

Early and timely intervention in dementia: Pre-assessment counselling

Briefing paper for Faculty for Psychology of Older People and Dementia Action Alliance

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Introduction

An important aspect of living well with dementia involves the provision of a timely diagnosis and intervention to enable people and their families to make appropriate choices; to access support in order to live well with dementia and to make decisions about the future (Prince, *et al.* 2011, Banerjee, *et al.* 2009). However, in spite of the recognition of the need for effective interventions, it is suggested that services have often failed to provide adequate support (National Audit Office, 2007, Alzheimer's Society, 2012). The considerable economic and personal costs of dementia combined with evidence of patchy service provision have provided a powerful argument for the need for services to do more, including the need to raise awareness and reduce the stigma associated with dementia (Alzheimer's Society, 2012, National Audit Office, 2007, 2010). In this context The National Dementia Strategy for England was launched in 2009, with 17 key objectives (Department of Health, 2009). These objectives included raising awareness of dementia; providing early assessment and diagnosis for people with suspected dementia; approaching diagnosis in a sensitive manner and providing high quality, accessible information to people with dementia and their families about the illness. Subsequently, further policy objectives have set out the need for good quality, early diagnosis and intervention as one of four key outcomes to be achieved by 2015 (Department of Health, 2012). Given that it is recognised that an earlier and timely diagnosis has not been the norm within the UK, an important area of research and practice development has sought to understand the factors influencing the journey to help seeking for people with suspected dementia and the practice of professionals when delivering an assessment and diagnosis. This has included considering the way in which a diagnosis of dementia is shared.

Werner *et al.* (2013) suggest that research in this area has progressed through a number of stages, beginning with whether people with dementia wanted to know their diagnosis, which included considering whether they should be told (c.f. Bamford, *et al.* 2004, Pratt and Wilkinson, 2003, Husband, 2009). Subsequently research has considered what best practice in a diagnosis of dementia should be and what influences the experience. Such research has culminated in the recognition of the diagnosis of dementia as a journey, which begins when the person and/ or their family notice changes and seek help. (Werner, *et al.* 2013, Derksen, *et al.* 2006 a & b, Lecouturier, *et al.*, 2008). The majority of this research has indicated that many people with dementia want to know their diagnosis and do have the potential to live well with dementia (Pratt and Wilkinson, 2003, Bamford, *et al.* 2004). Nevertheless, it is also clear that for many, a difficult emotional journey occurs alongside assessment and diagnosis. This journey is influenced by many factors, including the considerable stigma associated with dementia, all of which need to be addressed if we are to achieve a timely and earlier diagnosis (Moniz Cook and Manthorpe, *et al.* 2009, Batsch and Mittelman, 2012, Vernooij-Dassen, *et al.* 2006, Gibson & Anderson, 2011, Moniz Cook, *et al.* 2006).

Consequently in considering what can enable people and their families to live well with dementia, recent research and practice has begun to address how a diagnosis of dementia should be given, considering the methods of delivery, what should happen following diagnosis, the skills of practitioners involved and the processes required to facilitate adjustment (Werner, *et al.* 2013, Karneili-Miller, *et al.* 2012a, Karneili-Miller, *et al.* 2012b, Manthorpe, *et al.* 2011, Robinson, *et al.* 2012).

Throughout these three phases, a growing body of evidence has highlighted need to place the perspectives and experiences of people with suspected cognitive difficulties and their families at the centre of the process. This is particularly important because significant psychological and social adjustment is needed to manage the transition to living well with dementia beyond the diagnosis and also to challenge the stigma associated with dementia (Prince, *et al.* 2011, Manthorpe, *et al.* 2011, Robinson, *et al.* 2012, Cheston, 2013, Bunn, *et al.* 2012). This evidence highlights that people living with dementia and their families have experienced shock, stigma and distress when a diagnosis has been disclosed and were often unprepared for the outcome of an assessment (Robinson, *et al.* 2012, Bamford, *et al.* 2004, Manthorpe, *et al.* 2011, Karnieli-Miller, *et al.* 2012 a&b). Therefore a number of authors have argued for the provision of pre-assessment counselling prior to assessment and diagnosis which can facilitate preparation for possible outcomes and offer choice about assessment (Williams, 2004, Derksen, 2006b, Lecouturier, *et al.* 2008).

This briefing paper reviews current opinion, emerging research and practice on pre-assessment counselling, offered prior to the commencement of assessment and diagnosis. This begins by considering the factors influencing the journey from first noticing symptoms to help seeking, the impact this may have on the way in which people present for assessment and the implications of this for practice. The processes, principles of practice and theoretical frameworks informing pre-assessment counselling are then described. This includes discussion of a number of key issues arising in the initial contact with persons with cognitive difficulties and their family members, including openness and honesty, achieving informed consent, managing expectations and family involvement.

Limitations

Although literature concerning diagnostic disclosure has increased over the past decade, limited evidence concerning interventions and practice in the period prior to assessment and diagnosis exists. Furthermore, this evidence base uses a range of methodologies including reviews, small scale qualitative research and some quantitative studies, thus it is only possible to provide a narrative review at this time. Of those references included in this briefing paper few explicitly address the perspectives of minority communities, such as people from migrant communities. Furthermore, many of the early studies concerning the experiences and perspectives of people receiving diagnostic disclosure were studies of family members in care-giving roles, thus the perspective of people with cognitive symptoms or a diagnosis of dementia are less well represented.

