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Improving Practice in Supported Decision-Making and Mental Capacity Assessment

An Ethical Imperative for Speech and Language Therapists

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Abstract

Current models of evidence-based practice are predicated on the inclusion of patients/service users in decisions about their healthcare. In the United Kingdom (UK), healthcare policy and legislation require practitioners to provide support with decision-making and, if necessary, complete mental capacity assessments to identify if service users can make informed decisions. People with communication disabilities may have difficulties understanding, thinking and talking about decisions and may require communication support. In this paper, I discuss the current challenges associated with mental capacity assessment and supported decision-making. I propose that healthcare professionals should look beyond legal and policy imperatives to consider the ethical foundations for their practice, when they face such challenges. I compare two conceptual approaches to ethical reasoning. I describe a practical solution to the clinical challenge: the development of the MCAST, a toolkit to support multidisciplinary staff to assess mental capacity and provide support to service users with communication disabilities during the decision-making process.

Keywords

Evidence-based practice, Decision-making, Mental capacity assessment, Speech and Language Therapy.

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Patient involvement in decision-making: ethical, clinical, political and legal imperatives

Autonomy, or the right to self-determination, is central to most Western ethical traditions in healthcare (Beauchamp & Childress, 2008; McLean & Mason, 2003; Seedhouse, 2009). Respect for patient autonomy includes the requirement to establish informed consent before any healthcare intervention and the need to provide opportunities for patients¹ to be involved in decisions about their treatment and care. These decisions might involve choosing between different treatment options (e.g., surgery versus drug treatment) or whether to enter a residential care facility or return to one's own home on leaving hospital. Service user involvement in decision-making is integral to the provision of «patient-centred care», which has been promoted in Western healthcare for over 30 years (Elwyn et al., 2012). According to this approach, decisions about medical treatment options and other aspects of care should be based on patients' individual needs, preferences and values, as well as evidence about the relative risks and benefits of different decision options and practical aspects of resource availability (e.g., clinician expertise, specialist equipment).

In the UK, government policy actively promotes the involvement of service users in decision-making in the National Health Service (NHS) (e.g., Department of Health, 2012). To enable greater service user involvement in healthcare processes, UK policy also requires provider organizations to make healthcare information more accessible to service users, based on their individual communication needs (NHS England, 2015). The «shared decision-making» model, which proposes active partnership between professionals and service users in healthcare decisions, has been recognised internationally for its potential to engage people in the management of their health conditions (Hoffman et al., 2014). Patient involvement in decision-making has been associated with increased satisfaction with services, improved adherence to treatment regimes, superior health outcomes and reduced health costs (Bunn et al., 2018; Lai & Karlawish, 2008). Therefore, this approach to patient care has the potential to lead to better clinical outcomes for patients and efficiency benefits for service providers.

In different jurisdictions throughout the world, legal frameworks also promote the involvement of service users in decision-making (e.g., Carling-Rowland, Black, McDonald & Kagar, 2014). In England and Wales, the Mental Capacity Act (OPSI, 2005) is designed to protect the decision-making rights of three different groups of people:

¹ The terms «patient» and «service user» are used in this paper to mean a person in receipt of healthcare services.

- those who are capable of making an autonomous decision (they have intact mental capacity) but need to be given the opportunity to do so;
- those who require support to make a decision (e.g., communication support) and need to be offered that support;
- those who cannot make a decision for themselves even with support (they lack mental capacity) and need others to represent their preferences and wishes when making decisions on their behalf, in their best interests.

The Mental Capacity Act (2005) requires healthcare professionals to complete a mental capacity assessment if they have reason to believe an individual over the age of 16 may have difficulty making a specific decision at a specific time. A mental capacity assessment involves checking if a service user can make the decision autonomously, needs support to make it (so called «supported decision-making»), or is unable to make it even with support. The assessment requires healthcare professionals to complete a functional test of an individual’s decision-making abilities, usually during a clinical interview. The following decision-making abilities need to be investigated during the assessment: the ability to understand, retain, use or weigh information about the decision and to communicate the choice the individual wishes to make. If an individual is unable to make a decision, the law describes a process whereby other people can make it in her/his best interests (so called «substituted decision-making»).

Current challenges associated with supported decision-making and mental capacity assessment

Supporting people to make decisions and assessing mental capacity present a number of inter-related challenges to service providers and individual practitioners.² First, incapacity is relatively common and large numbers of service users are likely to require support with decision-making and mental capacity assessment. A recent review paper estimated that 34% of medical inpatients lacked mental capacity to make decisions about their treatment (Lepping, Stanly & Turner, 2015). Thus, mental capacity assessment and actions to support decision-making are becoming increasingly common clinical tasks in the UK and in other jurisdictions with similar legal frameworks (e.g., Aldous, Tolmie, Worrall & Ferguson, 2014). The number of people requiring this type of support is likely to rise due to demographic changes (Moye & Marson, 2007). This creates challenges in terms of the staffing resources required to meet this demand.

² The term «practitioner» is used to mean a professional providing healthcare.

Second, the quality of current practice needs to be improved. Commentators have identified that the use of authentic shared decision-making within modern healthcare remains limited, because clinicians may fail to adapt evidence about the risks and benefits of different treatment options to the needs and situations of individual patients (Greenhalgh, Howick & Maskrey, 2014). These authors argue that in order to provide truly evidence-based, ethical patient care, clinicians need to engage service users in meaningful conversations about healthcare decisions and ensure that the information they provide to individuals about their treatment and care is personalized and accessible. Furthermore, evidence from a parliamentary enquiry (House of Lords, 2014) indicates that the quality of mental capacity assessment practice in the UK is also low and needs to be improved. Many practitioners appear to lack awareness of their legal obligations under the Mental Capacity Act. As a result, they may not offer patients support with decision-making or complete mental capacity assessments when these are indicated or they may make inaccurate judgements about mental capacity on the basis of incorrect or irrelevant information.

This inferior practice may be related to prevailing paternalistic organizational cultures and individual professional attitudes towards service user autonomy, which mean that support with decision-making is still not always identified as necessary, or made available to patients (Jayes, Palmer & Enderby, 2016). These cultures and attitudes may result from, or operate in combination with, practitioners' lack of understanding of legal requirements or the fact that they may not know how to operationalize the law or implement clinical guidelines. This type of clinical work is complex and relies on subjective judgements (Ripley, Jones & Macdonald, 2008). There is currently no gold standard way to complete a mental capacity assessment and there are no evidence-based tools for practitioners to use to improve the quality and reliability of their assessments (NICE, 2018).

Mental capacity assessment becomes even more challenging when it involves people with communication disabilities. A communication disability may impact directly on specific decision-making abilities: a person who has receptive language difficulties (e.g., due to aphasia) may find it more difficult to understand information about decision options; someone with expressive language difficulties or a motor speech disorder may struggle to express their opinions or ask questions about options (Carling-Rowland & Wahl, 2010). Furthermore, a communication disability can mask decision-making abilities, making capacity assessment for this patient group more complex (Ferguson, Duffield & Worrall, 2010). Practitioners without specialist skills in completing communication assessments may make assumptions about a person's mental capacity based on inaccurate perceptions about her/his communication skills or may conflate communication impairment with decision-making incapacity.

For example, a practitioner may erroneously assume that a patient with an expressive language or motor speech disorder is unable to make a decision, either because the practitioner cannot understand the patient or because s/he assumes the patient cannot understand her/him (Stein & Brady Wagner, 2006). Another practitioner may base a judgement about mental capacity on an under- or over- estimation of a patient's ability to understand language, due to inaccurate assessment of language skills (Savage, 2006). These factors mean that there is an increased risk that people with communication disabilities may be deprived of opportunities to engage in autonomous or supported decision-making (when practitioners incorrectly assume they lack capacity), or conversely, that they may be asked to make uninformed decisions (when practitioners wrongly conclude they have intact capacity) (Ferguson, Duffield & Worrall, 2010).

When communication difficulties are identified accurately, the Mental Capacity Act requires practitioners to offer service users support to make decisions, including support to understand information and express their preferences and choices. This includes the provision of information that is adapted to make it more accessible to people with comprehension difficulties and the use of augmentative and alternative communication methods (AAC) for those with expressive language or speech difficulties. Again, non-specialists may find it difficult to use these methods (Jayes & Palmer, 2014). As specialists in communication assessment and support, speech and language therapists are uniquely placed to support decision-making, mental capacity assessment and communication access for patients with communication needs (Suleman & Kim, 2015; Zuscak, Pesiah & Ferguson, 2015). However, although speech and language therapists are involved in this area of practice, their role as facilitators of mental capacity assessments and as actual capacity assessors is still poorly understood and is sometimes not recognized by other professional disciplines (Jayes, Palmer & Enderby, 2016; McCormick, Bose & Marinis, 2017).

In settings where their role is recognized and valued, speech and language therapists may find it challenging to provide this support, because they have limited staffing resources. Speech and language therapy services operate with finite resources and need to provide services to a range of clients with both communication and swallowing disorders (dysphagia). Within SLT provision for adults in acute hospital settings, there appears to be a current focus within clinical service delivery on dysphagia (based on anecdotal evidence in the UK, but published research in Australia by Foster, O'Halloran, Rose & Worrall, 2016). If speech and language therapists do not offer this support, there is a risk that service users will not receive the personalized, specialist support they need; there is a further risk that the professional identity of speech and language therapists as experts in communication disorders will be eroded and the discipline's status in multidisciplinary teams weakened. This presents an important ethical challenge to the profession.

Meeting the challenge: the benefits of ethical reasoning

The above discussion illustrates that delivering supported decision-making and robust mental capacity assessment presents both practical and ethical challenges. To meet these challenges, healthcare service providers and practitioners may benefit from re-considering the ethical foundations of their practice.

Various conceptual approaches can be used to guide ethical reasoning and practice. A dominant tradition in Western healthcare ethics, *Principlism*, involves the use of bioethical principles to inform ethical reasoning. Important advocates of this approach are the North American medical ethicists Beauchamp and Childress, whose book *Principles of biomedical ethics* (2008) has been very influential. These authors propose four main bioethical principles, which they argue can be used to guide clinical thinking and practice. The first principle is autonomy, which as previously described, relates to a patient's right to make her/his own decisions and the practitioner's obligation to obtain informed consent; it also places an obligation on practitioners to tell the truth, keep promises and maintain patient confidentiality. The second principle, *non-maleficence*, requires practitioners not to do or risk harm to patients. Related to this, the third principle *beneficence*, requires practitioners to do good to patients and to ensure that the benefits of interventions outweigh the risks. Finally, *justice* refers to the need to ensure equal access to healthcare resources for all patients.

Bioethical principles have been used to form the basis for many speech and language therapy professional codes of ethics or deontological codes, including those of the Royal College of Speech and Language Therapists (RCSLT) in the UK and the Federazione Logopedisti Italiani (FLI) in Italy. This explains why many speech and language therapy ethical codes across different countries tend to include similar content (Stacey-Knight & Mayo, 2015). These professional ethical codes tend to be aspirational and used for regulatory purposes. Practitioners may experience difficulty in interpreting or operationalizing their content, due to the nature of the principles upon which they are based.

Acknowledged limitations of bioethical principles are that they are too general, are decontextualised and can often conflict or compete with each other; practitioners need to be able to choose between them, but Principlism does not provide a mechanism to facilitate this (Gillon, 1994; Westin & Nilstun, 2006). As a result, bioethical principles lend themselves more to abstract ethical thinking and their use may not easily support practitioners to find practical solutions to real world ethical dilemmas or challenges (Page, 2012).

The provision of speech and language therapy support for decision-making and mental capacity assessment represents such a real world dilemma. The use of speech and language therapy resources to improve support for people with communication disability during mental capacity assessments would help service providers

to uphold the principle of autonomy. However, allocation of limited resources to this area of practice might mean that resources would need to be transferred from a different area of practice, for example care for people living with dysphagia. As a result, service providers would not be able to uphold the principle of justice (equal distribution of resources) and might not be able to ensure the resulting practice was beneficent and non-maleficent (because those with dysphagia might be put at risk due to a reduction in the amount of care they received).

An alternative approach to ethical reasoning has been proposed by the philosopher David Seedhouse. This approach invites practitioners to reconsider the very purpose of healthcare. In his book *Health: The foundations for achievement* (2001), