EXPLAINING RENAL TREATMENT TO PEOPLE WITH LEARNING DISABILITIES

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ABSTRACT
Jenkins, J.P. et al (2008) Explaining renal treatment to people with learning disabilities. Nursing Times; 104: 44, 28–29. Patients with chronic kidney disease need to understand different treatment options if they are to make informed choices about which to accept. This article outlines the development of a booklet designed to improve information-giving to people with learning disabilities who have CKD.

INTRODUCTION
As a clinical team, we recognised there was a lack of information to inform people with learning disabilities who have chronic kidney disease (CKD) about the many treatments and interventions available. In the past we had tended to focus on relatives and carers to give information and take decisions, undermining possible patient involvement.

We wanted to improve our communication with this patient group, recognising that we could enable them to participate more fully in decision-making.

PRE-DIALYSIS EDUCATION
When glomerular filtration rate falls to around 25–30ml/minute, patients and families begin to receive pre-dialysis education. It is vital that both understand the treatment options in order to make informed choices about therapy, which can include dialysis and/or transplantation or conservative management.

People with learning disabilities may have difficulties in understanding and using information. They need specific consideration when developing CKD education to ensure it is accessible and appropriate, and enables them to make decisions.

INFORMED CONSENT
This issue has become an overarching principle in the NHS. Staff should not make assumptions about a person’s ability to give consent just because they have a learning disability. They should be empowered to participate actively in decision-making.

Healthcare staff have an ethical obligation to involve patients in a process of shared decision-making and to seek informed consent for treatments and procedures.

Those who are deemed competent to make an informed choice should be able to understand and consider information they are given. Where patients are not deemed competent to make decisions for themselves, a third party may become involved.

The Mental Capacity Act 2005 serves to protect people with learning disabilities, especially concerning informed consent.

MENTAL CAPACITY ACT
The Mental Capacity Act gives people with learning disabilities the legal right to be involved in any decision-making that affects their lives. It also recognises they may require support to make decisions.

The act also includes provision to protect those who lack capacity, when the use of ‘best interests’ applies. It outlines how ‘best interests’ decisions should be made and sets out a duty to ‘do whatever is possible’ to permit and encourage people to take part in decision-making (DH, 2008). ‘Best interests’ requires the decision-maker to consider the best course of action for a person. It considers both their current and future interests, weighs them up and decides which course of action is, on balance, the best for them (Joyce, 2007).

The independent mental capacity advocate service provides statutory advocacy that is independent of the NHS (DH, 2007). It is important that healthcare teams know about this service. A person is assessed as lacking the ability to make a decision and in need of an independent mental capacity advocate if they cannot satisfy one or more specific criteria (DH, 2007). These are the ability to:

- Understand information given to them about the decision;
- Retain the information long enough to make a decision;
- Use or weigh up the information as part of the decision-making process;
- Communicate their decision (by any means such as talking, sign language or blinking).

IMPLICATIONS FOR PRACTICE
- This initiative provides an example of good practice in terms of teamwork and collaboration across professional boundaries to develop a resource for use with people who have learning disabilities.
- This approach to patient education can be easily transferred to other areas, for example to primary care for consultations with GPs and practice nurses.
- We would encourage nurses in all spheres of practice to examine the need for such educational tools and to work with specialist learning disability services and clients to formulate learning resources.

PRE-DIALYSIS EDUCATION
We reviewed the education programme for patients with CKD. It was clear the patient case-mix was changing, with increasing numbers of groups, such as older patients, black and minority ethnic groups and those with learning disabilities, all of whom need different types and complexity of information.

We recognised it was difficult to deliver meaningful education to patients with learning disabilities as many were unable to read or comprehend existing written
BACKGROUND

• People with learning disabilities are much more likely than the general population to have significant health risks and major health problems (Disability Rights Commission, 2006). It is often harder for them to access assessment and treatment (Michael, 2008).
• As a result, more have complex health needs and are at an increased risk of developing age-related health problems such as CKD (Barr, 2004).
• Adjustments are not always made to allow for communication problems, cognitive impairment or anxieties and preferences concerning treatment (Michael, 2008). This group will often need more support to understand information and to communicate concerns.

Service users’ views were also obtained to identify the best pictorial representation of symptoms. For example, they were shown a selection of pictures to represent a person feeling tired and asked to choose the one that best represented this to them. Often their choice was completely different from the expectation of the clinical nurse specialist who had designed the booklet, which shows why service user input is important. The group reviewed the revised booklet, and approved changes for the final version.

The booklet’s contents incorporate a pictorial guide which describes:
• Functions of the kidneys;
• Symptoms related to CKD;
• Treatments available – haemodialysis, peritoneal dialysis, transplantation and conservative management;
• Symptoms and treatment of renal anaemia.

OUTCOMES

The booklet has been piloted as one of a range of teaching resources used by the pre-dialysis team and has made it much easier to provide information to patients with learning disabilities. It can also be used with others with communication difficulties.

The team has gained satisfaction from being able to involve patients directly in education. So far, feedback from patients about the booklet’s usefulness has been informal and based only on the subjective view of the nurse providing the information. Nevertheless, it was noted that patients particularly appreciated being included in the education process and they seemed to be able to gain some understanding of how CKD was already affecting the way they were feeling or may do in future. Our goal is to develop a questionnaire specifically designed for this group to enable them to give effective feedback about the booklet.

CONCLUSION

Empowering patients with learning disabilities with information may help to ensure that they fully collaborate in important treatment decisions at all stages and so improve their opportunities for better health. This project has gone some way towards enabling us to provide an inclusive pre-dialysis service to this group. Involving service users and the multidisciplinary team has greatly contributed to the project’s success, and the benefits gained from their assistance cannot be overstated.

REFERENCES