Recognising Early Signs: The journey to help seeking

In recent years, a wide range of research and auto-biographical literature documenting the experience of living with dementia has emerged (c.f. Christine Bryden, 2006, Lucy Whitman, 2009). These narratives have presented a nuanced understanding of the person and family members' experiences, highlighting that while there are considerable difficulties associated with dementia, there is also room for hope, wellbeing, maintenance of identity and continued success. Furthermore, they emphasise that the journey through dementia involves considerable changes and challenges, and that each family's journey is unique, for them as a whole and for each person within that family. The changes and challenges brought about by dementia require that the person with dementia and their family engage in an on-going process of assimilation, adaptation and adjustment (Cheston, 2013, Keady & Nolan, 2003, Hellström, *et al.* 2007, La Fontaine & Oyebode, 2013, Manthorpe, *et al.* 2011).

Recent research has highlighted that people commonly experience changes for at least two years before presenting concerns about cognitive difficulties to a health care professional. Thus in considering the pre-assessment phase, it is necessary for us to understand the factors influencing the journey to help seeking as these will impact upon when, whether and how people seek help and the expectations they have when approaching services (Chrisp, *et al.* 2011). These and other authors indicate that the process may begin by the person with symptoms recognising something might be wrong. However it may be some time before the person discusses their concerns with a family member (Chrisp, *et al.* 2011). During this time changes may also be recognised by family members (Chrisp, Taberer & Thomas. 2013, Chrisp *et al.* 2011, Manthorpe, *et al.* 2011, Leung *et al.* 2010, Koppel & Dallos, 2007). However, the decision to seek help, and who does this will be strongly influenced by a range of factors including;

- The gradual progression of symptoms and attribution of changes to normal ageing (Leung, *et al.* 2010, Boustani, *et al.* 2006, Jones, *et al.* 2010, Chrisp, *et al.* 2012);
- Viewing changes as associated with other health problems (Leung, *et al.* 2010, Chrisp, *et al.* 2012, Jones, *et al.* 2010);
- Unwillingness to recognise the severity of the difficulties by the person with symptoms and/or their family members (Chrisp, *et al.* 2012, Jones, *et al.* 2010);

- Stigma (Boustani, *et al.* 2006, Leung, *et al.* 2010, Iliffe & Manthorpe, 2004; Batsch and Mittelman, 2012);
- Relationships with health care professionals (Chrisp, *et al.* 2012, Jones, *et al.* 2010)
- Knowledge, understanding and previous experience of dementia in family members (Leung, *et al.* 2010, Jones, *et al.* 2010)
- Cultural conceptualisations of dementia, including the presence of the word in different languages (La Fontaine *et al.* 2007, Seabrooke & Milne, 2009, Tilki, *et al.* 2010)

Research emphasises the difficult emotional and psychological processes occurring for the person and their family members during this period, which may involve distress; disagreement and conflict; fear for the future; concerns about loss of self and identity and the experience of stress (Manthorpe, *et al.* 2011, Chrisp, *et al.* 2011, Chrisp, *et al.* 2012, Rosness, Ulstein & Engedal, 2009, Moniz-Cook, *et al.* 2006). This complex emotional journey can result in considerable challenges within the family context. While some families are able to work together to achieve a way forward, it is evident that such challenges can also result in the person with symptoms and their family members working apart or separately (Keady & Nolan, 2003, Chrisp, *et al.* 2012).

It is evident then, that the initial contact with health care professionals may be made by family members rather than the person with cognitive symptoms, particularly where the person has been experiencing symptoms for some considerable time. While people with cognitive symptoms may seek help, this is often with prompting from family members who were concerned and had noticed changes (Chrisp, *et al.* 2013, Manthorpe, *et al.* 2011, Leung, *et al.* 2010, Koppel & Dallos, 2007).

The first contact is generally with the family doctor or other primary health care professional whose response to the concerns is of critical importance. Evidence suggests that the knowledge, attitudes and skills of health care professionals can act as a barrier to timely help seeking. Consequently improving knowledge and skills among family doctors, primary health care professionals and others who may be in a position to recognise early and timely cognitive changes is of particular importance if people are to come forward for assessment and diagnosis (Koch & Iliffe, 2010; Mitchell, *et al.* 2011, Hansen, *et al.* 2008, Martinez-Lage *et al.* 2010, Belmin, *et al.* 2012).

The complexities involved in the journey to initial assessment as highlighted above would suggest that when people finally present for assessment, it is likely that they and their families will have a range of concerns, expectations and fears and may be more or less willing to undergo assessment. Accordingly, the need for pre-assessment counselling is of fundamental importance in addressing these issues. Intervention at this stage would seek to ensure that the person is empowered and enabled to make an informed decision concerning further assessment and diagnosis; make decisions about the involvement of their family in this process and begin to address the psychological and social implications of the difficulties they are experiencing. The principles of pre-assessment counselling are now discussed.

Principles of practice in pre-assessment counselling

Pre-assessment counselling involves providing the opportunity for the person with suspected dementia and their families or significant others to fully understand;

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- The reasons for referral;
- what assessment will involve and
- The possible outcomes of an assessment.

These are necessary steps to achieving an informed decision about undergoing an assessment that may lead to a diagnosis of dementia. (Derksen, *et al.* 2006b, De Lepeleire, *et al.* 2008, Doncaster, Hodge & Orrell, 2012, Cheston & Bender, 1999, Williams, 2004, Moniz-Cook *et al.* 2006);

Pre-assessment counselling generally involve meetings between the person with cognitive difficulties and (with their permission) family members or significant others prior to the commencement of assessment (Derksen, *et al.* 2006b, Moniz-Cook *et al.* 2006, Manthorpe, *et al.* 2011, Aminzadeh, *et al.* 2007). It will also frequently include providing information and education, which also has the goal of challenging stigma. While this process frequently facilitates significant information about the person and their family that can inform assessment, it is not intended that formal assessment of cognitive function should take place at this stage, unless the person indicates a desire for this to take place.

