to care, knowing the person's life history and that person's reactions to events and experiences in their life is an extremely important part of any assessment process (p. 12).	The article focuses on how to learn from the person with dementia if a practitioner is to practice in a person-centred way (p. 15).

Table 6 continued

Authors, date, aim	Study population, background, nature of intervention (including theory/ model of person-centred care)	Evidence of intervention effects/ major findings/comment
Ericson, Hellstrom, Lundh and Nolan 2001 Aim: To explore and better understand what constitutes 'best care' from the perspectives of both family and professional caregivers in order that both groups can work as partners in the caregiving enterprise	Family carers were recruited from existing service users whose relative attended either day care or respite care. Interviews were undertaken with 20 family carers exploring their perceptions of what constituted good care. The interviews lasted about 45 minutes and were tape recorded for later transcription and analysis (pp. 710-11). Interviews were also completed with 17 professionals who regularly worked with family carers. After the interviews, all the interviews were transcribed and subjected to a detailed content analysis to identify the main themes (p. 711).	• Results suggest that professional and family carers are aiming for the same overall goals, at least insofar as the person with dementia is concerned, focusing on the individual needs of the person with dementia and that a suitable environment was essential to the delivery of good care. There were, however, differences in emphasis about who has the most important type of knowledge and about the role and value of institutional care (professionals, more so than carers, saw the benefits of alternative environments such as care homes, when the need arose (p. 712). • More recently there have been shifts to recognise that lay knowledge is at least of equal importance to professional knowledge. The question remains as to whether professionals are ready for such a shift or whether they will continue to see 'expert' family carers as a threat (p. 714).
Jackson 2002 Aim: To discuss issues of care that arise for both carers at home and health care professionals generally, emphasising the importance of ensuring care is always person-centred	Final in a series of four articles about dementia This article implies that if society is unwilling to pay for the care of older people (including drug treatment), it is a form of abuse.	The abstract (p. 30) states: *'People with dementia, particularly in its early stages, are aware of their problems, therefore it is vital that they are told of their diagnosis so they can make decisions about their future. The development of new drugs has led to major changes in the management of dementia, but 'postcode prescribing' means that all drugs are not widely available. [Pfizer supports this paper/journal.] Various means of support are available for patients and their carers but at all times healthcare professionals must ensure that the person is at the centre of a patient's care.'* The key point in this article is that it is vital that people with dementia are told of their diagnosis so they can make decisions about their future.
Kitwood 1997	This book argues for a change to the traditional approaches to dementia care, away from a focus on the deficits of the person to a recognition and validation of the essential personhood of the older person with dementia. Based on person-centred counselling (Rogers) and other social and psychological theories, such as, symbolic interactionism. The book includes a description of a retrospective study conducted by the authors.	Models of person-centred dementia care are outlined, together with the limited research that has been done in the area. Focuses on person-centred approaches to dementia care and the therapeutic interaction (relationship) between clients and carers Chapter 6 identifies ten aspects or capacities of person-centred care required from the therapist: • recognition • negotiation • collaboration • play • timalation • celebration • relaxation • validation

Table 6 continued

Authors, date, aim	Study population, background, nature of intervention (including theory/ model of person-centred care)	Evidence of intervention effects/ major findings/comment
		- holding - facilitation and two from the person with dementia: - creation - giving. The book also discusses the organisational characteristics that support and confound good practice (Chapter 7).
LaFontaine 2004 Aim: To discuss the opportunities and challenges presented in seeking to provide person-centred care to younger people with dementia in the Birmingham Working Age Dementia Service	Practice is based on Kitwood's principles of person-centred therapy. Also refers to Cheston's (1998) work with people with dementia and Thorne's (1991) description of person-centred therapy: - Every person has a desire to reach their instinctive potential. - Each person is unique, therefore no diagnostic labelling can be fully justified. - The self-concept is the person's construction of themselves and is heavily influenced by others. - Self involves multiple roles and people have the capacity to change and develop these concepts of self.	The case study shows how practitioners can use the person-centred approach (for example, for assessment, developing the care plan including intervention program, providing different experiences). The paper identifies two challenges with the person-centred model: 1. criticism that the original model developed by Rogers was individualistic (did not apply to family care and did not apply to a community setting) 2. the impact of providing it to the staff within the team.
Neal and Briggs 2003 Aim: To evaluate the effectiveness of validation therapy for people diagnosed as having dementia of any type or cognitive impairment	Review All randomised controlled trials examining validation therapy as an intervention for dementia were considered for inclusion in the review.	The review found no evidence of the efficacy of validation therapy for people with dementia or cognitive impairment: - Three studies that met the inclusion criteria were identified. - Two significant results were found (validation versus usual care favours validation therapy; validation versus social contact favours validation), but they were not statistically significant and there were no assessments of carers.
Pritchard 1999 Background: The *Professional Nurse* 'Study' articles were developed as a self-assessed learning activity which can be used to meet United Kingdom Central Council (the statutory regulatory body for nursing, midwifery and health visiting in the United Kingdom) requirements for professional updating and as an entry in personal professional profile	This is the second of a four-part series of dementia articles, each focusing on different areas: 1. person-centred care 2. assessment 3. communication 4. risk management They are a self-assessment guide for nurses.	This article is predominantly a discussion about assessment and dementia. The article details 15 principles of good assessment, identified by Nolan and Caldock (1995). A good assessor will: 1. empower both the user and the carer, and inform them fully 2. involve, rather than just inform, the user and carer, and make them feel as if they are full partners in the assessment 3. shed their 'professional' perspective, have an open mind and be prepared to learn 4. start from where the user and carer are, establish their existing level of knowledge and what hopes and expectations they have 5. be interested in the user and carer as people

Table 6 continued

Authors, date, aim	Study population, background, nature of intervention (including theory/ model of person-centred care)	Evidence of intervention effects/ major findings/comment
		6. establish a suitable environment for the assessment, which ensures there is privacy, quiet and sufficient time 7. take time, build trust and rapport 8. be sensitive, imaginative and creative in responding 9. avoid value judgements whenever possible 10. consider social, emotional and relationship needs as well as practical needs and difficulties 11. listen to and value the user's and carer's expertise and opinions 12. present honest, realistic options 13. not make assessment a 'battle', where people feel they have to fight for services 14. balance all perspectives 15. clarify understanding at the end of the assessment. Underpinning the assessment of people with dementia with such principles emphasises the importance of person-centred assessment practice (p. 657). Apart from discussion of the principles of good assessment, the article focuses on these ideas: • Nursing assessment of people with dementia is likely to be holistic (p. 658). • Attitudes towards people with dementia are important (p. 658). • There are problems with assessment tools (pp 659-60). • Person-centred nursing assessments that focus on the person's social and biographical history will contribute to the assessment of people with dementia as well as to their ongoing care (p. 660).
Rae and Colles 2000 Aim: To describe a Scottish training scheme, which demonstrates that nurses can make a difference	Training scheme aimed at raising awareness of the needs of people with dementia and their carers in the community	Training was well attended and most nurses said they would recommend it to others.

