

BOOK REVIEW

Karen Watchman, (ed). (2014). Intellectual Disability and Dementia: Research into Practice. London: Jessica Kingsley Publishers. ISBN 978-1-84905-422-5

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Introduction, organisation and target audience of the book

Pictures can speak louder than words as does the front cover of this book illustrating two happy disabled people. 'Learning disability' is the term that the Department of Health, UK uses within their policy and practice documents, but the term *intellectual disability* is now preferred by advocates and researchers in most English-speaking countries. This book concentrates on three themes in discussing intellectual disabilities and dementia. Firstly investigating what we know, secondly how we know and, thirdly, what we are going to do with such knowledge. Part 1 of the volume is entitled "The association between intellectual disabilities and dementia: What do we know?" and focusses on medication and non-pharmacological interventions such as psychological, environment design and communication. Throughout the book there is a focus on working with carers and families in relationship-centred care. Part 2 of the book "Experiences of dementia in people with intellectual disabilities: How do we know?" describes the experiences of dementia among a group of older people with intellectual disabilities who regularly meet together. These case studies provide invaluable learning tools for anyone involved in caring for people with these disabilities. Part 3 of the text, entitled "Service planning: What are we going to do?" discusses the difficult problem of sharing the diagnosis, breaking bad news, staff knowledge and training and descriptions of services provided in the UK and other countries.

Intended Audience

The targeted readership of this invaluable compendium is everyone working with people with intellectual

disabilities and dementia, including their families. As the contributors include internationally renowned experts the text provides excellent teaching material for practitioners, academics with reference to current practice and developments in this area. Dr Watchman's book is an essential tool for the health and social care sector.

Epidemiology of dementia in people with intellectual disabilities

Considering the epidemiology of dementia in people with intellectual disabilities, there is the need to identify those at risk, offer diagnostic assessments to those with emerging symptoms and to provide appropriate treatment and environmental and care adjustments, because those affected will continue to increase. This means that a corresponding increase in resource allocation is required, along with the development of strategies to ensure that carers are provided with appropriate training. The development of specialist residential, day and health services is thus worthwhile as is the improvement of generic services. There are merits for specialist dementia clinics for those with an intellectual disability, as well as increasing the skills for generic memory clinics to be able to provide appropriate and timely diagnostic, treatment and intervention services to these individuals. The volume concludes that the prevalence of dementia in people with Down's syndrome increases from under 10% in individuals in their 40s to more than 30% for those in their 50s, with some studies reporting rates in excess of 50% for those aged 60 and over. Dementia may also be three to four times more common in older people with an intellectual disability who do not have Down's syndrome than in the general population. Despite the diagnostic issues, there is a need to offer suitable diagnostic services and treatment and to consider the support and care needs of the increasing

number of adults with an intellectual disability and dementia.

Definitions

The book highlights a lack of knowledge about dementia and the risks of its early onset among some groups studied, including families and in, for example, people with Down's syndrome. For these families this causes unnecessary anxiety as they ponder explanations for changes, or come to terms with an unexpected diagnosis. Either denial, or being unprepared for the possibility of early onset dementia, may add to the delay in gaining access to appropriate services. Where there is limited guidance on how to explain dementia to people with intellectual disabilities, this increases the potential for individual stereotyping. It also means that until information is shared, we are unable to position people with an intellectual disability and dementia as an authority on their own condition. As a consequence of this, co-production, meaningfully positioning people with intellectual disabilities in the commissioning, design and delivery of ageing and dementia services remains out of reach and will require a cultural change for many organisations.

Individuals who are not aware of their diagnosis of dementia or of why they are experiencing changes, experience frustration, particularly when they are unable to find the correct word or words to use or to cope with daily activities. Staff believe that a person would be able to maintain his previous living skills for longer than is the reality, based on an overestimation of his retained verbal capacity. But increased isolation can cause silence as the person stops speaking and being spoken to. Individuals can live in a group home among peers who have no knowledge of their condition and without contact from previous friends who may be unaware of where the person has moved to. A challenge in dementia care, generally, is to provide appropriate post-diagnostic support and to promote awareness that everyone is entitled to be informed of their diagnosis. A cultural process is needed in order to acknowledge the human rights of people with an intellectual disability to receive their diagnosis, as part of accessing appropriate support. Kitwood, a leading authority in dementia care, found that when a person with dementia did not have their individual basic needs met, the result was de-personalisation, a negative process creating withdrawal and social isolation.

