

Original Article

A consideration of the needs of the adult patient with dementia attending for radiotherapy and its impact on the practical consent process

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Abstract

Dementia, which affects about 5% of those aged over 65 years, is the progressive decline in cognitive function due to damage or disease in the body beyond that expected from normal aging. It causes the loss of mental abilities such as thinking, remembering and reasoning and memory impairment, which is important when considering informed consent in radiotherapy. Radiotherapy treatment often involves many visits for a patient and each time it is the legal responsibility of staff to ensure that patient is aware of what is happening and why. Informed consent is challenging in patients with dementia because of the memory impairments and the nature of the information. There is enormous variation in how this illness affects people, depending on the type of dementia and the individuals themselves. Full information about the treatment itself, the benefits and risks of the treatment and the availability of any other reasonable alternatives to the proposed treatment or procedure must be made available. Dementia patients respond well to set approaches and these are detailed. It is important for staff to be familiar with the most effective approaches and consider these in obtaining informed consent.

Keywords

Informed Consent; Dementia; Radiotherapy; Cancer

RADIOTHERAPY

Radiotherapy can be delivered as a treatment to patients at any age, but in practice is predominantly a treatment of adults. Around 242,000 cases of cancer are registered in England each year, of which 74% are in those over the age of 65 years and 20% are in those over the age of 80 years.¹ Demographic changes in population mean that there is an increase in the aged population, and this will be reflected in the

increased need for radiotherapy treatment in the future.² As 52% of cancer patients receive radiotherapy as part of their treatment, it is inevitable that a large proportion of the patients treated with radiotherapy will be elderly.

DEMENTIA

The term ‘dementia’ is used to describe the symptoms that occur when the brain is damaged by specific diseases. Dementia is the progressive decline in cognitive function due to damage or disease in the body beyond that expected from normal ageing. It causes the (usually gradual)

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loss of mental abilities such as thinking, remembering and reasoning. Dementia is not a disease in itself, but is a term used to describe a group of symptoms that may accompany certain diseases or conditions affecting the brain. There are three main types of dementia: Alzheimer's disease, vascular dementia and dementia with Lewy bodies.³ The most common symptoms include loss of memory, confusion, and changes in personality, mood and behaviour. The ability to solve problems will also be impaired. Currently 600,000 people in the United Kingdom have dementia and this is expected to increase to 840,000 by 2024.⁴

During the diagnosis stage a clinician may carry out a number of tests to determine whether the patient has dementia. These include tests of co-ordination, balance, reflexes, muscle tone, eye movement, strength and sensation. This is in addition to a comprehensive neurological investigation with particular attention to the nervous system.⁵ As a degenerative condition there are a huge variety of implications that should be considered during diagnosis and in the continuing treatment of patients. These should be evident in any care plan developed.

Alzheimer's disease is the most common form of dementia, affecting around 400,000 people in the United Kingdom. 'Plaques' and 'tangles' develop in the structure of the brain, leading to the death of brain cells. Vascular dementia is the second most common form of dementia. It is caused by problems in the supply of blood in the brain.⁶ Dementia with Lewy bodies presents with symptoms similar to Alzheimer's disease due to the death of brain cells in the brain's cortex and part of the midbrain.⁵ It is widely accepted that dementia is a debilitating cognitive condition and affects not only the person diagnosed but the family and carers. Health-care professionals may be presented with complex and varying patterns of the illness.

The major cognitive impairment in patients with dementia is memory impairment. This affects the explicit more markedly than the implicit; however, both the long- and short-term memory are affected.³ Carers often report

patients being able to recall memories from their past but not what might have happened 10 minutes ago. Memories that have personal meaning are often better remembered than memories of public events or people.⁷ This would implicate impairment in the remembering and processing of medical treatment information by a patient with dementia.