Given the complex psycho-social processes taking place for the person and their family, pre-assessment interventions should also include the opportunity for the person and their family/ significant others to discuss their experiences, concerns and fears. Creating the space for articulation of these concerns is critical to enabling the person and their family to make an informed decision and begin the process of understanding and adjustment. Furthermore, such discussions can assist practitioners in tailoring assessment and diagnosis, understanding the strengths and well-being needs of the person and their family, providing tailored information and education and can inform future planning.

The complexity of this process requires that practice is informed by appropriate theoretical frameworks. Commonly, person centred care (Kitwood, 1997, Brooker, 2008) informs practice within dementia care. The principles of person centred care have recently been applied to early and timely diagnosis, and emphasise the necessity of timely diagnosis which;

- Places the rights and wishes of the person with cognitive symptoms as paramount in engaging with the process of assessment and diagnosis;
- Emphasises the importance of assessment and diagnosis as key interventions in adjustment to living with dementia, thus the needs of the person and their family should be central to the whole process and;
- Creates opportunities to challenge the stigma and discrimination associated with dementia

(Brooker, *et al.* 2013)

These authors further describe the principles that underpin person centred practice in timely diagnosis, including pre-assessment counselling.

Other theoretical frameworks can also usefully inform practice in this area. Cheston (2013, Betts and Cheston, 2012) has recently discussed the assimilation of problematic voices model of change (Stiles, 1999) and describes its potential value in working with people living with dementia. This framework describes three tasks;

1. Helping the person to acknowledge the experience of dementia without becoming emotionally overwhelmed. The person is described as progressing from warding off, to achieving vague awareness;
2. Identifying dementia as the problem while gaining distance and perspective, which is described as enabling the person to understand the impact that dementia is having upon themselves;
3. Working through and trying out problem solutions, which involves the person's active engagement in the development and assimilation of new strategies and ways of being. (Betts and Cheston, 2012).

The assimilation model can be appropriately applied to understand the experience of people who present with cognitive symptoms in the pre-assessment phase. Many of the early experiences identified in the literature, such as attributing difficulties to physical health or normal ageing could be understood in part as attempts to 'ward off' the emerging concerns and the associated emotional trauma this brings. Therefore a key task in pre-assessment intervention is to begin the process described in stage 1, of helping the person to acknowledge the experience of cognitive change and what this might mean for them, and importantly, assisting them to contain the emotions associated with this experience. It would appear that this process could equally be applied to the experience of family members, who as a consequence of the changes in the person with cognitive symptoms may also be undergoing considerable challenges to their own identity and the relationships between family members.

Finally, given the relationship challenges brought about by the experience of dementia, application of family theories may also inform interventions at this stage. Rolland (1994) describes a family systems illness model, which articulates;

1. the impact of chronic illness upon the normal developmental life cycle of the family;
2. a psychosocial typology of illness including the onset, course, outcome and level of incapacitation experienced;
3. The time phases of the illness, including an articulation of the crisis phase occurring prior to assessment, through to initial adjustment following diagnosis and finally
4. How family adaptation and resilience can be supported in order that they can manage the impact and experience of chronic illness.

In the pre-assessment phase, the application of this model is helpful in assisting practitioners to understand how the cognitive changes are impacting upon family functioning, and furthermore to identify how the family have responded to challenges such as ill health in the past. This can facilitate an exploration of how and in what way family involvement in the process of assessment and diagnosis can be supported, while retaining the rights of the person with cognitive difficulties to make decisions about whether to go forward for assessment and diagnosis. Furthermore, learning about family experiences and strategies for managing ill health and other transitions can support post diagnostic interventions.

A number of challenges are known to exist in engaging in pre-assessment counselling, including;

- Honesty and openness including using the word dementia
- Expectations, fears and coping strategies

- Facilitating informed consent
- The involvement of family members

Each of these issues are now addressed in detail.

Honesty and openness, including using the word ‘dementia’

Dementia is among the most feared diseases associated with getting older (Batsch & Mittelman, 2012). Stigma can influence the meanings associated with dementia and can discourage people from seeking help or pursuing an assessment of cognitive difficulties (Moniz-Cook *et al.* 2006; Batsch & Mittelman, 2012, Boustani *et al.* 2006; Bunn *et al.* 2012; Chrisp *et al.* 2011 & 2013). In addition to this, once diagnosed, people can feel stigmatised by the label of dementia (Robinson *et al.* 2011).

Despite this, research with people with dementia suggests that they want to know their diagnosis (have it named), or to have a choice about whether or not they receive this information (Harman & Clare, 2006, Manthorpe *et al.* 2011). It has been suggested that the majority of people with dementia wish to be told their diagnosis (Robinson *et al.* 2011; Manthorpe *et al.* 2011), however people with cognitive symptoms and their families can also experience ambivalence and conflict in this respect. People with symptoms may experience a dilemma between wanting to find out more and a wish to avoid thinking about the future or having ‘too much’ information (Harman & Clare, 2006). Research has also highlighted that differences can exist between the view of the person and their family about whether they should be told about their diagnosis (Robinson *et al.* 2011).