Another facet of care examined by the book is that the use of anti-dementia medication among adults with an intellectual disability, as recommended by NICE, UK. However, the evidence to support their prescription is argued to be small. The reasons for this, as the book discusses, include the difficulty in making a diagnosis of dementia early in the condition, the presence of existing cognitive impairment, other existing illness, for example, epilepsy, or a lack of awareness and experience among healthcare professionals of the potential benefits of medication on behavioural difficulties and psychiatric disorders associated with dementia. Systematic reviews of

the literature have indicated that there is a clear need for greater support after diagnosis, including advice, social and psychological support and access to community and respite care. The book is clear that the information needs of individuals with intellectual disabilities and dementia and their carers varies over time and information provision needs to be ongoing, with flexibility in timing and format.

Good Practice

Having some sense of what it must be like to live with a life-limiting condition such as dementia is crucial to being able to understand what people with intellectual disabilities with a diagnosis of dementia face in their daily lives. However, it is not only about understanding from a clinical, professional or carer point of view that is important. The core premise, as the book explains, in considering the experience of living well with dementia for an individual with intellectual disabilities, is the maintenance of the person and thus his/her personhood, the individual and the centre of their experience. The focus of enhancing psychological wellbeing relates to the social, inter-personal and emotional aspects of living life with dementia. Memory loss is only one experience that contributes to the difficulties faced by people with dementia. Many behavioural, physical, social and emotional activities can be impaired which are just as, or even more, debilitating. If meaningful engagement is to occur and a true person-centred approach is to be adopted, it is essential that opportunities are grasped that involve value and respect the experiences of the individuals concerned.

The premise of psychosocial interventions is that neurological conditions such as dementia will affect each individual differently. The individual biography, life history and personality of the person with intellectual disabilities and dementia will serve as moderating factors. Furthermore, the presence of co-existing physical and mental health problems, such as anxiety and depression and the extent and type of dementia, will also shape the experience in an individual with intellectual disabilities. Where a person does not have the mental capacity to take a decision an anti-dementia treatment and where efforts have been made to enhance their level of understanding, provision is made to decide in the person's best interests on their behalf. This process should involve carers, family and professionals in reaching a decision that weighs up the advantages and disadvantages of treatment. It should take into account the person's expressed wishes before they lost their mental capacity, if any had in fact been stated. In spite of the debated benefits of employing anti-dementia medication, the person has the right not to accept treatment. In the absence of mental capacity legislation, the volume insists that clinicians should follow such principles and be guided by their professional codes of practice.

Anti-dementia medications, though controversial, are a useful intervention in the management of people with intellectual disabilities who have dementia. They offer the potential to improve memory function, the skills used in

daily living and to improve a person's quality of life. Anti-depressants are beneficial in treating dementia-associated apathy and some behavioural disturbances. They are potent drugs that require skilled assessment and prescribing for people who have complex health conditions. The effects of the drugs need to be monitored by clinicians during treatment because of the higher risk in people with intellectual disabilities of developing side-effects. The evidence base to support the use of anti-dementia medication in people with intellectual disabilities and dementia is not, as discussed, robust or broad and in common with all medication, anti-dementia drugs have side-effects. There is much debate in the literature on the side-effects of these drugs experienced by people with an intellectual disability. There have been reported cases of urinary incontinence and aggression that led to the decision to discontinue treatment. Yet other studies report no such experience when employing anti-dementia medications, some adverse effects proving temporary in duration.

Non-pharmacological interventions, as the book documents, consist of an array of approaches that generally aim to promote quality of life, proactively or reactively address symptomatic issues that arise over the course of dementia and/or provide support to family and other carers. These interventions require staff adjustments to engage people in daily activities and routines. Initial findings from one longitudinal study described by the volume suggest positive outcomes in taking such an approach. One factor that may sway the use of non-pharmacological interventions is whether an intellectual disability service provider has engaged in strategic planning to become 'dementia capable', this referring to a notion of being knowledgeable and skilled in providing support to individuals affected by dementia and their families, as well as being knowledgeable of other available services that may assist. Strategic planning of this nature should, as the book emphasizes, also be considered as a non-pharmacological intervention. It has direct bearing on the quality and type of support provided by a service agency to the individual affected by dementia and to their family or staff carers.