Research indicates that there are specific areas of the brain affected by the disease and most evidence has been acquired through comparisons to 'normal' brains that provide an age-appropriate comparison. The hippocampus is often reduced in size and this can, for example, affect the ability to recall stories after a short delay. This also correlates with the ability to recall information gathered after a short delay, and could be significant when patients are given information by health-care professionals and their treatment starts later.

There is an enormous variation in how this illness affects people, depending on the type of dementia and the individuals themselves. However, there are usually three distinct stages. In its early stages, people often appear confused, and forget about things that have just happened. They may not remember where they are, or what they did 5 minutes ago, but their long-term memory is usually not affected much. Understandably, people with dementia often dwell on past experiences. Concentration and decision-making become difficult, and mood changes are frequent. A previously happy person may become irritable or depressed over trivialities, and friends and relatives may notice changes, without understanding why.

The second stage, known as moderate dementia, brings more obvious confusion, forgetfulness and frequent mood changes. The person may become anxious and aggressive. They may wander restlessly around the house, and be up and about at night. They may try to search the streets for a place or person from the past. They may also become suspicious of loved ones. Personal safety can be an issue, especially for those who smoke or cook; even simple things like dressing may become difficult as focus and motivation may deteriorate. The

pressure upon carers is enormous, as it becomes increasingly difficult to leave someone with dementia on their own.

In the final stages of the illness, long-term memory may still be strong, but often people are unable to recognise even close family and friends. People stop being able to talk properly or to understand what is said to them, and incontinence is common. During the later stages, most people become increasingly frail and may be confined to a wheelchair and then to bed. This makes them especially vulnerable to infections, which can be fatal.⁸

Dementia becomes more common with increasing age. About 5% people over the age of 65 years will develop some degree of dementia. This figure increases to about 16% over the age of 85 years. Dementia can develop in younger people, but is less common, affecting <1% of those under 65 years. Pathological changes in the brain can be seen to increase in the elderly and it is also a time when organic and functional illness can coexist.⁹ Diagnosis of dementia is confirmed by assessment of structural changes using magnetic resonance imaging (MRI) and single photon emission computed tomography (SPECT) scanning. In assessing images to diagnose malignant disease progression, the existence of a pre-existing mental disorder will make the expert opinion of a radiologist vital.

CONSENT

Patient consent is the principle that express permission must be gained before any medical treatment can be carried out. The type of treatment is unimportant; consent is needed for anything from a blood test to a surgical procedure under general anaesthetic. The principle of consent is one of the cornerstones of medical ethics and is also enshrined in international human rights law. Consent can only be said to have been given if it is both voluntary and informed. The treatment must be the decision of the patient and not be the result of coercion by medical staff, friends, or family. Full information about the treatment itself, the benefits and risks

of the treatment and the availability of any other reasonable alternatives to the proposed treatment or procedure must be made available. The patient should also be aware of what will happen if no treatment is given

Consent should be obtained by the health-care professional directly responsible for any treatment. This could be a doctor prescribing medication or treatment, or a radiographer delivering radiotherapy treatment. Where treatment proposed consists of a series of events, the overall responsibility for gaining a patient's consent may be seen to lie with the doctor who initially proposes the treatment; but each step/patient interaction provides an opportunity for the patient to refuse treatment or question decision making, and for the health professionals involved to confirm that the patient is still willing to proceed with the proposed plan. It is important to be cautious in relying on a patient's apparent compliance with a procedure as a form of consent. For example, the fact that a patient lies down on a treatment couch does not in itself indicate that the patient understands what is proposed and why. A signed consent form is not sufficient evidence that a patient has given, or still gives, informed consent to the proposed treatment in all its aspects. Each member of the team is responsible for taking action if there is evidence that the patient does not wish to proceed. This is especially relevant where significant time has elapsed between the initial consultation and the start of treatment.