Table 6 continued

Authors, date, aim	Study population, background, nature of intervention (including theory/ model of person-centred care)	Evidence of intervention effects/ major findings/comment
Younger and Martin 2000 Aims: • To assess the use of the DCM tool as a measure of quality in dementia care • To calculate the resources required to insert the tool into a quality cycle • To collect secondary data about client profile within units (dependency)	The audit reported in this paper and submitted to the Psychiatry of Old Age Management Group assessed six units within each of two health districts in the United Kingdom. The audit used a non-participatory observation method in the units selected. Dependency levels of the clients/residents were also estimated to give a clearer picture of the setting and the care requirements. This was intended to establish a baseline for the units mapped and to enable care developments to be focused on intended outcomes. The method was developed by the Dementia Research Group at Bradford University and the underpinning values are based on Kitwood's (1993) social-psychological theory of personhood in dementia. Kitwood produced a manual, now in its seventh edition, which provides coding and data analysis to enable the observer to assess and measure the level of person-centred care in a given care setting (p. 1,207).	Results led to a number of observations related to the levels of interaction between staff and clients/residents, the need for a wider range of activities to promote person-centred care, and a suggested route to the improvement in quality of life for this group (p. 1,206). Assessment of dependency levels linked to the results of the mapping showed that high dependency does not automatically lead to lower quality of person-centred care (p. 1,206). Good dementia care is that which enables the person to feel supported, valued and socially confident (p. 1,210). Activity to take place at recreational, interpersonal and therapeutic level Activity co-ordination is essential.

Twelve articles were identified which focused on person-centred care and neurological conditions (see Table 7). The study designs included qualitative (eight), commentary (one), tool development (one), one level I review (Kwan & Sandercock 2004) and one level II randomised controlled trial (Thapar et al. 2002).

Table 7: Literature on person-centred care with people with neurological conditions

Authors, date, aim	Study population, background, nature of intervention (including theory/ model of person-centred care)	Evidence of intervention effects/ major findings/comment
Abreu, Zhang, Seale, Primeau and Jones 2002 Aim: To gain an understanding of the collaboration that occurs in interdisciplinary team meetings at a post-acute brain injury rehabilitation centre	Methodology: • qualitative descriptive case study • participant observation of 51 meetings (natural environment) • five interviews with staff • document review of charts and memos • inductive analyses. Interdisciplinary team meetings include the client, caregiver, case manager, therapists and funding body. They are run monthly. Also biweekly meeting with clinical staff only	Findings: • Inclusion of the client in interdisciplinary team meetings does not necessarily lead to collaboration. • Interdisciplinary team did not accommodate cognitive impaired clients or use client-centred models for this client group. • Professionals described client care and objectives from their multiple disciplines, which led to a lack of cohesion. • There was a lack of client voice despite clients being at the meetings.
Chan 2002	Commentary paper	The paper: • defines autonomy; that is, deciding what one wants to do and doing what one decides to do • discusses the move from medical model to client-centred model of care of health and benefits of this for quality service provision • relates to the International Classification of Impairment, Disability and Handicap and the International Classification of Function; for example, measures such as range of movement cannot reflect a person's wellbeing. • advocates the need for health services to address autonomy. Because autonomy is personally unique, client-centred approach should be adopted to tailor services to individual needs • offers definitions for client-centred practice; address client's holistic and individualistic properties (work in partnership with clients, respect, active client participation, shared power, philosophy transferred into practice through a process of enablement (don't do things for, do with), emphasises participation, collaboration, partnership, reflection, experiential learning). *'It's a process of facilitating, guiding, coaching, education, prompting, listening, reflecting, encouraging … so that individuals … have the means and opportunity to participate in shaping their own lives'* (p. 984).

Table 7 continued

Authors, date, aim	**Study population, background, nature of intervention (including theory/ model of person-centred care)**	**Evidence of intervention effects/ major findings/comment**
		• says that through the above processes, patients are provided with information and education to enable autonomy and choice • questions whether the aim for patient autonomy is a luxury given the current health care funding • questions how autonomy can be evaluated • recommends a move to family-centred versus client-centred practice.
Chen, Rodger and Polatjko 2002 Aims: 1. To investigate the ability of the Canadian Occupational Performance Measure (COPM) to measure change over a one-month period of client-centred intervention with adults with neurological dysfunction 2. To investigate the relationship between the COPM and Reintegration to Normal Living Index (RNL) 3. To gain occupational therapists' perceptions on the use of the COPM and client-centred practice in a neuro-rehabilitation unit in an adult public hospital in Taiwan	Methodology: • Four occupational therapists trained in client-centred practice and the use of the COPM • Participation of 12 clients attending neuo-rehabilitation • COPM and RNL administered before treatment and after one month of neuro-rehabilitation • Pre and post interviews with occupational therapists conducted to gain their perceptions of the clinical utility of the COPM and their views on client-centred practice • Small sample size. Voluntary nature of involvement may mean that therapists were predisposed to new ideas and client empowerment	Summary: • Literature review referred to Allan and Giles (1999) stating: *'patients who made a functional independence focused goal statement on admission to the rehabilitation unit had significantly higher functional outcomes'* (p.168). • Matched t-tests showed significant increases in clients' self-ratings of performance and satisfaction on the COPM and in RNL scores between pre and post tests. Both COPM and RNL are sensitive to demonstrating change in occupational performance between pre and post test. • In relation to performance, there was a moderate correlation between the COPM and the RNL ($r = 0.72$, $p<.01$). In relation to satisfaction, there was a high correlation ($r = 0.93$, $p<.001$). • Pre-training: occupational therapists did not mention seeing the client's needs, goals, interests and motivations as influencing how they planned and organised assessment/intervention (spoke about other professionals' opinions/assessment results/own experience). Post-training, they reported increased awareness of clients needs and so on with respect to planning intervention. • One occupational therapist perceived increased client motivation and cooperation with the treatment process following use of the COPM. *'This concept makes my clients feel I care about them, and my clients begin to show higher motivation to participate in the intervention'* (p. 177). They also perceived that client satisfaction increased with therapy, because therapists pay more attention to client's needs and views. All therapists felt therapy improved quality of service offered. COPM assisted them to form a partnership with clients in the early phases of problem definition and negotiation of intervention goals.

Table 7 continued

Authors, date, aim	Study population, background, nature of intervention (including theory/ model of person-centred care)	Evidence of intervention effects/ major findings/comment
		• Value of the COPM included that it is not diagnosis-specific but rather the client's view of occupational abilities and challenges. It helped with working holistically, helped to prioritise treatment goals, helped client and therapist work in partnership, and helped clarify the role of occupational therapist to other team members as well as clients. • The COPM was easy to use, including client cognition, motivation, age, whether they wanted to take part in goal identification and directing intervention. The problem included that some older Taiwanese people were conservative or modest, not wanting to reveal personal issues or problems. Clients want to rest and be told what do. • There were issues with the administration, scoring (self-rating harder for older clients), language (satisfaction/ performance) and identification of problems in the COPM (particularly for clients used to medical model of therapist as expert, being told what to do; or for clients who lack insight). Difficulty explaining concept of client-centred practice and goals, at least initially. Fear that therapist could be perceived as being less skilled and less professional taking this approach • The problems with client-centred practice include lack of therapist knowledge and confidence with this approach, having to know the different options (needing a larger evidence base), and accepting the client's decisions and opinions. For client-centred practice one needs skills of interaction, negotiation and facilitation of problem solving and this is seen as more difficult. Client-centred practice training is required on communication, for example. • There would be a need for education for medical staff about the COPM and client-centred practice if it continued to be used.