Physical environment design and modifications

A particularly stimulating section of the volume is that which deals with physical environment designed and provided to dementia patients. Various aspects of the built environment can influence physical and psychological health, as well as the ability to perform the routine activities of daily living. Resources are available that provide suggestions on home design and modification to support people with dementia generally. These include floor plans to promote access, interior design elements such as plant selection, furniture, managing cable cords, lighting and the use of assistive technologies. Research indicates that a number of such innovations may be easily incorporated within the home setting. These include colour contrasts of food, plate and place mats in the dining room

and when dining alone to enhance visibility and promote food intake. There are suggestions on creating the right environment, one that is calm, familiar, predictable, makes sense and which is stimulating. With forethought, environmental design and modifications can negate the need to transition the person to a different living environment, thus supporting ageing 'in place'. Rather, the *onus* is on the organization and/or carers to alter the physical environment or to change their interpersonal communication strategies. The main constituents of these enabling environments are that they are calm, predictable, familiar, suitably stimulating and safe. There is increasing evidence that 'dementia unfriendly' environments further disable people whereas 'dementia friendly' environments help people with intellectual disabilities to maintain levels of independence as well as remain in their own homes if this is a preferred and viable option.

One of the dilemmas faced by many carers in communicating with a person who has dementia and succinctly discussed within the volume, is managing altered reality: beliefs that are held despite appearing or being delusional. For instance, the person may believe a parent is coming to pick them up for a visit, although the parent has been dead for years. In waiting, the person becomes distressed and agitated. Skype can be used as a tool for communication; for example, provide a means for keeping in touch with family who were living too far away to visit regularly. As dementia progresses, individuals commonly lose their abilities to converse and verbally to communicate their needs. While these losses are individually experienced, receptive and expressive communication skills tend to initially fluctuate and eventually diminish. These losses create frustrations for the person with intellectual disabilities, as well as for family and staff carers, which can affect relationships and ultimately the provision and quality of care. It is no surprise, then, that the volume strongly recommends that communication strategies used to manage these changes should be routinely incorporated as part of information and training sessions for carers and staff.

Common strategies across both fields of dementia care and intellectual disability are evident. These include the use of body language, such as facial expressions and gestures, keeping an amenable tone of voice, use of short sentences, taking advantage of long-term memories held by the individual and taking time to allow for response. Memory aids may also stimulate communication. For instance, the creation of memory boxes, life story work or individual life stories prior to late stage dementia may help communicate with the individual, provided that this does not stir negative memories, particularly if the person experienced institutional care when younger. This provides opportunity for reminiscence and, later, for familiar and valued topics, people or events to be discussed. While staff working with people with an intellectual disability may be familiar with alternative communication styles, they need to remain vigilant for changes in communication abilities that occur with the progression of dementia and open to adjusting communication over time, as required.

Caring and carers

The role of caring for a person with intellectual disabilities who has dementia often falls on carers. Therefore, efforts to raise awareness of dementia in people with intellectual disabilities among carers and family members have the potential, as the volume discusses, to facilitate people seeking help earlier in the condition in order to access evidence-based medical interventions. The presence of a pre-existing cognitive disorder can mask the subtle signs of memory difficulties until the diagnosis is more apparent when behavioural difficulties are present. For this reason, enhanced knowledge of the nature of dementia among carers could enable access to timely, appropriate care. The key characteristics of carers, as the volume points out, include the carer's ability to understand and know the person they are caring for, to understand issues in ageing and dementia and crucially to support the individual to cope with the challenges that dementia causes, for example, by predicting potential stressors that may challenge the individual and lead to distressing behaviours. Positive philosophies of care identified within the book include: being person-centred, ensuring a flexible and adaptable care system, providing individualised care, providing continuity of staff, enabling the provision of stress and failure-free individualised activities and the creative use of compensatory strategies to support changes in communication, memory and future planning considerations.

Family carers and the person with an intellectual disability should be encouraged to describe the kind of people they like to be supported by. This can be used, as the text outlines, in the future to create a profile to recruit support workers who have a compatible personality, share interests, or have specific skills that the person needs or wants. Suggestions to make sure the person with intellectual disabilities and dementia is at the centre of discussions include: supporting individuals to be as involved as possible and finding ways for the person to take the lead, choosing who they would like to plan with and where and when that planning should take place.