The pre-assessment process allows these issues (where appropriate) to be identified, named and discussed and allows people to decide whether or not they wish to progress with an assessment and receive the results of this.

This requires a willingness to be open on the part of professionals. However, research identifies considerable difficulties associated with honesty and openness, and disclosing a diagnosis has been rated by professionals as amongst the most difficult aspects of dementia management (Bamford, *et al.* 2004). This is thought to be challenging because of the incurable and stigmatised nature of the illness, along with the emotional aspects, familial and personal costs (Werner *et al.* 2013). Professionals report difficulty in discussing the diagnosis openly with patients (Bamford, *et al.* 2004, Kaduszkiewicz, *et al.* 2008). Furthermore, some studies with health professionals (primarily doctors) have specifically identified how clinicians may be reluctant to use the word ‘dementia’ during their conversations with patients and their families (Lecouturier *et al.*, 2008b). While some report using terms such as ‘dementia’ or ‘Alzheimer’s disease’, others prefer to use more vague descriptions such as ‘confusion’ or ‘memory problems’ (Bamford *et al.* 2004; Kaduszkiewicz *et al.* 2008). It is suggested that these euphemisms may be a way of professionals “dulling the negative understanding” of a diagnosis of dementia (Karnieli-Miller *et al.* 2007).

While professionals may report positive views about honesty, they also therefore sometimes report conflicting approaches to this in their clinical practice (Kaduszkiewicz *et al.* 2008; Werner *et al.* 2013). Lecouturier *et al.*, (2008b, p95) highlighted that while professionals identify the importance of explicitly naming dementia and avoiding euphemisms, they also reported ‘using terminology

carefully as a way of getting information across without telling patients what they don't want to hear'. Maguire (2002) summarise the dilemma often felt by health professionals of being truthful, but at the same time not causing harm.

However, the implications of avoidance or use of euphemisms is significant for the person with cognitive symptoms. People with dementia have reported vague terms to be upsetting, confusing and difficult to interpret (Bamford, *et al.* 2004). Ultimately, if the word dementia is not used by professionals, people with cognitive symptoms are rendered unable to make an informed decision about whether they wish to pursue an assessment (Kaduszkiewicz *et al.* 2008). There is also the danger that if professionals avoid using the word dementia, this may exacerbate the stigma surrounding the diagnosis. By using the word dementia at the pre-assessment stage, professionals allow people to discuss their thoughts and fears and make the best decisions for them and their situation at that time.

It should be noted however, that despite research highlighting the importance of honesty and clarity when discussing dementia, this is not necessarily implemented in practice, and evidence suggests that avoidance or inappropriate practice in this regard has been found to induce additional stress on the patient and reduce trust in the professional (Karnieli-Miller *et al.* 2007; Street *et al.* 2009). For example, Phillips *et al.* (2012) draw attention to the fact that whether or not the word dementia is used by professionals, being referred to a specialist service may itself indicate that a diagnosis of dementia is a possibility. This has implications for services, few of which have the word 'dementia' in their title, with many called Memory Clinics or Services.

In terms of "introducing the idea of dementia" Cheston, (2013) provides a framework which discusses how this might be raised, as described earlier. It is suggested that this should take place at the pace a person can manage; that symptoms are discussed before syndromes; and that taking an indirect approach ('some people worry they may have an illness like dementia, is that something that has ever worried you?') might be helpful in allowing a person to explore this as a possibility for themselves.

Some authors identify the importance of retaining a focus on positives and skills within these discussions, which can often draw attention to limitations, losses and difficulties. The process of assessment can be stressful because it uncovers limitations and cognitive deficits (Derksen *et al.* 2006) and it is therefore suggested that it may be important to also focus on positive aspects of life within the context of the process (Robinson *et al.* 2011).

While reinforcing the strengths of the person with dementia appears to be beneficial for the relationship between the person and their family (Vernooij-Dassen *et al.* 2006) and hope can be important for quality of life, Lecouturier *et al.* (2008b) warn against minimising the seriousness of dementia and avoiding detailed discussions if that is what the person requires.

It therefore appears that balancing honesty and hope, or "fostering a (realistic) sense of hope" (Lecouturier *et al.* 2008, p4) is an important (and difficult) balance within these interactions (Fisk *et al.* 2007; Milne, 2010). "The move between truth telling and being honest while being sensitive and

showing concern to patients' abilities and needs and fear of doing no harm is a continuing struggle that no simple guideline can resolve" (Werner *et al.* 2013; 82).

This is evidently skilled and emotional work, which presents challenges for the person with cognitive symptoms and their families. Gomes Martins & Palmares Carvalho (2013, p67) also highlight the potential impact of this on professionals, noting that if staff feel insufficiently trained in communication skills, they are more likely to experience distress "when faced with patient's suffering".

Exploring expectations and experiences, fears and previous ways of coping with difficulties

Significant factors influence a person's willingness to seek help regarding their cognitive problems and to consent to an assessment (which may result in a diagnosis of a dementia) including their expectations, fears and previous ways of coping with difficult life events. People have different expectations and fears which may influence whether they chose to pursue an assessment; how they experience this and subsequently respond to a diagnosis of dementia should this be the outcome. Chrisp *et al.* (2011) highlight how people may have low expectations about what can be achieved by seeking a diagnosis (that the situation is hopeless and nothing can be done). It is possible that in these circumstances, people may be more likely to decline an assessment, or not seek help in the first place, and experience low mood.