Table 7 continued

Authors, date, aim	Study population, background, nature of intervention (including theory/ model of person-centred care)	Evidence of intervention effects/ major findings/comment
Craik and Rappolt 2003 Aim: To examine the research strategies of occupational therapists practicing in adult stroke rehabilitation	Grounded theory method to examine the self-reported research strategies of a sample of 11 'elite' occupational therapists practicing in adult stroke rehabilitation Triangulation of interview data, organisation policies of the occupational therapists' work places, and existing theories	Findings: • The study developed a theory and practice model to guide research in occupational therapy. • The Occupational Performance Process Model is used in clinical practice to guide client-centred decision making and to promote the use of research. • A new model was built on the Occupational Performance Process Model, to be used as a guide to enhance therapists' ability to maintain a client-centred approach while informing clinical practices with research evidence. • There is a need for structured reflection (clinical experience is a vital source of evidence), and case application and peer consultation to help put evidence into practice.
Dow Black, Bremner and Fearn 2004	Study completed by the National Ageing Research Institute for the Victorian Department of Human Services. It's three aims were: • to describe the current practice models in home-based rehabilitation in Victoria • to compare outcomes for clients (with orthopaedic and neurological diagnoses) and carers between inpatient rehabilitation only and when inpatient rehabilitation is combined with or replaced by different models of home-based rehabilitation (ambulatory and bed substitution) • to recommend a framework for best practice in home-based rehabilitation.	*'Participants in all three rehabilitation service types improved significantly from admission to discharge and post discharge ... client outcomes were found to be related to the intensity of therapy provided. Inpatient participants showed the greatest level of improvement across discharge and post discharge and bed substitution participants improved more than ambulatory participants... Clients and carers ... expressed a preference for home-based rehabilitation ... Staff also noted many benefits of home-based rehabilitation such as, the applicability of therapy; the opportunity to involve the carer and other family members in the rehabilitation process ...'* (p.14).
Kwan and Sandercock 2004 Aim: To assess the effects of care pathways, compared with standard medical care, among patients with acute stroke who had been admitted to hospital	Searched the *Cochrane Stroke Groups Trials Register, the Cochrane Central Register of Controlled Trials, MEDLINE, EMBASE, CINAHL, ISI Proceedings: Science and Technology, and HealthSTAR*. Aslo handsearched the Journal of Integrated Care Pathways and the Journal of Integrated Care Includeed three randomised controlled trials and 12 non-randomised studies which compared care pathway care with standard medical care	Findings: • Significant statistical heterogeneity in the analysis of the outcomes • No significant difference between care pathway and control groups in terms of death or discharge destination • Patients managed with a care pathway were more dependent on discharge, less likely to suffer an urinary tract infection, less likely to be readmitted, and more likely to have neuroimaging • Patient satisfaction and quality of life were significantly lower in the care pathway group • Not enough evidence to justify the routine implementation of care pathways for acute stroke management or stroke rehabilitation

Table 7 continued

Authors, date, aim	Study population, background, nature of intervention (including theory/model of person-centred care)	Evidence of intervention effects/major findings/comment
MacLeod and MacLeod 1996 Aim: To assess the effectiveness of a goal planning process with spinal cord injured patients	The study was undertaken in an inpatient rehabilitation unit for people with spinal cord injury. Clients were asked to complete a questionnaire and were given assistance (if required) to complete it by the unit psychologist The authors used self-efficacy theory to interpret the questionnaire findings. They hypothesised that internal/external locus of control may impact on uptake and efficacy of person-centred practice	Patient and staff satisfaction questionnaires indicated that staff and clients perceived that clients had more control over their rehabilitation and more information about their injury as a result of the goal planning process; however, there was an increase in staff workloads. Relatives who were involved in the process also found it useful in understanding rehabilitation. There was a relationship between information provision and perceived client control. Staff perceived training to be adequate, but made some suggestions, including using role plays; more gradual assumption of responsibility, including mentoring; and sitting in on goal planning meetings prior to assuming the facilitation role. Other suggestions for improvement from staff were: • earlier involvement of community services • more regular input from medical staff, and involvement of an associate worker to relieve workload.
Sim 1998 Aim: To examine the ethical principle of respect for autonomy within the context of neuro-rehabilitation	Commentary paper	Some of the difficulties in working to respect autonomy for this client group include: • difficulties with communication • issues of competence related to patients' making informed decisions • problems with gaining consensus on rehabilitation processes and outcomes between patient and practitioner • difficulties in negotiating agreements between the patient and the family where the consequences of a patient's decision may have a major impact upon family members. A number of practical strategies are discussed based on a client-centred model of practice, which may assist with overcoming the identified problems and assist in respecting the patient's autonomy while seeking to attain quality rehabilitation outcomes. Examples include: • ongoing negotiation and renegotiation of the goals and methods of rehabilitation, rather than a one-off discussion • informed consent being a process rather than a one-off event • the professional being sensitive to patients' non-verbal or behavioural cues, which show they may disagree • patient input being necessary for goals about handicap[2] or quality of life

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[2] 'Handicap' in this context refers to the International Classification of Impairment, Disability and Handicap, which has since been replaced by the International Classification of Function.

Table 7 continued

Authors, date, aim	Study population, background, nature of intervention (including theory/ model of person-centred care)	Evidence of intervention effects/ major findings/comment
		• acknowledging that goals about handicap or quality of life may be more relevant to patients and may improve motivation with the therapy process • seeing the role of therapist as one of facilitator to find the means to achieve the goals • not dismissing cognitively impaired adults as having no goals • involving patient in deciding outcome goals, which will make them more motivated within the intervention process • promoting that patients also have responsibilities in a client-centred relationship (to be knowledgeable about their condition, to understand the implication of their decisions, and to be active in the rehabilitation process) • using a multidisciplinary or interdisciplinary approach as opposed to using a single discipline approach better • allowing patients to delegate decision making to others as appropriate • considering the family dynamic within the rehabilitation process. If involving family, consider using an independent patient advocate so that their voice doesn't become minimised.
Swaine, Dutil, Demers and Gervais 2003 Aim: To develop a tool to assess client's perception of the quality of head injury rehabilitation services	Methodology consisted of: • reviewing existing questionnaires (for example, the Measure of Processes of Care and the Client Satisfaction Questionnaire) • conducting a literature search to identify dimensions of care to be included (searched articles relating to satisfaction with services for persons with head injury and the service need for them and their families) • generating items • validating items (TRIAGE methodology) • seeking consumer opinion.	A need was identified to develop a tool that assesses client's perceptions of the quality of services. This tool was developed. The tool has 87 items; each item is on a five-point rating scale. Requires a trained administrator
Thapar, Jacoby, Richens, Russell, Roberts, Porter, Wall and Roland 2002 Aim: To determine whether a general practitioner-completed prompt and reminder card is effective in improving the quality of epilepsy care when used opportunistically	Methodology: • 1,275 people with epilepsy • Across 82 practices • Practices randomly categorised as 'control'; doctor held card or patient held card	Increased record of seizure frequency in doctor-held card practices; not in patient-held card practices No differences found in proportion of seizure-free patients Patients in both intervention groups reported more medication side effects. Patients in doctor-held card practices were less satisfied with information provision. Participating general practitioners found the card useful.