Enhancing the relationship-centered approach

The relationship-centred approach maintains that the triad of person, their family and those who provide paid care should all experience relationships within an appropriate environment that enables a sense of: security, belonging, continuity, purpose, achievement and significance. Putting together a person's history or life story can sometimes be the easiest place to start and is especially important when someone has dementia and is losing their short-term memory and communication skills. Sharing life stories and memories can help a person with dementia to develop and affirm their sense of identity. Family members can facilitate this by supporting their relative to remember important life events, significant people and everyday

memories. A life story can also be shown to people who spend time with the person socially or as a paid worker; it enables others to learn about the person before they developed dementia and aids conversations. Individualised memory boxes, which may also be multi-sensory, can also be created. Written information can be added, which others can use to support the person to reminisce.

The main focus here is to preserve as much quality of the person's previous lifestyle as is possible to do. This approach not only retains the person's dignity, but in the early stages of dementia also helps to maintain orientation and a sense of reality. It is also relevant in preventing or alleviating potential conflicts between family and staff, something seen at times in residential dementia care and which is a major stress that disturbs effective relationships. For family carers, reviving memories of their relatives in a holistic manner enables them to see beyond the condition and problem-saturated context, while for staff creating possibilities of viewing the resident as part of a family context, it enhances their engagement with the individual with dementia.

Daily routine may become more important after a diagnosis and providing details about what makes a 'good day' and a 'bad day' will help establish what needs to be built in to a person's day and what needs to be avoided. Mapping the people in a person's life can identify who could be involved in planning, making decisions, helping out in emergencies or providing social contact. Making a list of what is important for a person helps to keep them safe, healthy and well. The list, as outlined, is likely to include medication, diet, meaningful activities, home adaptations and information about their daily routine. Families often have detailed knowledge of what is important to their family member with dementia and the person her or himself may say what is important to them or they may show this through their actions and behaviour. For example, having a specific duvet cover on their bed, meeting up with a group of friends, eating certain foods and avoiding others and being spoken to in a certain way. Identifying what is important to and for a person helps to prioritise what needs to address in order to 'make things work'.

Individual patient experiences of intellectual disability and dementia

The volume usefully describes the individual experiences of people ageing with an intellectual disability and dementia. When she went with a woman in the park, all the way down to the canal: "Edna was trying to talk a bit, not a lot, I couldn't understand, we had a lovely afternoon out. We had a cup of tea in a cafe." The consistency of having the same worker who came to know and understand Edna's likes and needs over five years enabled her to have a much richer and more interesting life. As Edna regularly went out and about in her local community she became well known. Support staff valued facilitators present when they visited Edna. The difficulty of seeing someone so changed by dementia is shared by many people without intellectual

disabilities. Celebrating birthdays together each year by bringing party food to the nursing home or sharing local picnics where the person lived is judged to be particularly important. All of these simple needs contribute to a meaningful existence and thus to life itself. It is all too easy for an older person with intellectual disabilities, who no longer has family members caring for them, to become lost in older people's services, their unique identity becoming invisible and they become treated more and more like an object in receipt of care. Group support demonstrates how important it is to work towards keeping a sense of the identity of the person around them at all times. The temptation for services and staff involved with someone who has become so frail that they can no longer tell carers anything about themselves, is to de-personalise them. One man with dementia who had been attending a support group for a long time often talked about his father with great frustration, before it was realized that his father might have dementia. His father made him angry, but it took a long time for the support group to understand what was really going on.

The volume emphasises the importance of talking to people with an intellectual disability about making plans for the future. They will involve discussing wills and advance care plans for health in case of loss of capacity. In the case of one man and his sister, they worried about what would happen if either of them developed dementia or another condition which challenged their ability to cope. They are each so dependent on each other for everything. Up to the point of the husband's death they had lived without any input from local services because he had been able to support them both in so many ways. The support group decided that they should aim to provide them with an increased level of support and also make sure that the local social services team were aware of their predicament than wait for a crisis. With family permission, they asked social services to carry out community care assessments and carer's assessment on each of them. This highlighted exactly what each was doing for the other and showed just how mutually dependent they were.

Independence should not be viewed as a long-term goal for people with an intellectual disability syndrome and dementia, even if this is the lifestyle that the person may have been used to, although it should be supported for as long as is possible. If the person lives alone, then ageing 'in place' is only appropriate if the support level continues to increase on an individual basis, including at night time. A dementia specific or 'dementia capable' environment does not necessarily involve a move. This person may be able to continue to live at home, with appropriate supports and adaptations. People with an intellectual disability often choose to live with others in a shared setting. This should not be ruled out as inappropriate after a diagnosis of dementia. Instead, it requires different support and input for the person with dementia, other residents and staff seem to be in the best position to lead the co-ordination of future care, due to the fundamental basis of their work being across the lifespan of the person.