COMMUNICATION AND CONSENT

When looking at informed consent the key element is communication. It is a health-care professional's responsibility to fully explain and inform a patient of the process, risks and potential outcomes of any procedure or health treatment. When a patient has been diagnosed with dementia a unique set of challenges is faced by all health-care professionals involved. From the diagnosis to the final treatment intervention each patient contact brings with it the responsibility to be clear about all aspects of treatment. The pragmatic and semantic areas

of language breakdown in Alzheimer disease patients may result in the loss of functional communication.¹⁰ The semantic area of long-term memory relates to conceptual information, general knowledge and facts and information.³ The pragmatic refers to the context of language. The way information and conversation is presented is important, any inferred ambiguity or meaning that relies on the interpretation of context and time or other factual information can be misinterpreted more easily. This would be specifically relevant when trying to gain informed consent as the patient would need to recognise the relevant context and time frame. The semantics, as opposed to episodic (or autobiographical) memories which remain stronger in dementia patients, can deteriorate and affect general understanding of what the treatment will entail and thus the ability to give informed consent.

Communication is a major stressor for the carers of patients with dementia and so should be a consideration when investigating and making recommendations for health-care professionals and their approach to informed consent. There are a number of strategies that can be used when communicating with dementia patients; however, training and supervised practice would be important factors. The resources any additional training would take up, for a relatively small percentage of patients, may be a consideration in determining what can be made available.

It is also important to consider the information a carer needs when informing the patient. A carer is often present and may ask as many, if not more, questions during the information and consent process. As dementia patients find it so difficult to hold dual attention it may be important to have a separate information session with a carer and to give them the opportunity for their questions.³ For example, if a patient is in a room with a carer and a health professional, any questions from the carer may draw the patient's attention away from the information being given and it could be difficult to regain this. Communication with dementia patients should consider different factors that influence the effectiveness of any conversation.

It is important to consider whether questions were understood and whether answers can be deemed relevant, adequate and informative; also the possible existence of factors such as dyspraxia, delirium or disaffection.⁹ These factors should be considered in informed consent as it is important to ask pertinent, consistent and insightful questions to gauge a patient's understanding of the situation and course of treatment. The patient's understanding may have been assessed in the community using specific tools, and this integrated into the care package for the individual patient. This information is seldom directly available to staff in radiotherapy, and any information regarding individual needs is often provided by relatives and carers who may be stressed by the diagnosis and treatment issues relating to the cancer diagnosis in the same way as the patient themselves.

MENTAL CAPACITY ACT

Under the terms of the 2005 Mental Capacity Act, all adults are presumed to have sufficient capacity to decide on their own medical treatment unless there is significant evidence to suggest otherwise. The evidence has to show that the patient is unable to make a decision on a specific occasion. Someone is thought to be unable to make a decision if they cannot understand information about the decision; remember that information; use that information as part of their decision-making process, or communicate their decision by talking, using sign language, or by any other means.¹¹

A patient's capacity to understand may be temporarily affected by factors such as confusion, panic, shock, fatigue, pain or medication. However, the existence of such factors should not be assumed automatically to render the patient incapable of consenting. There are a number of assessments that are used in psychogeriatric assessments; the NICE guidelines¹² recommend assessment of dementia using the Mini Mental State Examination (MMSE) and the Clifton Assessment Schedule looks at information/orientation, mental ability and psychomotor scores.¹³ The MMSE is a brief 30-point scale that estimates the severity of

cognitive impairment at any one time and only takes a few minutes to perform. It is commonly used in a hospital setting and may be repeated if there is any doubt as to the ability of the patient to understand and effectively consent at any stage. Where decision-making capacity has been assessed and is judged to be absent or severely impaired the requirements of the Mental Capacity Act must be adhered to. The Act requires that, as far as possible, health professionals must consult other people, if it is appropriate to do so, and take into account their views as to the best interests of the person lacking capacity, especially anyone previously named by the person lacking capacity as someone to be consulted. Other parties to involve would be those engaging in caring for patient and the patient's family and friends. The Act also places a duty on the NHS to instruct an independent mental capacity advocate (IMCA) in serious medical treatment decisions when a person who lacks capacity to make a decision has no one who can speak for them, other than paid staff. IMCAs are not decision makers for the person who lacks capacity, they are there to support and represent that person and to ensure that decision making for people who lack capacity is done appropriately and in accordance with the Act.¹⁴

THE PRACTICAL CONSENT PROCESS IN RADIOTHERAPY

Radiotherapy involves various stages and requires continuous cooperation and collaboration. Every stage and overall treatment effectiveness may suffer without effective communication. The delivery of services is intrinsically linked to informed consent and without proper professional guidelines the treatment plan may be flawed from the start.

