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Implementing Mental Capacity Act in the everyday decisions of the hospice multi-disciplinary team

Abstract

The Dove House Hospice has always held Multidisciplinary Team (MDT) meetings and made every attempt to ensure that patients wishes are met. No return.

By highlighting one or two patients per week whose care might be affected by the Mental Capacity Act we have added another layer in our quest to ensure that the patient receives the best and appropriate care for him, in line with his wishes, and that competent decisions are made.

It has also helped staff to become familiar with the Act and apply it in real situations.

Key words: Mental Capacity Act, multi-disciplinary team, hospice

Adv. Pall. Med. 2008; 7: 115–118

Introduction

It is the general feeling by the public that United Kingdom healthcare professionals tend to “know better” what is good and what is bad for the patients especially when they are very ill and they are approaching death. Traditionally the decision making was focused at the axis between the family and the professionals and the patients’ voice was frequently not listened to. These kind of situations lead in the past to a lot of frustrations and in some countries lead to new legislations empowering the patients even to take a decision about assisted suicide and euthanasia.

To give more weight to the patients’ voice, but also to avoid unnecessary and overzealous treatments, after long parliamentary and public debates the Mental Capacity Act became obligatory from October 2007.

The Mental Capacity Act 2005 provides a statutory framework to empower and protect vulnerable people who are not able to make their own decisions. It makes clear who can take decisions, in which situations, and how they should go about this. It enables people to plan ahead for a time when they may lose capacity (Department of Health 2005). The Act has major implications for decision making in end-of-life care.

The Act states that ‘A person is unable to make a decision if he cannot understand relevant information, retain that information, use or weigh that information as part of making a decision, or is unable to communicate his decision by any means (National Council for Palliative Care 2005).

The Act makes clear that the Health Professional is deciding whether or not the patient/client has the capacity to make a specific decision and not whether the patient/client has capacity per se. For exam-

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Advances in Palliative Medicine 2008, 7, 115–118
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ple the patient/client may have the capacity to decide what he wants for breakfast but not where he wants to live.

As part of preparing our staff for the implementation of the Act in October 2007, some paperwork was devised. Part of this focussed on when patients had to make a significant and specific decision and the staff were unsure of the patient's capacity.

Staff were encouraged to look at the four areas discussed above in coming to their decision i.e.:

- can the patient understand the relevant information?
- can he retain the information?
- can he weigh up that information?
- can he communicate the decision?

It was made clear to staff that they should give the patient every opportunity to make his own decision and be able to demonstrate that this was the case.

After discussion with the team leaders it was decided that we would highlight one or two patients per week whose care might be affected by the Mental Capacity Act. This was to ensure that the patient received the best and appropriate care and it was seen as a good way for staff to become familiar with the Mental Capacity Act. Any professional within the multidisciplinary team (MDT), can bring forward a patient for discussion in the weekly MDT meeting. In this article we shall highlight three patients most illustrative for the nature of Mental Capacity Act and its implication for decision making by the team. In this way we hope to illustrate the issues Mental Capacity Act is solving, but also which are more complicated and unclear.

Case one

Mrs A., age 76 years with lung cancer infiltrating the brachial plexus nerves and severe neuropathic pain radiating to her left arm. Mrs A. was a widow and lived alone. However she had caring relatives who lived quite close by. This consisted of a brother, niece, great-niece and the great-niece's partner. Mrs A. had been admitted to the hospice for pain and symptom control. Over the previous few weeks, Mrs A. had become progressively more "confused" and "disorientated". The medics at the hospice, basing on the interview with the family, suspected a pre-existing dementia in Mrs A. but she was never formally assessed and the diagnosis was not confirmed. With her pain under control, it was now time to plan for discharge. When the social worker discussed this with Mrs A., she stated that

she wanted to go home. Her family had grave concerns about Mrs A.'s safety if she was to return home alone. Even though the family were caring and lived close by they could not give 24 hour care to Mrs A., nor could the Social Services. Her family but not Mrs A., felt that a better option would be a nursing home. This option was also found more feasible by the other involved health care professionals. It was felt by the MDT that Mrs A. did not fully understand the likely dangers of living on her own. The significant and specific decision that Mrs A. had to make was where she wanted to live, after being discharged from the hospice. She stated that she wanted to go home. There was doubt that Mrs A. had full capacity to make this specific decision. When looking at the capacity check list despite her "confusion" she could communicate her wishes.

On discussion at the MDT meeting it was felt that it was in the first three areas of the checklist e.g. weighing up information, where there was a problem. It was concluded that Mrs A. did not have full capacity to make this specific decision. It was decided that a best interests meeting was needed. There was a discussion at the MDT meeting about involving a third party i.e. an independent mental capacity advocate. This was deemed as unnecessary as Mrs A. had close family to support her (Mental Capacity Act 2005 code of practice). At the meeting attended by the pertinent health and social care professionals and Mrs A.'s family it was decided that it would be in Mrs A.'s best interests to be discharged to a nearby nursing home, in close proximity to her family. This point of view was communicated to Mrs A. by the senior social worker. Mrs A. was discharged to a nearby nursing home, which she had visited on several occasions before discharge. She appeared very content with the Home and her family could visit regularly. She died soon after there with the hospice doctors still involved in her symptom control.

Case 2

Mr B. was an elderly gentleman with squamous cell carcinoma of the epiglottis with lung metastases. Mr B. was married and had three daughters and four grandchildren. Mr B. had been admitted to the hospice for pain and symptom control. On admission to the inpatient unit he was weak and his ability to tolerate feeding via his jejunostomy was deteriorating and causing frequent regurgitation. This troubled him with aspiration induced chest infections despite his feeding rate being reduced.