Planning the support of families

The chapter of the book which considers planning ahead the support of families to shape the future after a diagnosis of dementia explains that this has major implications for a person with an intellectual disability and their family. As growing numbers of people with intellectual disabilities live to an older age and develop other age-related illnesses and conditions, it is important to develop strategies to help families cope. Family carers often find it difficult to think about and plan for the future when they have a son or daughter with intellectual disabilities, especially when they themselves are older. Their perception of the need to plan ahead is likely to change as they will have to think about - and come to terms with - a different future. The immediate focus is more likely to be on the diagnosis and coping with day-to-day matters. Families may feel that practitioners and service providers have more expertise regarding the long-term needs of people with intellectual disabilities and dementia and can lose sight of the wealth of knowledge and understanding they themselves have of their relative and what is important in their life.

The individual with an intellectual disability as the text stresses, should be involved as much as possible in discussion about the support they need and to ensure they receive appropriate healthcare treatments. Families usually know the person best and their knowledge and understanding is central to finding the right solutions and it is very important that such knowledge is not lost or ignored. Using person-centred tools and bringing together a group of people who know and care about the person, will gather different perspectives and lead to creative ways of supporting the person. The involvement of parents and other relatives in planning for the future is thus paramount. Small details often make a huge difference in ensuring the quality of a person's life and the knowledge and use of them is particularly important as an individual may seem to change with the onset of dementia and the person that they were may be forgotten. Person-centred approaches can therefore help to keep a focus on issues that have always been important in the person's life, a sense of continuity that is invaluable especially if formal carers or accommodation change over time. Family involvement needs to be combined with information from trained practitioners who have detailed knowledge about the signs, symptoms and progression of the different types of dementia and can offer timely advice and support.

A key point about planning in a person-centred way is that it starts with the person rather than the services that are available, producing ideas and solutions that fit the person, in order to keep them safer and maintain quality of life. Families should be encouraged to make a written record of the information they gather, so that it can be shared with others who may be involved in the support of their relative. The information can be used to develop a person-centred plan that can be adapted as their relative's needs change and the volume is particularly insightful in describing the ways in which these things can practically be achieved.

The 'ideal' support worker

In considering the profile of the 'ideal' support worker it is important, as the volume emphasises to make sure that any discussions are directed to the person rather than around them. Thus, it is entirely inappropriate to talk about them in the third person and very important to make sure that discussions are carried out at a speed that works for each individual, giving space for them to think through their ideas about the future and to say or indicate what they think. This may be different from what other family members are saying. Here, the use of drawings, pictures, objects, photographs or any other resources or media that is meaningful for the individual is highly useful. For a person who finds it difficult to communicate their needs and wishes, it is even more important that there are people who can speak up for them and act as an advocate. It is best to have a number of people involved in this process so that they can support each other and co-ordinate matters between them - some may need to withdraw from active, front line care when they experience pressures in their own lives. A network of support is particularly beneficial if the person's parents are frail or where family no longer live nearby. Developing an informal support network of unpaid people, is not a substitute for services and paid support, but rather a complement. The two should work together to improve the person's life and to keep them safe.

Communicating the dementia diagnosis

The difficulty of sharing the diagnosis of dementia is clearly addressed within the book. However, not giving someone bad news doesn't make the bad news disappear. If we do not help people to understand the changes in their lives that are occurring or which are set to occur, we may make it more, not less, difficult for them to cope. We are invited to consider the case of a person who has not anticipated the death of someone close to them. They will experience it as sudden and unexpected and this is usually much more difficult to come to terms with than a death for which there has been some form of preparation. Many people cope best with bad news if they are helped to understand the changes they will come to experience. Denying that there is bad news, or pretending that changes are not being experienced, can be very confusing; the person's emotions thus fail to match with what they are being told. Indeed, there is often a culture of people with intellectual disabilities being 'jollied along', being expected to smile even when they have every reason to be sad. Families, carers and professionals may be tempted to gloss over the bad news situation.

Conclusion

The current volume is an important contribution to the literature on intellectual disability and dementia. The

individual chapters are well written, with accessibility of style and the volume is cohesively edited making the book a delight for the reader. The comprehensive nature of the volume in terms of its aims and scope make this publication highly recommended reading not only to all those colleagues involved in the health and social care of persons with intellectual disability and dementia, but also for the families and friends of those who suffer with these conditions.

Conflicts of Interest

The author declares no conflicts of interest.