Meanings attached to dementia and beliefs about this are likely to be influenced by a person's current situation, past experiences and exposure to others with dementia (Bunn *et al.* 2012; Manthorpe *et al.* 2011; Moniz-Cook *et al.* 2006). Societal, familial and personal experience, expectations of normal aging and current health status (Moniz-Cook *et al.* 2006; Robinson *et al.* 2011) have all been implicated in influencing expectations and fears about dementia, whether a person wishes to know their diagnosis and how this is processed (Chrisp *et al.* 2012; Manthorpe *et al.* 2011; Robinson *et al.* 2011). The influence of information from the media has also been highlighted as an important factor in this regard, especially when people do not have personal experience of dementia (Manthorpe *et al.* 2011; Moniz-Cook *et al.* 2006).

It is necessary therefore to know what a person's expectations about a diagnosis of dementia are before they are given this information (Derksen *et al.* 2006a & 2006b; Karnieli-Miller *et al.* 2012; Milne 2010). Lecouturier *et al.* (2008b) note that some of the distress caused by a dementia diagnosis relates to a person's negative attitudes and preconceptions. It has therefore been recommended that "Before disclosing a diagnosis of dementia, health professionals should explore the concerns of both the patient and their family as to what they think the cause of their cognitive difficulties may be and identify any particular individual concerns around diagnosis" (Robinson *et al.* 2011, p1041). It is also suggested that health professionals need to not only identify concerns and expectations, but also offer a more balanced or realistic view where appropriate (Karnieli-Miller *et al.* 2012; Lecouturier *et al.* 2008b).

Exploring a person's point of view in this way also allows any explanations to be linked to their personal experience, which may enhance their understanding of a diagnosis of dementia should they receive one (Lecouturier *et al.* 2008b). Pre-assessment counselling therefore provides the opportunity for people to talk about expectations, express their fears and potentially address inaccurate beliefs (Moniz-Cook *et al.* 2006). These may differ in families (Fisk *et al.* 2007; Karnieli-

Miller *et al.* 2012). For example, Moniz Cook *et al.* (2006) identified fears around losses for both the person receiving an assessment and their carer, with a slightly different emphasis for each. It also allows these conversations to start at the persons understanding so that further discussions are at their pace and are meaningful to them.

In addition, this pre-assessment process allows professionals to use the information and understanding gained at this stage to plan an appropriate assessment and diagnosis disclosure and to start to identify possible needs for the person and their family where appropriate (Derksen, 2006, Lecouturier, 2008). This allows their care throughout this process to be based on actual rather than perceived needs (Wilkinson, 2002), or a 'one-size-fits-all' approach. Pre-assessment counselling further raises the diagnosis of dementia as a possibility and therefore allows a 'progressive disclosure' (Manthorpe *et al.* 2011). Involving people in pre-assessment discussions about expectations regarding possible outcomes of assessment can reduce feelings of shock if a diagnosis of dementia is received (Beattie *et al.*, 2004, Derksen *et al.* 2006; Lecouturier *et al.* 2008; Manthorpe *et al.* 2011; Robinson *et al.* 2011, Vernooij-Dassen *et al.* 2006) and research indicates that people who receive informal feedback about the possible diagnosis before the formal disclosure were less anxious (Carpenter *et al.* 2008; Lecouturier *et al.* 2008 & 2008b; Manthorpe *et al.*, 2011).

In addition to this it can be helpful to identify a person's expectations, hopes and fears about the assessment itself and prepare them for the reality of what this might involve. Several difficulties with the assessment and diagnosis process have been identified and prior discussion about expectations and what will happen when, may avoid these problems.

- Manthorpe *et al.* (2011) note that waiting can be a time of great uncertainty and worry for people, commenting that for participants in their research it was not generally the waiting that caused distress but the "lack of information about why that was occurring". People sometimes felt that the pathway was fragmented and feared never getting a conclusion (Manthorpe *et al.* 2011). This is echoed by Koppell *et al.* (2007) who found that people often expected that clarification of memory problems would happen at assessment and that how far they felt they had an explanation at this time influenced their satisfaction, along with how much they felt involved in the process. Robinson *et al.* (2010) found high levels of anxiety regarding what to expect and when and that participants wanted to be informed about what was happening at every stage, highlighting the relationship between uncertainty and anxiety.
- Inaccurate expectations of scans as diagnostic tools may also be present (Manthorpe *et al.* 2011) and research has also identified that people are often not prepared for the possibility of diagnostic uncertainty. Many people seek assessment because they believe there will be an answer and experience disappointment when this is not provided (Karnieli-Miller *et al.* 2012; Manthorpe *et al.* 2011).
- Research also suggests that people may have unrealistic expectations regarding 'solutions' such as medication or other treatments (Bunn *et al.* 2012; Karnieli-Miller *et al.* 2012; Manthorpe *et al.* 2011, Milne, 2010, Moniz-Cook *et al.* 2006).

Discussions at the pre-assessment stage therefore enable these expectations to be identified and explored. People frequently experience anxiety and frustration when their expectations are not met (Manthorpe *et al.* 2011) and this process may therefore aim to “reduce or manage the gap between the information to be disclosed and patient beliefs and expectations” (Lecouturier *et al.* 2008, p4). This in turn may facilitate engagement, adjustment and coping and reduce anxiety and distress.

In terms of the impact of a diagnosis of dementia, coming to terms with loss on multiple levels (psychologically, socially and functionally) may be the greatest difficulty people with dementia face (Robinson *et al.* 2011; Manthorpe *et al.* 2011). It is therefore possible that previous experience of loss may influence this experience. In addition to this, family members in caring roles may also increasingly have to cope with greater responsibility while maintaining “emotional status quo” (Robinson *et al.* 2011).