Table 7 continued

Authors, date, aim	Study population, background, nature of intervention (including theory/ model of person-centred care)	Evidence of intervention effects/ major findings/comment
		Doctor-held card was retrieved and completed more often than the patient-held card. Overall, the doctor-held prompt and reminder card was effective in improving the recording of key clinical information, was useful for general practitioners and was completed more often than the patient-held card.
Von Koch, Wottrich and Widén Holmqvist 1998 Aim: To explore differences between a therapy session with a stroke patient in two different contexts: in the patient's home and in hospital	Qualitative case study: • Participant observation in two different contexts (one in the patient's home and one in hospital); • Semi-structured interviews with the therapists • Therapist documentation reviewed Looked for similarities and differences in behaviour of two therapists and their patients when working in the hospital and in the home	There were differences in therapist behaviour between home and hospital. In hospital, the therapist was seen as teacher/expert characterised by: • no explanation of activities • impairment-based activities (for example, kicking a ball, bilateral peg board activity) • goals not asked. In hospital, the patient was seen as patient/student: • Hospital is an unfamiliar environment, not inviting them to take initiative or assume responsibility • They are passive receivers doing what they are told • Goals are not offered • They are not sure how to act or behave in this context. In home, the therapist was seen to have many roles: • guest • host (for example, asking permission to use telephone) • friend (for example, sharing a coffee break) • student (listening). In the home, therapists focused on functional activity more than impairment. In the home setting, the patient was seen to: • have initiative and confidence • prompt goal setting • refuse to perform some recommended activities. There is a need to understand patient in his or her context (for example, home, work, as a neighbour and so on). The environment can facilitate a shift in power, and this could be considered threatening to some therapists. Hospital can be disempowering for patients, whereas the home can be motivating. The study suggests that if a therapist works with patients in hospital they should encourage them

Table 7 continued

Authors, date, aim	Study population, background, nature of intervention (including theory/model of person-centred care)	Evidence of intervention effects/ major findings/comment
		to take on different roles. This helps them to deal with the consequences of their disability. Goals set at different levels of the International Classification of Impairment, Disability and Handicap bring about differences in behavior (for example, an impairment goal may require assessment or monitoring by an expert, while change at the level of the handicap are, by definition, based on the patient's opinion).
Watson and Quinn 1998 Aim: To outline a model for stroke rehabilitation in both community and hospital settings	Methodology: • Informed by observations made by multidisciplinary staff working on a 16-bed stroke rehabilitation unit • Follow-up, observation and documentation of effect of stroke on patients and their families from admission through to community-based care • Literature review and critique of other models of stroke rehabilitation (for example, Prigatano, Quinn and Merrian)	Authors propose that the 'stages of stroke' model they have devised offers patients more control of their treatment choices and the future. The authors feel the model encourages a client-centred program rather than a service-centred program. The paper discusses the need to integrate spiritual issues. A major event in a person's life can be the starting point for that person reassessing priorities, especially if they are feeling dependent or out of control (such as when sick). The authors feel it is essential to incorporate spiritual issues into holistic assessment. The model has three categories for engagement: red (disengaged/poor insight), amber (passive engaged, carry over slight, progress slow), and green (fully engaged). The paper describes the stages that a person goes through after a stroke and provides suggestions for actions. For example, the initial reaction to a stroke may be that of shock. Some strategies for assisting people during this phase are – ensuring that staff are educated about strokes; making written information available; using stroke associations; and having contact people and counsellors available. At the acute phase there is a need for a full multidisciplinary team within 48 hours. At the post acute phase there is a need for a key contact person and a multidisciplinary team care plan. At the reintegration/long term recovery phase it is time to reshape the care plan and to provide carer support and crisis management. The paper advocates for an interdisciplinary team approach: knowledgeable staff, enthusiastic staff, and a supportive organisation (with opportunities for client-centred practice). The paper identifies one of the barriers to client-centred practice and implementing the model of care as protecting professional boundaries via interdisciplinary team models.

Thirteen articles were identified which focused on person-centred palliative care (see Table 8). The study designs included videotaped scenarios, questionnaire reporting, descriptive studies, discussion papers, reviews (of theory), editorials, and literature reviews. There were no level I or II studies and more than half (eight) of the thirteen studies were either descriptive or discussion papers.

Table 8: Literature on person-centred palliative care

Authors, date, aim	Study population, background, nature of intervention (including theory/model of person-centred care)	Evidence of intervention effects/major findings/comment
Ashby and Dowding 2001 Aims: • To assess how patients, relatives, doctors and nurses in a palliative care unit view pain and pain management • To examine how the 'optimal care philosophy' worked with the freedom of choices, when patients were asked, 'How is your pain?' • To examine whether hospice philosophy and partnership of care statement is being followed; and • Examine whether total pain (for example, physical, spiritual) is being recognised and discussed with patients and carers and managed in an acceptable way	Pilot study involved two patients as case studies. Main study had eight patients. Questionnaires to patients, relatives/friends, nurses and doctors. The questionnaire asked about pain severity, explanation of their pain (location and so on) and their participation in pain control.	Findings: • Research-based pain management enables the provision of pain control that is acceptable to patient, relatives, doctors and nurses. • Partnership of care is important. Establishing such a partnership enables patient and professional autonomy to be recognised and respected, international recommendations for pain relief practiced, and professional codes of conduct upheld. • Valuing patient-centred care and using assessment tools to assist communication and information sharing helps to establish this 'partnership of care'. • Good pain management requires accurate assessment, which is best achieved by open and honest discussion in a supportive environment. • Specialist knowledge of pain management options, including non-pharmacological therapies, creates an environment that encourages quality of life. • Differences exist between patient perception of pain and that of the relatives, nurses and doctors. Only the person with the pain can feel it.
Black 2004 Aim: To discuss issues related to the provision of good palliative care for patients with colorectal cancer	Descriptive/educational	Palliative care depends on an interdisciplinary approach with mutual respect for all team members and good communication that enables the patient where possible to be involved in any decision making about care and treatment. Problems that can be avoided by good communication include effective pain relief. Some relatives and patients believe pain is inevitable; however, pain can usually be managed. Adopts the World Health Organization definition of palliative care, which is *'a person-centred approach concerned with physical, psychosocial and spiritual care in progressive disease'* (p. 586).

Table 8 continued

Authors, date, aim	Study population, background, nature of intervention (including theory/ model of person-centred care)	Evidence of intervention effects/ major findings/comment
		The article cites a study by Higginson, Wade and McCarthy (1990) aimed at finding out patient and family views on the palliative services they had used. Comments were sought on health services from hospital, doctors and nurses, general practitioners, community nurses and support staff. Negative comments related to hospital services' communication, co-ordination, and overworked staff, as well as care from the general practitioner, especially in the areas of diagnosis delays and treatment. Palliative care patients were also concerned about the difficulty in getting home visits and out of hours care.
Breitbart, Gibson, Poppito and Berg 2004 Aim: To explore the existential foundations of meaning and spirituality in light of terminal illness and palliative care	Discusses existential themes in terms of patients awareness of death and search for meaning Discusses Viktor Frankl's existential logotherapy as an emerging psychotherapeutic intervention Discusses meaning-centred group therapy as a means of encouraging dying patients to find meaning and purpose in living until their death	Key issues: • Dying patients require attention to their physical, psychiatric, psychosocial, existential and spiritual domains. • Palliative care literature emphasizes the need for greater focus on spiritual and existential therapeutic interventions in end-of-life care. • Research suggests that symptoms of psychological distress and existential concerns are more prevalent than pain and other physical symptoms. A poll was conducted where high percentages of people said, for example, it would be very important to have a doctor who was attuned to them spiritually (their concerns regarding not being forgiven by God and so on). • The paper talks about research among advanced cancer patients which has demonstrated that spiritual wellbeing and meaning have a central role as buffers against depression, hopelessness, and desire for hastened death. These issues are associated with poorer survival rates in cancer patients and with dramatically higher rates of suicide, suicidal ideation, desire for hastened death and interest in physician-assisted suicide. • The paper discusses the Rousseau model for the treatment of spiritual suffering: – controlling physical symptoms – providing a supportive presence – encouraging life review to help recognise purpose, value and meaning – exploring guilt, remorse, forgiveness and reconciliation – facilitating religious expression – reframing goals – encouraging meditative practices focused on healing rather than on cure.

