Involving Advocates in Critical Care Units – Why Not?

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Introduction

- Mental Capacity Act 2005 (MCA)
- Independent Mental Capacity Advocate (IMCA)
- Wellcome Trust Symposium
- ‘IMCA Clinic’

Aims and Methods

- Aim – explore knowledge and awareness of the MCA and role of the IMCA and possible role expansion.
- Methods
  - Two NHS Trust with large critical care unit
  - 15 participants (6 clinicians, 5 relatives, 4 IMCAs)
  - Semi-structured interviews
  - Questionnaires sent to 50 IMCA services
  - Interview transcription and analysis

Data Analysis

- Thematic Analysis Approach. (Braun & Clarke 2006)
- Broad themes e.g. MCA
- Further themes emerged with constant re-reading and review of interviews until saturation point was reached.
- MCA – MCA knowledge – MCA training – best interest

Results – MCA knowledge

- Explored clinicians’ and families’ knowledge & understanding of the MCA.
- None of the clinicians interviewed had received any formal training on the MCA.
- C5 - “The Trust provides a mountain of training on all things. Whether in that haystack there was something about the Mental Capacity Act, I can't tell you”.
- Concern about lack of formal training on the MCA.
- One of the five relatives interviewed had heard of the MCA.

Results – Role of the IMCA

- The MCA places an obligation on clinicians to instruct an IMCA for a patient who has nobody to represent them when a decision about serious medical treatment (SMT) is being made and the individual lacks capacity to make the decision.
- IMCAs support and/or represent an individual. They advocate on the patient’s behalf.
- IMCAs find out the person's wishes, values and preferences, promote their rights, gather the views of others and check the the MCA principles and best interests checklist is being followed.
- Explored clinicians’ understanding of the IMCA role and when patients are entitled to the support of an IMCA.
- General understanding across both Trusts that IMCAs are for people who lack capacity.

Results – Role of the IMCA

- Some confusion about the circumstances of when a patient must be referred to IMCA.
- C6: IMCAs are "the voice for a patient who isn't competent at that point in time”.
- C3: “100% certain that there are “patients who are eligible but not referred […] there are frequently situations where you could make a case for involving IMCA”.
- IMCA 1: "Some have a slightly cavalier attitude to it in the sense of they feel it's not necessary".
- IMCA 4: “A lot of the nurses are straight onto it if they think the person lacks capacity and they need someone to stick up for them”.
- Disparity between the two Trusts:
    - Timings of referrals
    - Patient’s type of treatment

Results – disparity between Trusts

- C2 explains that “most of the time I think that we would realistically need IMCA is when you are actually considering limiting or withdrawing treatment”.
- C2 goes on to say “treatment withdrawal is actually changing. The do not resuscitate order and do not escalate decision order which are often preludes to withdrawal of treatment, then it would be appropriate to involve an IMCA”
- C6 “If I’m honest with you, a few weeks of court judgments have made end of life decision making tricky”.
- IMCA 4 says that they are “instructed early because there hasn’t been a decision yet”.
- IMCA 3 says “..the team here is quite good [..] they see the value of having the safeguard for the person”.

Results – Role of the IMCA

- Some clarity about when to instruct IMCA, some confusion about what IMCA’s do.
- C2: IMCAs “make a neutral decision”.
- IMCA4: “people can be quite confused by what our role is and think we come along to make a decision, which is obviously not true”.
- Confusion about IMCA as capacity assessor or mediator
- All the IMCAs spoke about the importance of ascertaining the person’s past/present views – in contrast to some clinicians expressing involving IMCA so “that we’ve gone through due process” (C2)
- C6: “to do as much research as he or she can and do the best to provide a voice on behalf of the patient when there isn’t a friend or relative available.”

Results – IMCA clinic

- We asked participants what they thought of the idea of an IMCA ‘clinic’.
- The relatives, once informed about the role of advocacy, thought it would be useful to have access to an IMCA.
- Clinicians were on the whole positive “Yes I do actually; I do think there is something in that. I think we have something to learn from IMCAs […] I also think that IMCAs would benefit from collaborating with us to have a better understanding as what we want as well”. (C6)
- Clinicians generally raised challenges about relationships between staff and families.
- C3 thought IMCA may become “ a tool for angry families”.
- All the IMCAs interviewed felt it was a good idea in principle, but had understandable concerns over resources and commissioning of services.
- Families did not propose any challenges.

Results – Communication

- R1 “I was sitting there waiting and hoping for someone to come and explain”
- R3 “they weren’t giving me the full information [..]we had to ask all the questions”
- R4 “ I still found it hard sometimes to get the information […] some nurses would give it to me and some wouldn’t”
- R4 “there were times when I asked to see one of the consultants […] its was quite difficult […] there didn’t seem to be anyone that could give a complete overview”

Results – Communication

- R1 “and people are so busy you don’t like to interrupt what they’re doing”
- R2 “we would have like to have spoken to the doctor, as such, we realised that that was a very busy unit, you know, resources are probably stretched”
- R4 “they’re so busy, they’re doing surgery, I know. They clinics and they’re dealing with people that are due on the surgical list. It’s just the way it is”
- R1 “the nurses who were far too busy to bother about a whingeing relative”

Results – Communication

- R1 “he spoke to J the whole time”
- R2 “the nurses, they, you know, responded to our questions […] I think we found out more from them, than pretty much anyone else”
- R3 “we got a bit more information from the ICU nurses”
- R4 “some nurses would give it to me (information) and some wouldn’t, which I think is very hard, and was very hard”

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Conclusion

- Basic understanding of MCA
- IMCA referrals good in one trust but poor in another
- Communication issues with relatives unsatisfactory
- Advocacy an option in critical care
- Small scale study

Recommendations

- Critical care environments should have readily accessible information about how to contact the local IMCA service.
- All clinicians should have knowledge about the circumstances in which referral to IMCA must be made.
- Early referrals to the IMCA service
- Regular contact between IUCs and IMCA providers to develop good working relationships.
- Updating knowledge of case law and practice issues.
- Sharing of best practice with other ICUs
- Further exploration of the advocacy role for all in ICUs
- Raising awareness of the MCA and all its components with the general public.
- House of Lords review.

  http://www.publications.parliament.uk/pa/ld201314/ldselect/ldmentalcap/139/139.pdf