Dementia can represent “a profound existential threat” (Cheston, 2013) and a range of ways of coping with these experiences and feelings has been identified in the literature, including feeling empowered, experiencing difficulty accepting the diagnosis, ambivalence in this respect and active denial (Cheston, 2013; Manthorpe *et al.* 2011; Robinson *et al.* 2011). These ways of coping may be conducted individually, in couples or wider systems (Hellstrom *et al.* 2005).

Taking notice of a person’s awareness of their cognitive problems prior to diagnosis (Derksen *et al.* 2006) might be beneficial in supporting them following this. Working with people at the pre-assessment stage may help to identify how people might cope with a diagnosis of dementia (and build on their natural strategies) and also to highlight those who may experience greater difficulty adjusting. Previous ways of coping may indicate how a person might cope with this news (Cheston 2013). If it is possible to understand how people naturally cope and adjust we may therefore be able to build on these strategies to support them in adjusting to a dementia diagnosis (Clare, 2002). It has also been noted that people sometimes develop ways of coping with dementia prior to diagnosis (Moniz-Cook *et al.* 2006) and describe how they might cope or “achieve positive outcome for the ‘self’ in the face of the threat [of dementia]” (Moniz-Cook *et al.* 2006, p387), again supporting the possible benefits of an awareness of these issues at the pre-assessment stage.

Different ways of coping may of course be helpful in different circumstances, for different people and at different times (for example; problem solving versus reframing, Ducharme *et al.* 2009). Research has identified people, couples and systems that may be more likely to experience greater difficulty in adjusting to, or coping with, a diagnosis of dementia. In particular, those whose worth depends on what they do, rather than who they are (Cheston, 2013; Manthorpe *et al.* 2011) and those with a family history of conflict (Manthorpe *et al.* 2011). In addition to this it has been suggested that those with poor previous marital relationships might experience increased fear about the future of the relationship (Manthorpe *et al.* 2011).

It may therefore be beneficial to assess the “potential for adverse psychological consequences [which] may be avoided or moderated through educational interventions early in the diagnosis process” (Fisk *et al.* 2007, p408). Therefore pre-assessment may offer the opportunity to provide people and families time for support with recognition and change (Moniz-Cook *et al.* 2006) and

facilitate the timely identification of those who need specialist psychological support as has been recommended (Robinson *et al.* 2011; Manthorpe *et al.* 2011; Milne, 2010).

Informed Consent

A fundamental aspect of pre-assessment counselling is providing the person with cognitive symptoms with the opportunity to make an informed decision about going forward with assessment and diagnosis. The Mental Capacity Act (MCA) (2005) and Human Rights Legislation (1998) therefore have particular relevance to the provision of pre-assessment counselling. Human Rights Legislation indicates that the rights of the person must be respected when delivering care and that professionals are morally and legally bound to ensure that the person is able to express their opinion and have choice and control over their lives. Furthermore, the MCA provides a structure for working with people to maximise their involvement in decision making concerning their own lives. The act is underpinned by the following 5 key principles:

- A presumption of capacity
- The right for People to be supported to make their own decisions
- Retain the right to make to make what may be seen as unwise or eccentric decisions
- Best interests
- Least restrictive interventions (Mental Capacity Act 2005)

A person must give their permission before they receive any type of intervention, regardless of what intervention is required. The MCA provides a statutory framework for working with people to support their involvement in making specific decisions, and to assess the person's ability to make the particular decision. The MCA also ensures good practice when a decision must be made on a person's behalf due to loss of capacity.

Legislation therefore provides a foundation for the professional when delivering pre-assessment counselling to ensure that the person with cognitive difficulties is assisted to make an informed choice about whether they wish to pursue an assessment of their cognitive abilities. The process of informed consent should be an ongoing process which begins when the person with cognitive symptoms makes contact with a primary care health professional, as it is at this point that a person may give consent to a referral for assessment.

Seeking valid consent during pre-assessment counselling involves a discussion which ensures that the person understands that any further involvement with the service is with their consent and that they understand the options available to them. To provide valid consent the person must understand what they are consenting to, which requires that good quality, personalised information is provided.

Therefore the pre-assessment appointment begins with a discussion of their concerns which led them to seek support from their GP. This provides the opportunity to sensitively explore the person's understanding of the word dementia and conditions that can cause dementia. Evidence suggests that people who refuse a clinical diagnostic assessment for dementia after screening do so in part, because of the stigma associated with mental health (Boustani *et al.* 2006). Therefore in

addressing informed consent within pre-assessment counselling, it is important that information giving incorporates explanations about the physical changes that occur in the brain with conditions such as Alzheimer's disease and Vascular Dementia, which can help to address the stigma and fears associated with dementia including pre-conceived beliefs about losing one's mind.

Information should be provided on what will be offered should a diagnosis of dementia be confirmed. This includes information concerning treatments, information and support available and discussing the advantages of future planning. It is also important that people understand that at times diagnostic uncertainty is a possibility. The person is also encouraged to consider whether they wish to be informed of their diagnosis and with whom this information can be shared; where they wish to receive the outcome of their assessment and who they want to be present when outcomes of assessment are disclosed.