Table 8 continued

Authors, date, aim	Study population, background, nature of intervention (including theory/ model of person-centred care)	Evidence of intervention effects/ major findings/comment
		This article reports that Brady and colleagues (1999) found that cancer patients who reported a high degree of meaning in their lives were able to tolerate severe physical symptoms more than patients who reported lower scores on measures of meaning and peace. Spiritual wellbeing and a sense of meaning are powerful predictors of both levels of hopelessness and desire for death in terminally ill cancer patients. The associations were seen as independent of depression. Spiritual wellbeing and a sense of meaning and peace appear to substantially benefit people suffering psychological distress at the end of life. There is a need to develop and assess interventions that focus on increasing or maintaining a sense of meaning and purpose. Limited empirical data to reach conclusion The paper is a general overview for understanding existential issues in end-of-life care. It is not a comprehensive review of literature on existentialism.
Casarett, Karlawish and Byock 2002 Aims: • To describe two kinds of public action that have been effective in improving health care in other areas: advocacy and activism • To discuss reasons for the lack of public response to end-of-life care • To propose ways to improve end-of-life care	Descriptive	Key points: • Problems include organisational barriers (for example, poor continuity of care, inadequate research to guide practice, and inadequate training for providers). • The paper defines advocacy and activism: *'Limited evidence suggests that patients and their families can receive better end of life care if they are educated about their rights and if their expectations are raised'* (p. 5). • If patients share their expectations, this may shift the standards that clinicians set for themselves and their workplace and tools. • The paper provided an example of how advocacy successfully changed prenatal and delivery care from a physician-directed set of encounters to a collaborative process in which women and couples act in partnership with their physicians and, increasingly, with midwives (p. 5). • Patients lack 'benchmarks' of a 'good death' and therefore fail to recognise deficiencies in their own care. The following are needed for effective advocacy: • stories of good deaths through patient education materials and media (themes and case studies; a realistic goal is to disseminate a variety of diverse accounts in which all patients can find examples of what a good death would be for them)

Table 8 continued

Authors, date, aim	Study population, background, nature of intervention (including theory/model of person-centred care)	Evidence of intervention effects/major findings/comment
		• bill of rights: expectations that patients and physicians should have of the health care system • accessible standards for care, able to be accessed by families, clients and service providers • an awareness among patients and families of legal means for improving care. Patients or families suffer obstacles for being activists including the stress they are currently going through. Clinicians should be encouraged to become activists. Stories have the potential to change policy in a way statistics alone cannot.
Chaplin 2004 Aim: To explore the challenges nurses face when caring for patients with wounds in a palliative care context	Descriptive	Combining the principles of effective wound management with the key elements of holistic, person-centred care will ensure that realistic and patient-focussed aims of management are identified. Nurses with effective communication skills can play an important role in supporting patients and families at a difficult time. Describes wounds in palliative care, and principles of management
Chung 1993 Aim: To explore the difficulties faced in a hospice when offering brief intervention work with friends or relatives of patients	Reviews various theories of interventions	Need to use elements of a number of theories when working with people over one or two sessions
Dowsett, Saul, Butow, Dunn, Boyer, Findlow and Dunsmore 2000 Aim: To examine patient and relatives' or friends' preferences for and satisfaction with patient-centred and doctor-centred consulting styles	This study came about because of the identified need to get patient data to help develop appropriate communication guidelines for staff working in oncology. Existing guidelines were based on clinical opinion and open to debate. One hundred and thirteen women who had been treated for breast cancer and 48 relatives or friends watched videotaped scenarios of an oncology consultation using professional actors. Viewers were randomly allocated a good prognosis video or a bad prognosis video in which the oncologist discussed patient's diagnosis, treatment and prognosis. Segments on the videos were presented in both styles-patient-centred and doctor-centred-to allow viewers to compare and contrast. The patient-centred style had greater patient involvement in decision making and more	Results: • Both patients and relatives or friends significantly preferred a patient-centred consulting style across all aspects of the consultation ($p<0.0001$), except within the treatment segment of the good prognosis video there was no significant difference between the two styles. • One-third of the viewers preferred the doctor-centred style for the treatment and prognosis segments. • Predictors of a patient-centred style preference in the treatment and prognosis segments included watching a poor prognosis video, and being employed in a professional occupation.

Table 8 continued

Authors, date, aim	Study population, background, nature of intervention (including theory/ model of person-centred care)	Evidence of intervention effects/ major findings/comment
	affective behaviours (empathy, openness and reassurance). The doctor-centred style involved the physician being task focused and exhibiting high controlling behaviours. Demographic details, information and involvement preferences, anxiety and depression levels were obtained.	Overall, patients and their relatives or friends prefer a patient-centred approach to the consultation, particularly when the patient has a poor prognosis. A need was identified to enhance physicians' abilities to recognise different patient needs throughout the consultation.
Ellis 1999 Aim: To describe a person-centred care model implemented into a hospice setting	Study undertaken in a short stay 16-bed hospice with adult patients The hospice had previously used the activities of living model of nursing (Roper, Logan & Tierney 1980). The problem with this model was it was too physically oriented and did not reflect the ethos of hospice or holistic care (balance of mind, body, spirit). There was the presumption that care focused on physical condition as opposed to individual needs; little attention given to the 'total care' of the patient; patient negotiation largely excluded; medical paternalistic model. Staff devised a revised version of the Burford Nursing Development Unit model (Ellis 1997) which, along with daily debriefing and clinical supervision, was successfully initiated initially within the hospice. (The problem was that it then stopped being individualised and just became a checklist.) Benefits of that model included: • familiarisation of staff with principles and practice of reflection • separation of nurse and patient notes (that is, nurse notes about pain, wounds, and so on, and patient notes more a written commentary on care given and the assessments from the patients perspectives). Enabled patient and clinician problems to be identified Staff set out to review the hospice philosophy. Multidisciplinary team review, family and patient comments. Philosophy statements agreed on. Person-centred care model developed as a tool that could put the philosophy into practice Six-month pilot: • Training of staff included familiarity with documentation, person-centred care model itself and the philosophy behind it. • Training began one month before and continued throughout the six-month pilot. Ten core nurses, each responsible for training and support of two to three staff.	For the person-centred care model to be effective, the use of reflection and experiential learning is imperative. The new model claims to be multiprofessional, reflective, and facilitatinf of an unbiased and non-presumptuous approach, thereby overriding the tendency of health care professionals to rely on paternalistic and habitual practice. It empowers patients, allowing them to determine their own needs, encouraging self-reflection, self-awareness and personal and professional growth in the health care professionals who adopt it.

Table 8 continued

Authors, date, aim	Study population, background, nature of intervention (including theory/model of person-centred care)	Evidence of intervention effects/major findings/comment
	• Everyone was given the opportunity to discuss the model prior to implementation. Proved a valuable technique: it helped to share responsibility and workload for the implementation. • The model implemented with various guidelines. Guidelines helped prevent the model from becoming another form of documentation. • For example, initial contact just a sheet of A4 paper. Staff were given the Gibbs reflective cycle on a small pocket sized laminated card. Questions open enough to minimise temptation for a prescriptive interview. Emphasis was on getting to know the individual as opposed to completing a task.	
Fraser, Eades, Glackin and Holmes 2002 Aim: To explore the experience of four senior nurses who introduced primary care nursing in to a palliative care setting	Descriptive methodology used Move from team nursing to primary nursing because primary nursing seemed better able to relate to concepts of person-centred care. Also because problem with recruitment and retention and nurses being undervalued. This seemed a way of nurses being better able to reach their potential. This study reviewed what primary nursing was. It found that the essential elements include accountability, authority, autonomy, advocacy, assertiveness, continuity, collaboration, communication, commitment and coordination. The fact that team nursing did not fulfil those elesments was identified via a strengths, weaknesses, opportunities and threats (SWOT) analysis.	Primary care nursing can offer a structure that can facilitate the development of patient-centred care. The role and status of the nurse can also be promoted through the move to primary nursing.
Kraus, Levy and Oliviere 2003 Aim: To present issues that need to be addressed when organising a user forum. A user forum is a system for gaining patient's and carer's views in order to ensure these are given adequate consideration in planning and providing services	Descriptive	This paper stated that user forum organisers need to mutually agree on who to invite, who should chair, the venue, the timetable and so on.