The process of gaining consent can vary between individual departments. There have been attempts to standardise the forms and share experience, but differences between referral processes have constrained Trusts and their insurers. Standardised consent forms were proposed that quoted the long-term effects of radiotherapy procedures, but there was felt to be too wide a variance between departments.¹⁵

Each professional group have their own guidelines, and these are mirrored by advice from the Department of Health (DoH, HPC and GMC guidelines^{16–18}). Where patients are to be entered into a clinical trial, there are other specific guidelines. The General Medical Council state that we need to find out what the patient wants to know as well as what they ought to know. It is also advisable that there is not a significant gap between seeking consent and any procedure. Where this does occur it is important to clarify that patients still understand what is proposed and are still happy to go ahead.

The audit commission carry out national surveys to examine service information and local needs. The provision for people with dementia is “very patchy,” often no specific person having responsibility for gathering information and identifying the expenditure on “functional” mental health issues.¹⁹ As the expenditure is undefined it would be complex to assign training resources and provide a comprehensive system in each local authority. Most emphasis to support dementia care is focussed on the Primary Care sector, but the active treatment of disease should still be provided for this group of patients, amongst this being radiotherapy, so some resources may need to be available to ensure that the staff and facilities to support the treatment of patients with dementia is provided.

DISCUSSION

All patients attending radiotherapy treatment are subject to the stresses of having received a diagnosis of a potentially life-limiting disease. This can lead to issues in comprehending and dealing with information as a result of denying the realities in an effort to cope. Elderly patients commonly suffer from co-morbid conditions (for example cardiovascular disease, type 2 diabetes, musculo-skeletal disorders). In addition age and infirmity can cause deterioration in eyesight and hearing, and this together with the presence or fear of pain may distract and inhibit communication leading to poor attention span. Dementia is increasingly common in patients

attending for radiotherapy treatment, and its affect on the individual and their interaction with the health professional can reduce the effective understanding of information and influence personal decision making during the consent process. The patient suffering from dementia together with co-existing physical issues presents a challenge in aiming to deliver accurate and timely treatment with informed consent.

Communication is both verbal and non-verbal and so it is important to consider both when looking at giving information to any patient, and there are specific considerations with dementia patients. Non-verbal communication is particularly important for a person with dementia who is losing their language skills. Challenging behaviour may be an attempt on their part to communicate, but staff should be careful not to behave in a patronising manner. It is also important not to intimidate the patient by standing over them, eye level contact is more reassuring. Many people with dementia have a fragile sense of self-worth and it is important that they are treated with courtesy.²⁰ Where verbal communication is slow, and the patient becomes distracted it is important to allow more time to listen to what they are saying and observe their reactions.

Dementia tends to be accompanied by poor cognition which impairs the individual's ability to express their wishes and verbalise their feelings of pain discomfort and emotional anguish. This can lead to difficulties for health professionals in assessing pain and symptoms.²¹ Research has shown that attention is not significantly impaired in Alzheimer's patients and it was only when patients were asked to perform dual tasks that they showed decreased performance.²² This means that in gaining consent from patients with dementia clear and concise language should be used, and information should be given in a setting that provides no distractions for the patients. Enabling the patient to focus on the information they are being told may allow for better informed consent and increased memory of what they are being told when they return for treatment.