Facilitating informed consent involves considerable skill, as professionals are involved in emotionally charged communication about an incurable and stigmatized condition that is associated with personal, familial and societal costs (Werner *et al.* 2013, Karnieli-Miller *et al.* 2007). Studies in other chronic disease showed that interpersonal ability and the professional skill of the professional involved in 'disclosing bad news' had a profound effect on the level of hope and anxiety in adapting to condition identified. The nature of pre-assessment counselling may hold considerable fear for people and may in itself be misconstrued as 'the beginning of the end'. It may be that more than one appointment will be required, to sensitively explore, for example, concerns about loss of a driving licence or the impact on travel and independence before the person is ready to make a decision.

Nevertheless, for some people, the appointment can be a difficult experience (Keady and Gillard 2002) and for their own reasons the person may choose to not continue with the assessment process. Professionals at this stage may need to explore reasons including for example, an inability to recognise the symptoms others have observed or the potential implications of receiving a diagnosis of a dementia, such as having to inform the DVLA and increased holiday insurance premiums.

As autonomy is easily compromised by cognitive difficulties, a loss of personal freedom can be encountered, particularly when the referred person is facing an increased need to be dependent on others. In these circumstances, there are risks that other people may take over in talking for that person, thus their rights and autonomy can be denied. A skill for professionals involved in the pre-assessment phase is therefore to ensure a person's autonomy is respected and that their decision making ability is supported. It is important that the professional treats consent as an ongoing process and ensures that the person is aware they can withdraw from the assessment process at any stage. Following pre-assessment counselling, as long as the person has the capacity to consent, their right to refuse to continue with assessment should be respected. Where their decision to refuse is in conflict with those supporting them, opportunities should be given to explore ways of providing information and support to family members/ significant others.

Providing information for people with cognitive symptoms where they have refused assessment following pre-assessment counselling will be necessary. It is important to enable people to realise that they can come back to the service at a later date. Indeed, evidence from service evaluation in

one area suggests that those people who initially refused assessment following pre-assessment counselling, do return when the time is right for them to undertake assessment and diagnosis (La Fontaine, *et al.* 2011).

Involvement of Families or Significant Others

As highlighted previously, family members also experience difficulties associated with the onset of cognitive difficulties (Manthorpe, *et al.* 2011, Robinson, *et al.* 2012). They experience considerable changes in relationships and roles, including the transition to becoming a carer; all of which can negatively impact upon their own health and wellbeing (Prince, *et al.* 2011, Gallagher-Thompson, *et al.* 2012). Close family members may notice changes before or at the same time as the person and may also have difficulty in exploring these for similar reasons to those impacting upon the person's help seeking. Family members may also seek help at a point when the person with cognitive symptoms is not ready in an effort to make sense of the changes, with the resulting risks to personal autonomy (Chrisp, *et al.* 2012). While it is important to support the autonomy of the person with cognitive symptoms, as dementia impacts upon relationships and remaining at home is largely predicated on family care and support (La Fontaine & Oyebode, 2013, Brooker, *et al.* 2013), including family members in the process of assessment and diagnosis is an important consideration in the provision of pre-assessment counselling.

To engage family members in the pre diagnostic stage of an assessment requires consent from the person with cognitive difficulties. However, there is frequently a family member present at initial contact with services, indeed family are regularly called upon for collateral history (Tuffrey-Wijn, 2012). This is often invaluable, as the nature of cognitive difficulties, may mean that the person themselves is not aware of subtle changes (Koppel & Dallos 2007; Chrisp, *et al.* 2011). Their involvement in the pre-assessment counselling process also provides family members with the opportunity to discuss their concerns; express their expectations of the service (Williams, 2004) and highlight their agenda, which may or may not be similar to the person with cognitive difficulties. However, family members can find it very difficult to talk about their concerns and what they have observed in front of the person with the symptoms or vice versa, therefore it may be necessary to provide space to talk separately.

It is not uncommon for family to encourage an assessment, the reasons for which include wanting clarity and understanding (Lecouturier *et al.* 2008), access to treatment (Fisk *et al.* 2007), planning for later life (Lecouturier *et al.* 2008) and to provide guidance for suitable care provision (Connell *et al.* 2004). Some family members may not wish to proceed with assessment, often through fear or previous experience (Vernooij-Dassen *et al.* 2005), denial of difficulties or due to the geographical distance lived from the person with cognitive difficulties (Teel 2004). Some relatives fear the change of a relationship from being a spouse, a son or a daughter to a 'carer' and the implications this carries regarding shift in decision making and responsibilities (Adams 2008; Robinson *et al.* 2011). On occasions family members will encourage a person with cognitive difficulties to decline an assessment when they realise there is no cure and view this negatively as a service's inability to meet their expectations. This has at times been due to a drive by the media which has produced unrealistic expectations (Bunn *et al.* 2012) and treatments being symptomatic rather than a cure (Moniz Cook *et al.* 2006).

During the pre diagnostic appointment, it is not uncommon to experience a family member who is anxious to 'protect' the referred person and will rationalise the symptoms that led to the referral. Chrisp *et al.* (2012) suggests this to be 'normalising the problem' and Moniz-Cook (2008) refers to this as 'protective care giving', where the spouse is protecting the self image of their partner developing a dementia. Subsequently at a post diagnostic stage Bunn *et al.* (2012) observed carers continuing to balance protection and independence. Where such reactions are occurring, it is helpful to consider strategies which may assist both parties to acknowledge the difficulties occurring, and on occasions, it may be helpful to carry out an initial assessment such as the ACE III in order that the person and their family member supporter are able to move towards acknowledgement of the cognitive changes (Chrisp *et al.*, 2012), as well as highlighting the strengths of the person in order that meaningful discussions can take place about a way forward.