Table 8 continued

Authors, date, aim	Study population, background, nature of intervention (including theory/model of person-centred care)	Evidence of intervention effects/major findings/comment
Teno, Byock and Field 1999 Aim: To present a vision for the development of a toolkit of instruments to measure end-of-life care.	A tool should be: • patient-focused • family-centred • clinically meaningful • administratively manageable • psychometrically sound. Focus should be on quality of life firstly; the eventual goal would include measurement tools for clinical assessment, quality comparison and research. There is a need for quality of care measures that recognise the changes in priorities as one dies or the dimensions that acquire new significance (for example, spirituality and transcendence). Prioritising domains to measure quality of care should be based on consumer input and should be synergistic with ongoing efforts to formulate guidelines and standards of care. Data needs to lead to action to improve quality of care. The paper talks about dying: life takes on new shape. Values change and things once ignored become important. While dying is an inevitable stage of human life that holds potential for suffering, it also has discernible opportunities for personal growth. There is a period where medical care ought to be person-focused and family-centred. Patient-focused care reflects that patient preferences ought to shape the timing of transitions in the goals of care (treatment through to palliative care). Family-centred care acknowledges the important role of the family or other loved ones in a patient's final days.	
Tobias and Hamilton 2002 Aim: To present a service review, entitled *National Health Service (NHS) cancer care in England and Wales*, to analyse the present state of cancer services and provide formal benchmarks addressing national levels of progress	Editorial only	Paper regards the concept of patient-centred care as critical to the pursuit of quality. It defines patient-centred care in terms of the need for professionals working directly with patients to give careful attention to their individual needs and concerns, offering choice where appropriate, together with full information on the implications of making certain decisions. The Commission for Health Improvement makes clear that patients should be given full attention by a doctor, and be treated with humanity and honesty, and wherever possible, by a specialist or team able to offer good continuity of care. The Calman-Hine report, developed in 1995, which is an important report in the development of oncology services, also recognises this.
Wilkinson, Salisbury, Bosanquet, Franks, Kite, Lorentzon and Naysmith 1999 Aim: To examine the impact of specialist models of palliative care on consumer satisfaction, opinion and preference over the past 20 years	Systematic literature review	There were no reliable or consistent trends in North America, primarily due to methodological flaws. In the United Kingdom, consumers are more satisfied with all types of palliative care whether inpatient or community when compared with palliative care in general hospitals. Consumers appreciate the psychosocial climate in hospices. There is a dearth of research in consumer preference for, opinion of or satisfaction with hospice home care services and other palliative care services in the community.

Appendix E: Service user perspectives

In the published literature, there are few studies that explore what is important to older health service users. Four articles were located which focused on person-centred care and service users (see Table 9), and eight were located which focused on person-centred care and people of culturally and linguistically diverse backgrounds (see Table 10). Two additional reports are cited in Table 9, one which considers the older service user's view on factors that affect their ability to comply with health-promoting behaviours (Haralambous et al. 2004) and a study by Simces and Associates (2003) which explores the link between citizen engagement and quality health care. An additional study by Davies and colleagues (1999) is included in Table 2. This study canvassed older service users' perspectives, as well as staff perspectives on hospital care.

Of the four articles which focused on person-centred care and service users, the study by Corring and Cook (1999) is one of the few studies that seeks clients' perspectives on person-centred practice (focusing on people with mental illness). Two studies focus on carer issues (carer assessment tools and services for people with dementia and their carers), and the last review considers the findings from the 2002-03 Victorian Patient Satisfaction Monitor annual survey.

Table 9: Literature on service user (client and carer) perspectives

Authors, date, aim	Study population, background, nature of intervention (including theory/ model of person-centred care)	Evidence of intervention effects/ major findings/comment
Corring and Cook 1999 Aim: To explore the perspectives of mental health clients about client-centred practice	Provides a history and critique of the Canadian Association of Occupational Therapists client-centred practice development. Given the above critique, this study used focus groups to explore the experiences of mental health clients and to discuss the meaning of a client-centred approach to practice. The study used three focus groups with a total of 17 clients from two towns in Southern Ontario. All had a mental illness and all had had contact with mental health services. They were asked four questions: • What does client-centred care mean to you? • If mental health services revolved around you and your needs what would they look like? • What sorts of things in a hospital or community agency help or hinder a person with your kind of needs to achieve their goals in life? • If you were asked by the people who decide what and how mental health services are provided to you as a mental health client, what would you suggest as the number one priority?	The study found that participants needed to describe their own experiences and what went wrong before they could address the questions. Most of the discussion was around participants' relationships with individual service providers, although they also talked about the broader community and service system, housing, the law, and so on. The main messages for service providers were: • to engage more as human beings; to value and appreciate the clients' experience and to recognise their expert knowledge of themselves • to change the way they deliver services; to get close and be welcoming • to take the time to get to know the client and listen • to establish common ground so that the process of change is not hindered by issues of power and control • to advocate for change in the broader service system. A central message was the need for people with a mental illness to be viewed as valuable human beings by service providers and by society. This is one of a very few studies that seeks clients' perspective on person-centred practice.

Table 9 continued

Authors, date, aim	Study population, background, nature of intervention (including theory/model of person-centred care)	Evidence of intervention effects/major findings/comment
Guberman, Nicholas, Nolan, Rembicki, Lundh and Keefe 2003 Aim: To assess the impact on the practice of practitioners of using research-based carer assessment tools	The paper draws together the findings of studies conducted in Sweden, the United Kingdom and Canada and some comments from an Australian researcher and practitioner working on similar research questions. The three studies examine the impact on practice of various carer assessment tools in various community settings. Both assessors and carers were interviewed about the experience of using the assessment tools and they were found to be generally effective in improving practice.	Used sensitively, carer assessment tools can give carers a legitimate voice; making them part of the assessment process gives them status as active partners and as individuals with their own needs and aspirations. The article concludes that home-care programs should change their mandate to include carers among their clients. Although this article includes comments from an Australian colleague, she is not part of the formal study. It notes that Home and Community Care services (HACC) in Australia already have the mandate to include the carer as a client, but that there is still a general deficiency in service providers' understanding of carer issues and inadequate resources to meet their needs.
Haralambous, Black, Nankervis and Giummarra 2004 Aim: To identify the enablers, barriers and structural supports that affect an older person's ability to comply with health-promoting behaviours and to recommend strategies to further facilitate health-promoting behaviours	The project entailed a comprehensive literature review and a series of focus groups. Focus groups were held with service providers from Primary Care Partnerships and Falls and Balance Clinics and with older people using services in order to identify the issues that promote and prevent older people from taking up health-promoting behaviours and activities.	This project provided valuable insights of the experiences of older people and service providers in Victoria in achieving health promoting behaviour change, including the enablers and barriers. The factors identified by health professionals and older people have provided the basis for the development of strategies and recommendations to guide future service planning. These strategies have recognised that extensive work has occurred to date by both health professionals and government bodies in supporting positive health promoting behaviour change, but that scope exists for further refinement.
Longshaw and Perks 2000 Aim: To describe the development of an innovative service for people with dementia and their carers	The service was developed after a research study of carers' views identified the need for short breaks that were flexible, responsive and person-centred.	
Simces and Associates 2003 Aim: To review the literature linking public involvement/citizen engagement with quality health care	Key findings: • Many examples of public involvement/citizen engagement in health care decision making were found in the literature. • There is lots of variation in the reporting of public involvement/citizen engagement. • A number of evaluation frameworks to assist in measuring the effectiveness of public involvement/citizen engagement in relation to health care or health outcomes have been developed, but their application has been limited. • Many potential benefits of public involvement/citizen engagement in relation to health care or health outcomes were identified in the literature (for example, public involvement/citizen engagement generates better options, citizens are more likely to implement solutions that they have been involved in identifying, more efficient use of scarce resources, citizens have the right to be involved ('It's their health and their money'). • There is limited empirical evidence to support or refute the hypothesis that public involvement/citizen engagement contributes to quality health care. Evidence depends on the area or level of health care decision making.	

