

Home is Where the Heart is:
Training for home care
supporters for people living with
dementia from diverse cultures

The creation of this education resource
was funded by a grant from the
Department of Health

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Families and Cultural Diversity in Dementia Care

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The learning outcomes if learners attend all three 90 minute sessions in this programme.

Develop skills and knowledge in teaching others about person centred care in dementia
Understand the importance of the cultural context in which care is being given and
received

Appreciate and learn ways to involves relatives and other carers in providing supportive
care for the person living with dementia

At the end of this session you will have:

- An increased appreciation of the importance of family in the support of people with dementia
- An understanding of the pressures which family members feel in caring for someone with dementia and the additional strengths and stresses that different cultural backgrounds contribute
- Identified some of the strategies needed to provide care for a person with dementia and their family in a more culturally competent way

This slide sets out what attendees should expect to have learnt by the end of this education session.

Introductory Exercise

- **I'm Looking Forward To.....**

Introductory Exercise: I'm Looking Forward To.....

- Think of something enjoyable (outside work) that you are planning to do in the next month
- Each person in turn say your name and what event/activity you thought of, and who else is involved

Trainer records each participants name on a flip chart plus a word to describe the event they thought of and lists who else is involved (drawing this out from participant if necessary)

Then taking a different coloured pen and circle each event which involve family or friends

Thank everyone for sharing

Debriefing points

Family and friends are hugely important to us – they share huge part of our lives
Families and friends come in different shapes and sizes.

Some people may have a small family, others may have a large one. Relationships may differ with particular family members.

Importantly for some people friends are really important.

Why Think Family?

- Meaningful relationships are one of the key factors influencing feelings of being well, psychological, spiritually, physically and emotionally as we age
 - family is a key source of those relationships

The introductory exercise introduced the group to the key role family play in our lives. Having relationships with others (often but not exclusively family) is hugely important for our wellbeing, particularly as we grow older, and dementia doesn't reduce that need; if anything it increases it.

Views on Working with Families

- Families are 'problematized'

Or

- Families faced with chronic illness use their resources and coping capabilities to meet the demands they face

This gives the group an opportunity to discuss their own work and personal experiences.

People working with people with dementia tend to see families at either end of the spectrum either an added "problem", who don't cope, who make demands or who interfere

OR who pull together and cope and so don't need any help.

But most families lie somewhere between these 2 extremes.

Just as if we would say "if you've met one person with dementia you've met one person with dementia", we would also say "if you've met one family you've met one family", each one is different and will respond differently.

They will usually start out wanting to do their best for the person with dementia and may have coped as best they can for several years before they think to seek help. So by the time they seek help they will know a lot about the person and what works, and they will advocate for them.

They may also feel tired, stressed and guilty that they have needed to call in help.

There are frequently differences of opinion within the family in respect of what is the right thing to do.

Impact of dementia on family

- How a family has always operated:
 - its expectations and ways of functioning
 - its resilience and strengths
 - its dynamics and disagreements
 - its patterns of communication
- will influence how family members cope with a diagnosis of dementia and how care and support will be given and received both currently and as the dementia progresses

The way that families face any major issue is likely to be an indicator of how they face dementia and deal with the challenges throughout the journey. Some families will have family meetings and pull together with everyone taking a part.

For example, when a child carries a glass cup, and it drops on the floor and breaks. How do people react? Panic? Anger? Spring into action? Become paralyzed? Remind the child for the rest of their life to 'remember when they broke the glass and made a big mess'? Change all glasses in the house to plastic?

Some families will have a mother who has always taken everything on herself and protected her children (even as adults). She is likely to want to cope with her husband's diagnosis herself or just with him and minimise any distress when talking to her children, even finding excuses for them not to visit, so they don't realise the problems.

Brothers and sisters who have always had a turbulent relationship may likewise disagree over the care of someone with dementia in the family. If one sister has been the proactive one she's likely to take up the reins when a problem occurs, a brother who has always deferred to his older sister may continue to do that.

Dementia in Black, Asian and Minority Ethnic (BAME) communities

- Lower levels of knowledge and awareness about dementia
- No word for 'dementia' in any of the South Asian languages
- Stigma of mental health
- Hidden problem
- Low dementia diagnosis
- Present themselves in crisis situations: need for early intervention

The need for cultural competence is not restricted to work with black, Asian and minority ethnic groups – it includes LGBT people and a wider range of minority communities.

Research into how dementia impacts on different communities and cultures is limited. However, there is an increasing awareness of the needs of BAME communities. There is a growing recognition that domiciliary care has a role to play in supporting families from BAME communities. The following slides explore examples that are drawn from some of the BAME communities which domiciliary care services may encounter, but they illustrate the issues to be considered in culturally competent practice with any community.

In the UK the term '**Black, Asian and Minority Ethnic**' (BAME) communities is used to describe a group of people *'that share a similar experience and face particular challenges in getting the support they need'* (APPG 2013: 20).

Whilst research on the impact of dementia in BAME families is quite limited the work of Karan Jutla & Jo Moriarty are useful sources.

Also the All Party Parliamentary Group inquiry in 2013 produced an important report "Dementia Does Not Discriminate"

The key findings are:

That in many BAME communities dementia is a hidden problem, people have little awareness of dementia and as a result rates of diagnosis are low and help is often sought quite late when a situation has reached a crisis point. This is in part due to limited understanding of dementia, it's often thought of as a mental illness and is subject to stigma partly because of that.