It is necessary to acknowledge that all present will have a personal agenda and varied levels of knowledge (Williams, 2004), which may also include children. Managing expectations, frustrations and emotional distress of the family members (Bamford *et al.* 2004) can be a challenging service to deliver. This is best met with open dialogue, partnership approaches and continual assessment of the dialogue between the person, their family members and the professional.

Conclusion

Adjustment to a diagnosis of dementia (for the person and their family) is a process which is likely to be influenced by many factors including; societal and cultural perspectives, individual expectations, previous experiences and fears and a person's current situation, including whether they present early or later in the disease process. (Manthorpe *et al.* 2011). A person's experience of adjustment is likely to change over time and will influence their needs and facilitating transitions (particularly role transitions) has been indicated as being potentially one of the key roles played by nurses and other professionals (Ducharme *et al.* 2009).

This adjustment process begins before people come into contact with specialist services. People, couples and families have been through a process of becoming aware of difficulties, discussing these and seeking help, before being referred for assessment (Bunn *et al.* 2012; Chrisp *et al.* 2011 & 2012; Moniz-Cook *et al.* 2006). There may be two and a half years from noticing changes to seeking help, a period of time which may involve psychological, practical and relational processes (Chrisp *et al.* 2011; Derksen *et al.* 2006) and may influence what each person needs from services.

It is important to note that the person and their family may have different needs, which could be in conflict with each other and consequently difficult to manage. This may require support from two or more professionals over more than a single encounter (Karnieli-Miller *et al.* 2012). For example, it may not be the person with the possible dementia who has sought a referral (Chrisp *et al.* 2012) and it may therefore be that they and their family members have different perspectives, hopes and expectations and therefore needs (Bunn *et al.* 2012; Chrisp *et al.* 2012; Derksen *et al.* 2006(b); Ducharme *et al.* 2009; Lecouturier *et al.* 2008; Manthorpe *et al.* 2011; Gibson & Anderson, 2011). These may also be influenced by wider cultural factors (Bunn *et al.* 2012; Fisk *et al.* 2007; Manthorpe *et al.* 2011; Koppell *et al.* 2008; Robinson *et al.* 2011; Werner *et al.* 2013).

Some people will seek information and others will reject this (Bunn *et al.* 2012), preferring little or no information (Milne, 2010) and giving information at the wrong time may be unhelpful. For example Boustani *et al.* (2006) reported that 48% of those screened refused further assessment for dementia. Not all of these people had presented with concerns about their cognitive function, suggesting that this may not have been a concern to them at this stage, or they were not ready to engage in this process.

More generally research has highlighted the need for personally tailored, timely information as critical and noted that needs are likely to evolve over time (Bunn *et al.* 2012; Ducharme, 2009; Lecouturier *et al.* 2008 & 2008b; Manthorpe *et al.* 2011; Moniz-Cook *et al.*; 2006; Koppell *et al.* 2008; Robinson *et al.* 2011; Werner *et al.* 2013).

The process of adjustment is supported by delivering pre-assessment counselling, which allows for the opportunity to;

- Explore the perspectives and views of the person with cognitive difficulties and their family prior to disclosure in order to determine how best to communicate the diagnosis (Connell, *et al.* 2004, Karnieli-Miller *et al.* 2007; Robinson *et al.* 2011)
- Enable people with cognitive symptoms to retain autonomy and be in control of the process, including the pace of information, assessment and disclosure of the diagnosis should this be relevant (Manthorpe *et al.* 2011, Werner *et al.* 2013).
- Enable the process to be personally tailored to the person and their family members needs, including for example written information (Carpenter *et al.* 2008; Derksen *et al.* 2006(b); Gibson & Anderson, 2011; Lecouturier *et al.* 2008b; Milne, 2010; Robinson *et al.* 2011; Werner *et al.* 2013).
- Avoid the negative outcomes associated with unmet need at diagnosis (such as feeling that information and support were inadequate) (Bamford *et al.* 2004; Werner *et al.* 2013)
- And provide specifically tailored information to meet needs (Robinson *et al.* 2010).

Successful diagnosis giving and post-diagnostic support may be facilitated by good quality pre-assessment counselling, which highlights the persons needs and engages people in this process (Fisk *et al.* 2007), which it appears must be integrated in order that services can respond flexibly to needs from referral to discharge (Jha *et al.* 2013; Werner *et al.* 2013).

It is evident that in order to sensitively deliver pre-assessment counselling, the skills of the professionals will need to be addressed. The skills, attitudes and knowledge required of professionals working in this way are considerable, and evidence suggests that professionals working in primary and secondary mental health care do not necessarily feel prepared to deliver such interventions or to manage the emotional impact of such work (Werner, *et al.* 2013, Buckell, 2007, Kaduskiewicz, *et al.* 2008, Burgers, *et al.* 2012, Lecouturier, *et al.* 2008, Karnieli Miller, *et al.* 2007). Patient-centred approaches to enhance control and dignity (Zaleta & Carpenter, 2010) and the benefits of a patient-and-family centred approach in disclosing “grave medical conditions” has long been advocated along with the importance of communication skills and ability to respond to potential differences in needs among family members (Karnieli-Miller *et al.* 2012). Werner *et al.*

(2013) identifies the positive effects of communication skills training for staff members (increasing their willingness and desire to discuss diagnosis and prognosis) and the potential need for training around communicating in triads (the patient, carer and professional), which may enhance the ability of clinicians to take account of cognitive impairment in communication, build emotional rapport (Zaleta & Carpenter, 2010) and respond flexibly to need.

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