Table 9 continued

Authors, date, aim	Study population, background, nature of intervention (including theory/ model of person-centred care)	Evidence of intervention effects/ major findings/comment
	• There is evidence that involving patients in decisions about their own care leads to improved quality health care or improved health outcomes when specific criteria are met (that is, active involvement, good communication, and adequate education for patients). In summary, the public have contributed to the planning and development of health care services across a range of service areas and in many different countries but the impact of this on the quality and effectiveness of health services is not really known. A model of public involvement/citizen engagement put forward in the report includes readiness, a common goal, the right participants, the right process, appropriate supports, the right leadership and evaluation.	
TQA Research Pty Ltd 2003 Aim: To measure patient satisfaction with acute care services in Victoria	Victorian Patient Satisfaction Monitor Annual Survey – Year 3 (2002-03): • Older patients tend to report lower levels of dissatisfaction than their younger counterparts. Dissatisfaction reporting across age groups was as follows: 18-24 years (10 per cent), 25-34 years (9 per cent), 35-49 years (6 per cent), 50-64 years (5 per cent), and 65 years and over (3 per cent). • Satisfaction levels increase as hospital size decreases. • Overall care index is likely to be scored lower by patients from culturally and linguistically diverse backgrounds and younger patients. • All sub-categories tend to score well. The score represents a rating out of 100, based on the total of average ratings awarded by respondents (for example, to achieve an overall care index of 70, patients have rated most measures on average as very good, and a few on average as good). – Access and admission (72 in Year 3) – wait for admission, clarity of written information, staff attitudes before admission, staff attitudes at admission, explanation of hospital routines, consideration of needs and wants, and waiting for a bed after arrival – General patient information (77) – being treated with respect, helpfulness of staff, responsiveness of nurses, and availability of staff – Treatment and related information (73) – the way doctors explained treatment, staff communication, help with pain, opportunity to ask questions, explanation of the purpose of medicines, and explanation of side effects – Complaints management (72) – staff responding to problems, and willingness to listen to problems – Physical environment index (67) – cleanliness of room, quality of food, restfulness of hospital, privacy in the room, and cleanliness of toilets and showers – Discharge and follow-up index (69) – convenience of discharge time, information about looking after condition, and post-discharge service arrangements. This is the weakest performing index across all hospital categories. – The helpfulness of staff in general is the question most highly correlated with overall satisfaction. • Services across the continuum of acute care influence patient satisfaction (*'Hence any efforts to improve overall satisfaction with hospital services must be integrated across the continuum to be effective'* [p. 65]). • Items with greater than 10 per cent fair or poor responses were: – restfulness of hospital – quality of the food overall (27 per cent in the 65 years and over age group) – privacy in the room where you spent most time (26 per cent in the 65 years and over age group) – the way the hospital routine and procedures were explained – how well the possible side effects of medicines were explained – the temperature of hot meals (22 per cent in the 65 years and over age group).	

There is limited available evidence on person-centred care and people from culturally and linguistically diverse backgrounds, particularly regarding older people from culturally and linguistically diverse backgrounds. Eight references were located which had a focus on person-centred care and people from culturally and linguistically diverse backgrounds (see Table 10). The study designs included ethnographic, qualitative, a position paper and a letter to the editor in a journal.

Table 10: Literature on person-centred practice with people from culturally and linguistically diverse backgrounds

Authors, date, aim	Study population, background, nature of intervention (including theory/ model of person-centred care)	Evidence of intervention effects/ major findings/comment
Bent 2003 Aim: To explore relationships among health, environment, and culture in one Hispanic community	The study involved an ethnographic design, including interviews, participant observation, field notes, examination of artifacts and existing documents, and photographic images of the community. Purposive sample Interviews were conducted with 33 primary participants, followed by interviews with ten secondary participants.	Environmental health is complex and multidimensional, and it cannot be understood without due attention being paid to community experience within a cultural context. Environmental health cannot be addressed without first understanding that experience in a cultural context.
Dyck 1989 Aim: To address the particular issue of the 'problem of culture' in relation to health care	This paper has considered the contribution of different bodies of literature to the task of re-tooling knowledge base as therapists attempt to incorporate cultural considerations in meeting the needs of clients.	Ethnographic studies in the social sciences, which emphasise the complexity of the relationship between culture, environment and health experiences, contribute to the further development of an understanding of the immigrant client, and provide direction for both clinical practice and research.
Iliffe and Manthorpe 2004 Background: An epidemiological perspective on the relationship between ethnicity and dementia supports the idea that ethnicity (defined as particular shared cultural characteristics) is not likely to unduly influence the emergence of dementia in individuals	Position paper	The experiences of people with dementia and their carers show that the important issues for service providers to consider are language, religious belief and observance, cultural factors (including food and personal care practices) and social support and coping mechanisms. This position paper argues that these issues are applicable to all individuals with dementia, independent of apparent ethnicity, and that promotion of cultural competence in service provision should not be relegated to an ethnic minority agenda. The task for health and social care providers is therefore to recognise the diversity of users and to increase access to appropriate quality mainstream person-centred services, rather than to develop segregated or specialised services (p. 283).

Table 10 continued

Authors, date, aim	Study population, background, nature of intervention (including theory/ model of person-centred care)	Evidence of intervention effects/ major findings/comment
Lie and Biswalo 1994 Aim: To identify important characteristics of a HIV/AIDS counsellor who would prove to be culturally acceptable for the particular problems associated with HIV/AIDS in two regions of Tanzania	A qualitative research approach is used. Methods of data collection are interviews and focus groups. Sample consists of 155 participants, both male (73) and female (82).	As a result of cultural differences, investigators expected to find discrepancies between findings and predictions based on Western theories of counselling; however, findings fit well with Western theories of client-centred counselling (p. 147). Warmth and genuineness, empathic understanding and unconditional positive regard were identified as critical in the counselling. The findings indicated that confidentiality is central and that hospital counsellors must balance the fact-giving approach with a person-centred approach, exploring the client's problem conception and identifying who in the client's network can give the further necessary psycho-social support.
Mitchell, Malak and Small 1998 Aim: To present results from research that explored the roles of bilingual professionals in community mental health services in the Sydney metropolitan area of New South Wales. There were two main objectives to the research: to identify and describe the roles of bilingual professionals in community mental health services for clients from non-English speaking backgrounds, and to identify and describe the factors that facilitate and inhibit the conduct of these roles	Ethnographic research methods were used: • Fifty-six indepth interviews were conducted with five groups of workers associated with the Bilingual Counsellor Program. • Interviews were semi-structured and open-ended.	Bilingual mental health workers were found to have at least four critical roles: (i) direct clinical service provision to clients from non-English speaking backgrounds; (ii) mental health promotion and community development; (iii) cultural consultancy; and (iv) service development. Respondents reported that the latter three roles were seriously underdeveloped compared with the clinical service provision role. The paper concluded that it is critical that service managers implement strategies to make better use of the linguistic and cultural skills of bilingual professionals. In addition to their role in clinical service provision, ways must be found to facilitate the community-focused, cultural consultancy and service development roles of bilingual professionals employed in mental health services.
Pan, Chung and Hsin-Hwei 2003 Aim: To examine the reliability and validity of the Canadian Occupational Performance Measure (COPM) in Taiwanese clients with psychiatric disorders	The COPM was translated into Mandarin and tested on 141 Taiwanese clients. The average age of the clients was 35.6 years; 94 per cent were diagnosed with schizophrenia. The study was undertaken in acute, sub-acute, chronic, rehabilitation and psychosomatic settings.	It was concluded that the COPM can be reliably applied to Taiwanese clients: • COPM can be an effective way of identifying a client's occupational performance. • It provides incentives for clients to actively engage in treatment. • Appropriate education and training in the client-centred approach is necessary for the therapist. • Further studies are needed for other diagnostic groups.