The specific advice in communicating with dementia patients may be summarised as follows:

- Be calm and reassuring
- Speak distinctly and slowly
- Use simplistic language to avoid confusion
- Always ensure that you get the patient's attention before giving them key information and maintain eye contact
- Ask only one question at a time and wait for the answer
- Ensure that there is only one person who is doing the talking
- Recognise the importance of body language for all parties
- Face the patient front on and use gestures where appropriate to express feelings in your language

www.alzbrain.org²³

Where communication is difficult, it may be necessary to adapt the style of the consent procedure to ensure that patients, their supporters and staff are confident that there is no issue over acceptance or refusal of the treatment. Rephrasing, working with carers and looking at how to effectively replicate information for future reference is important. It might be appropriate to ask the patient open-ended questions to solicit responses in their own words. This is less likely to appear threatening, and if done in a conversational manner will help to determine the patient's understanding of what is proposed and their capacity to consent. It also allows further clarification and gives us an understanding of the patient's own goals and values and their reasoning process. Questions might be:

- Tell me in your own words what you understand to be your main medical problem.
- What treatment (or procedure) was recommended?
- If you receive this treatment (or procedure), what do you think will happen?
- If you do not receive this treatment (or procedure), what do you think will happen?
- Can you tell me what you have decided? Why?

Dalini²⁴

It is widely recognised that written information is valuable to all patients in recalling information after a medical consultation. Morrow et al.²⁵ studied cancer patients who were given written information to take home before being asked to sign the form. The experimental group were found to possess greater information and have greater knowledge of the treatment and possible alternatives. The inherent problem with giving information is that information is often new and frightening. The ability to comprehend and retain this information is decreased by the shock of the diagnosis.²⁵

We should, however, avoid being too passive in giving information and waiting for the patient and carers to ask questions as this only tends to happen when they have a high level of knowledge and initiative. Written information should support the verbal information and be of a high standard. Kusec²⁶ investigated patient narratives and found that more information was gained when given by lay experts as opposed to doctors. It is suggested that involving lay people in writing patient information would be beneficial. Another influencing factor can be our expectations of success in patients' interactions. If we have low expectations of interaction then they are less likely to be successful, and inherently the standard of care may be diminished.²³ Where dementia is present information may be given and received successfully by employing the strategies outlined. However, the limited attention span and short term memory-loss characteristic of the disease may still reduce the effectiveness of the interaction. The presence of a team, who need to communicate amongst themselves to effect an accurate beam/isocentre position to ensure accuracy, may distract the focus of the patient with dementia during the radiotherapy treatment appointments. Improving the awareness of members of staff of dementia will allow practice to be adapted to reduce distractions and retain the focus of the patient without causing undue distress.

Further adaptations to allow the patient with dementia to more easily cope with the procedures at each stage of the process may also be beneficial. It is the episodic memories that are

intact for the longest time and anything that reminds patients of events and people they remember can help maintain a calm and relaxed atmosphere. Additional time (longer appointment times with availability of supportive staff before and after treatment) may be beneficial. The provision of suitable transport, familiar clothing and adaptations to the environment such as presence or absence of background music, are all factors that could help reduce the stress experienced by the patient and in particular dementia patients. Information gathered regarding these factors must be communicated effectively to be put into practise.

Patients often feel that it is not their role to challenge medical staff and ask for further information and clarification. This follows from the view that physicians are experts who have a paternalistic duty to provide answers and cures to health problems.²⁷ Usher and Arthur²⁸ contend that many hospitals encourage patients to be passive recipients of expertise. Nazarko²⁹ states that professionals require education to enable them to identify incapacity and act ethically when caring for any vulnerable patient group. Clinicians should have access to clinical and psychiatric histories to take account of cultural and ethical backgrounds and beliefs. Friends, family members and advocates may advise professionals and support decision making, but this is not always necessary or desirable. Independent advocates can be used without friends and family to enable individuals to make decisions and encourage best standards of care whilst minimising legal intervention. Treating people who lack capacity as though they were competent adults means that they may agree to and go through with treatment they would not have consented to were they competent. However, it is important to see patients on their own first to avoid the influence of carers and give the opportunity to maintain independence. This allows them to tell their story and, even when severe cognitive impairment is present, permission should be sought to share information with others.⁹

Health professionals must act in the patients' best interest (beneficence) to protect their well being. Where the patient is at the beginning

of their treatment and their consent is being sought, lack of information regarding the patient's capability can cause delays and misunderstanding. The Mental Capacity Act requires that we make an assumption of capability, but staff need to consider what action to take if a patient appears to have no recollection of previous discussions and the proposed treatment. The presumption must always be that the patient wishes to be well informed¹⁵ and this must include dementia patients. Poor memory means that facts are not retained, but legal consent relies on the patient's understanding of what is being proposed for long enough to make an informed decision on each occasion. The key factor is the patient's understanding at that time and the procedure followed at the beginning of treatment may need to be followed at subsequent visits for patients with dementia. It should also be recognised that information is important to those supporting and caring for the patient. Both written and verbal information, together with help and information phone lines, should be available to friends and relatives when they are unable to attend with the patient. Written information is also a useful tool to recap information in a similar format when it has been "forgotten".

In radiotherapy the issues of physical safety of patients with dementia, when they are required to be left alone in a room, may pre-occupy staff and distract them from the important issues of communication and consent. Where short-term memory is largely absent it may be that patients can consent to treatment when in a calm room outside the treatment area, but when in the treatment position are so stressed that they cannot safely lie in position because they cannot recollect simple physical instructions. The patient is therefore unable to consent to that aspect of the process, and at the end of the day we might question whether they would consider it in their best interest when it is a cause of such distress. In these circumstances the importance of the written record comes to the fore to document the circumstances and actions taken. It is advisable to have a written record of consent where the treatment is complex and there is significant risk as a result of the procedure¹⁶. Where events occur that

cause delays, prolongation of treatment or result in clinical incidents, then all this needs to be annotated so that all members of the team are aware of the situation. It is advisable to use the patient's medical records or a consent form to record the key elements of any discussion with the patient. This should include the information you discussed, any specific requests by the patient, any written, visual or audio information given to the patient, and details of any decisions that were made.

It is important to remember that a person with dementia should still be treated with respect, and that they are still unique and valuable individuals.

CONCLUSION AND RECOMMENDATIONS FOR PRACTICE

It is important that all staff working in radiotherapy are aware of the issues relating to capacity to consent for all patients. With the growing numbers of patients with dementia, it is likely that we will all be in a situation where we may question a patient's capacity to consent at some stage. Staff training is therefore vital to ensure that we are aware of the law and the Trusts' guidelines for dealing with patients who may be unable to give informed consent to treatment.

The key role of communication in dealing with patients is highlighted, and again the training and education of all staff groups to deal with vulnerable patient groups is advised. Where a patient has dementia, it is important that this is communicated to all those who will come in contact with them, and that we take reasonable steps to meet the patient's needs by:

- discussing treatment options in a place and at a time when the patient is best able to understand and retain the information
- asking the patient whether there is anything that would help them remember information, or make it easier to make a decision; such as bringing a relative, partner, friend, carer or advocate to consultations, or having written

or audio information about their condition or the proposed investigation or treatment

- speak to those close to the patient and to other health-care staff about the best ways of communicating with the patient, taking account of confidentiality issues.

If a patient is likely to have difficulty retaining information, a written record of any discussions should be offered, detailing what decisions were made and why. This should be available to not only the patient but the carer and other health-care professionals involved in the case so that everyone is aware of the information presented to the patient.

If there is doubt remaining about the patient's capacity to make a decision then advice should be sought from:

- Those close to the patient and involved in their care.
- Prior assessments undertaken in a health-care setting and at the patient's home.
- Other colleagues with relevant specialist experience, such as psychiatrists, neurologists and speech and language therapists.
- An IMCA (Independent Mental Capacity Advocate) who will be able to check that the best interest principle has been followed and that the person's wishes have been taken into account in line with the recommendations of the Mental Capacity Act 2005¹⁴

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