Mr B. had choking episodes, breathing difficulties and left leg pain. A few days after admission Mr B. became much less well and refused feeds and medication via the jejunostomy. There was the feeling that perhaps the health care professionals would have kept the feeds and medication going a little longer. The specific and significant decision that Mr B. had to make, was whether to continue to have his feeds and medication via the jejunostomy. His decision was to stop having them. On discussion at the MDT meeting quite rightly it was felt that if Mr B. had full capacity to make this decision then we should honour it. When looking at the capacity checklist it seemed clear that Mr B. had capacity in all four areas and therefore had capacity to make this specific decision. His family were aware of his decision and respected his wishes.

It was decided by the MDT that we would offer Mr B. both feeds and medication at the times that they were due, to allow him to change his mind at anytime. He was in agreement with this.

Mr B. died peacefully several days after the MDT meeting being cared for under the Liverpool Care Pathway.

Case 3

Mrs C., 55 years old, was admitted to the inpatient Unit for terminal care and symptom control. She had end-stage renal failure and her main symptoms were poor appetite, nausea, chest pain/tightness, headache, abdominal pain, pain to the right side of her body and severe weakness/fatigue. Her condition was slowly deteriorating.

Mrs C. was married and had a daughter who lived close by. Her daughter had a young child.

Mrs C. had communication difficulties she did not speak English and had recently had a CVA, which left her with some dysphasia. Initially Mrs C. took analgesia orally for pain.

After several days she appeared to be refusing her oral medication and injections. Mrs C. would bang her chest, which the staff interpreted as her being in pain. However when staff brought analgesia to Mrs C. she put her hand out to imply that she was refusing it.

The specific and significant decision that Mrs C. had to make was whether or not to accept analgesia for her pain, the staff had to decide whether she had capacity to make this decision.

On discussion at the MDT meeting it was felt that we had to be sure that we were interpreting Mrs C.'s body language correctly. When looking at the capacity checklist, there was a possibility that

Mrs C. could meet the first three criteria, but needed assistance to communicate the decision the fourth element. Under the Act we had an obligation to give her every opportunity to communicate her decision (Mental Capacity Act 2005 code of practice).

It was felt that it was unfair and inappropriate to use Mrs C.'s daughter as an interpreter. We decided at the meeting to get an interpreter as quickly as possible for Mrs C.

After speaking with the interpreter it was ascertained that Mrs C.'s banging on her chest was due to physical pain.

She was refusing oral medication due to being frightened of being sick. She refused injections, because she did not like injections; however she accepted Fentanyl patches for her pain.

By using an interpreter, we allowed Mrs C. to make a competent decision in line with her wishes. The interpreter was also able to ask her questions about her faith, beliefs and her wishes for the future.

Mrs C. had full capacity to refuse oral analgesia and injections/syringe driver but also had full capacity to accept the patches.

Mrs C. slowly deteriorated whilst on the unit; she had a period of plateau and then died peacefully several days later.

How can we assure that the "best interest meeting" will really be in the patient interest and not for example in the interest of the carers or the family?

Discussion

In the case of Mrs A. even though she appeared to be able to communicate her wishes, the health and social care professionals involved and her family, felt that she had a problem in understanding the information, in retaining that information and in weighing up that information. They concluded that she did not have full capacity to make the specific decision about going home. They felt that she had not been able to fully understand and weigh up the risks of returning to her own home. If in some way she had been able to say for example, yes I understand that I may fall, or burn myself on the oven, but I still want to go home, then this may have put a different slant on the situation. She could only say "I want to go home" and this was not a persistent and balanced wish.

The discussion which took place at the MDT meeting was very focussed on the question of where she should live after discharge. However it had also been discussed at various other times by staff at the hos-

pice, so the decision was made to have a best interests meeting after much debate and soul searching.

The decision made at the Best Interests Meeting was in line with all the underlying principles of the Mental Capacity Act; for example given the circumstances, the decision made was one that was the least restrictive of Mrs A.'s rights and freedom of action (National Council for Palliative Care 2005).

In the case of Mr B., he had full capacity to make his decision in relation to stopping his feeds and medication. The issue was that some staff felt a little uneasy about this. After discussion at the MDT meeting and with the agreement of Mr B. it was decided that we would offer Mr B. both feeds and medication at the times that they were due, to allow him to change his mind at any time. This I would suggest felt more comfortable and sensible to both staff and Mr B., rather than have a blanket decision to stop all feeds and medication completely without ever re-visiting the situation.

Again the process was in line with the underlying principles of the mental capacity act, for example, one of the principles states that "people have the right to make decisions which may seem eccentric or unwise to other people" (National Council for Palliative Care 2005). For some staff Mr B.'s decision may have seemed a little unwise, but after discussion they understood the need to respect his wishes.

The case of Mrs C. was very interesting. Under the Act we had an obligation to give her every opportunity to communicate her decision. Even without the Act in place, we from our experience of our Hospice know that we would have got an interpreter involved anyway. Without the help of the inter-

preter there may well have been a situation where Mrs C.'s wishes were not respected. This could have manifested itself in two ways. Firstly we could have decided that Mrs C. had full capacity and was telling us that she did not want any analgesia at all for her pain. We could have respected her wishes to remain in pain. Alternatively we could have decided that Mrs C. lacked capacity and decided to give her analgesia in her best interests, (perhaps by injection).

However with the help of the interpreter we established exactly what Mrs C. wanted and therefore allowed her to make a competent decision for herself.

Conclusion

Our hospice has always held MDT meetings and made every attempt to ensure that patients wishes are met.

By highlighting one or two patients per week whose care might be affected by the Mental Capacity Act we have added another layer in our quest to ensure that the patient receives the best and appropriate care for him, in line with his wishes, and that competent decisions are made.

It has also helped staff to become familiar with the Act and apply it in real situations.

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