Table 10 continued

Authors, date, aim	Study population, background, nature of intervention (including theory/model of person-centred care)	Evidence of intervention effects/major findings/comment
Sekimoto, Asai, Ohnishi, Nishigaki, Fukui, Shimbo and Imanaka 2004 Aim: To investigate whether Japanese patients would want to participate in treatment decision making if they were fully informed	Survey interviews with 134 patients with diabetes	Findings: • 12 per cent preferred active roles • 71 per cent preferred collaborative roles • 17 per cent preferred passive roles.
Yurugen 2002 Background: Letter to the editor about patient-centred care in Turkey	The letter outlines a patient-centred care model in Turkey which includes 'care pair' (team work between nurse and technician), division of labour, and shared responsibility. It mentions that this approach is more feasible in the private hospital system in Turkey, where there is access to: • well furnished rooms • pager • more flexible visiting times • nurses' stations close to patient • nurses' stations equipped with computers.	The article concludes that the Turkish care model is not in accordance with what has been reported in the literature about patient-centred care (but the article is not clear about why). While not clear about why patient-centred care in Turkey is not in accordance with what has been reported in the literature, this article provides some good examples of how person-centred care is applied in Turkey, which seems to reflect good practice.

Appendix F: Benchmarking

Ten articles were located which focused on person-centred care and benchmarking (see Table 11). The study designs included qualitative, exploratory, descriptive, discussion papers, reporting on surveys, literature reviews, reporting on test/re-test and internal consistency, and inter-rater reliability studies.

Table 11: Literature on benchmarking or assessing person-centred care

Authors, date, aim	Study population, background, nature of intervention (including theory/model of person-centred care)	Evidence of intervention effects/major findings/comment
Attree 2001 Aim: To explore the perceptions of and criteria used by health care professionals, managers, patients and relatives to represent and evaluate their concept of quality care	Exploratory descriptive study: • Semi-structured interviews were conducted with nurses, doctors and managers (36), patients (34) and relatives (7).	There was a consensus on criteria, supported by the literature. Three categories of criteria were identified: • care resources: human and environmental resources • process criteria, including care practices, standards and interpersonal processes • outcome criteria, including patient satisfaction and health progress. The paper suggests that findings could be used to develop a method of evaluating care.
Baker and Edwards 2002; Baker, Edwards and Packer 2003a; Baker, Edwards and Packer 2003b; Baker, Edwards and Packer 2003c; Baker, Edwards and Packer 2003d Aim: To develop and pilot a benchmarking tool to evaluate person-centred care	Series of five papers on the development of a benchmarking tool for person-centred care	Six factors were identified: 1. assessment of need 2. providing person-centred support 3. monitoring 4. reviewing person-centred care 5. carer involvement 6. organisational strategy. The *Essence of care* is a patient-focussed benchmarking tool developed in the United Kingdom which has been an integral part of evaluating health services since February 2001. The tool that Baker and colleagues have developed is to address the gap in the *Essence of care* document (a benchmark for person-centred care). They have developed and piloted a tool for measuring person-centred care in health settings. It was initially based on the work of Kitwood with people with dementia, but the authors believe that it is applicable across a range of health care settings. The tool asks staff to rate their service on a scale of A to E, with A representing best practice and E representing areas that need improvement on six factors. The A to E scale is described. They are then asked to provide evidence 'which comparison group members agree would justify an A rating'.

Table 11 continued

Authors, date, aim	Study population, background, nature of intervention (including theory/ model of person-centred care)	Evidence of intervention effects/ major findings/comment
Bowers, Fibich and Jacobson 2001 Aim: To explore how nursing home residents define quality care	Indepth interviews	Residents defined quality in three ways: 1. care as service - instrumental aspects of care: efficiency, competency and value 2. care as relating - affective aspects of care, friendship and reciprocity 3. care as comfort - care that allowed them to maintain their physical comfort, maybe requiring minute and repetitious adjustments in response to their bodily cues.
Chou, Boldy and Lee 2003 Aim: To identify factors influencing residents' satisfaction in residential aged care	Cross-sectional survey of 996 residents and 895 staff in 36 hostels and 26 nursing homes	Staff satisfaction plays a crucial and central role in determining resident satisfaction in nursing homes, but has less impact in hostels.
Clark, Scott and Krupa 1993 Aim: To review traditional methods of collecting information about client satisfaction and to discuss how clients are involved in evaluation and research in mental health settings	Shift towards client involvement in research and service evaluation consistent with the shift to client-centred practice Traditional method of client satisfaction surveying is not considered valuable.	This paper suggests that hiring clients to be involved in service evaluation has produced new and valuable information, but to date there is little empirical data about the changes to practice that client involvement in evaluation will produce.
Coyle and Williams 2001 Aim: To identify the frequency and distribution of inpatients' 'personal identity threat'	Cross-sectional survey design: questionnaire completed by 97 patients from general medical, surgical and otolaryngology wards	Although many patients expressed positive sentiments about their care, problems were around power/control, involvement in care, and the approachability and availability of staff.
Hebert, Thibeault, Landry, Boisvenu and Laporte 2000 Aim: To introduce a new assessment tool which can be used to evaluate community occupational therapy interventions from the client's perspective	Tool tested on a group of 48 clients in a pilot study on metric quality	The research process led to the design of an assessment tool; however, there is a need to consider what to do with the information when collected via the tool. Use of the tool in itself does not guarantee service quality.
Martin and Younger 2001 Aim: To consider an audit process using Dementia Care Mapping as the audit tool	The study was conducted in day units and inpatient units for people with dementia. The sample consisted of five patients mapped on each day for a four-day period.	It is argued that this tool is best for identifying the lived experiences of the people in receipt of care. The tool is able to identify the overall culture of care and its level of person-centred approach.

Table 11 continued

Authors, date, aim	Study population, background, nature of intervention (including theory/model of person-centred care)	Evidence of intervention effects/major findings/comment
Salvatori, Baptiste and Ward 2000 Aim: To describe the development and evaluation of a chart-stimulated recall measure to assess the clinical competence of practicing occupational therapists	Pilot study involving two independent raters who assessed 12 occupational therapists on two occasions using a random sample of client records	Results indicated that the tool is reliable and valid and sufficiently generic to be used in a variety of practice settings as a global measure of performance.
Wellard, Lillibridge, Beanland and Lewis 2003 Aim: To explore nurses' approaches to working with consumers to support their participation in health care delivery	Three focus groups were conducted with nurses working in acute care in an Australian public hospital. The findings from these groups about nurses' espoused beliefs and practices relating to involving the consumer in health care delivery were compared with 18 hours of observations made on a cardiovascular medical unit by a trained researcher.	The authors found marked discrepancies between the ideas that nurses expressed and the actions observed in practice. For example, although participants stated that patients should be fully informed and involved in decision making, those making decisions about patient care were observed as doing so *'away from the bedside and apparently without consultation with patients'* (p. 258).