Dementia in BAME communities: Findings cont...

- Lack of knowledge & access to services
- Lack of culturally appropriate services
- Language barriers
- Reluctance to ask for, and accept, formal support
- Familial roles and a duty to care
- Assumptions about community support – *'They look after their own don't they?'* (DoH 1998)
- Need to portray an image of well being to those outside of the family

Moriarty *et al* (2011)

As a consequence of that lack of awareness people with dementia and their families are less likely to access services, partly because they don't know what is available, but also because they fear that services won't meet their cultural needs.

Language may be a factor but also services' understanding of religious or cultural factors. Many BAME families feel strongly that they should care for their family member with dementia, that it is their duty, and this may be underlined by pressure from wider family and community.

Equally services have relied on that assumption and not felt they need to engage and provide services that are culturally appropriate, sometimes also suggesting that numbers may be small and therefore not cost effective.

Video Clip

In Their Own Words

Play the video clip, by clicking on the title of the video. **Depending on your security settings it may open automatically, but you may be prompted to confirm that you would like to open the file.**

At the end of the video clip, ask the group the following questions.

You can ask people to work in pairs, threes or small groups or do this activity as a whole group.

How did they know that mum was developing dementia?

Why might that be the case?

What was their response to the GP's diagnosis?

Do you think they coped well with the care of mum?

What were the challenges?

When they put a piece in the local paper to raise awareness what was their family's response?

Why might they have responded like that? (Thoughts may include: Stigma, concern that having diagnosis might have for marriage of children)

Discussion

Do you have an experience from your work setting where you have delivered care to someone of a particular background where their family were also involved in their care ?

- What happened?
- Were there any issues/concerns/challenges?
- What did you learn?

Get the group to discuss in pairs or triplets for 5 minutes and then ask whole group for 2 or 3 examples from their discussion.

What this means

- Such situations can lead to feelings of loneliness, isolation, pressure and sometimes even depression for family members
- A need for formal and informal support (emotional and practical)

The examples illustrate some of the complex pressures that BAME families and individual family members can feel in living in their community and working with services. There is also a need to acknowledge that some families are isolated from their community and this further increases isolation.

Working with BAME Families

- People living with dementia and their families:
 - May not have had contact with services before
 - Or may have had poor experiences of services
 - Generally want people to see them as caring
 - Are generally not seeking to abandon their family member
- Want to be partners in the ongoing care plan

Like all families, BAME families who you work with are likely to want to do the best for their family member, be and be seen to be caring and involved.

But they may not have had contact with services before or may have had bad experiences of services and therefore don't know what you need from them or may be suspicious of what you do.

Most want to be involved, but it may need you and your teams to help them to know how to become partners in the care you give, and that also needs you to go into the situation ready to build that trust and partnership

Understanding cultural *diversity*

Think about the impact of differences between generations and family members on issues as:

- Religion
- Language
- Culture

And within a family there may be different

- Migration and post migration experiences

We need to acknowledge that whilst specific communities may share experiences (of migration, loss of power, political differences) with other communities, each community will have its own culture born of ethnicity, language, religion., etc.

Each family will have its own adaptation of that culture

Equally individual family members will have different experiences. For example, second and third generation British born African Caribbean children may have very different experience and ambitions to their grandparents arriving in Britain in the late 1950s. They may feel a social and economic driver to move away from the town or city they grew up in and may care at a distance with all the different pressures that entails.

The Scenario

- You are asked to visit Randeep Singh at lunchtime each day to reheat a frozen meal and help him eat . When his food is served he will not eat it and pushes it away. This has become a regular problem.
- *Why might this be happening?*

Possible considerations to draw out:

Re culture

Randeep Singh is possibly a baptised Sikh. It is important that when preparing food, that the same utensils should not be used to cook for Sikhs which have been used to cook meats. When serving food for a baptised Sikh, utensils must be firstly washed.

Randeep Singh could not see this was happening and so pushed his food away.

But also think about this from the other aspects of person centred care.

Is there something wrong with his physical health, does he have toothache, do his teeth fit?

Does he recognise the meal as food, has his dementia taken him to a time when he would eat food served on a partitioned metal tray?

Has his sense of taste changed?

Does he feel unhappy eating alone, does he miss his family and communal eating?

Is he depressed?

The importance of...

- Understanding the role of the family in daily life
- Foods and nutrition
- Rituals and ceremonies
- Cultural norms (including gendered norms)
- What are the families traditions and wishes around end of life care?
- Having activities that different family members can share

It is important to have some appreciation of all those things. But more than anything it's about building up a rapport and having the sensitivity and humility to say, "I don't know everything about you and your parent/brother/sister" "talk to me about them, tell me what's important to them and to you"

Case Studies

How might the dementia being experienced by the individual be influencing her/his relationship with her/his family and support network?

Develop a care plan/action plan to provide support for these changes. The plan should identify at least 5 actions which have the potential to achieve a positive outcome.

Summary

- Family relationships are complex and impact on many aspects of care
- It is important to include different members of the family in conversations and respect different opinions
- Culture, religion and experiences impact on family dynamics, how different family members undertake care roles and how they relate to formal carers

Any Questions?

Thank you for listening and
taking part.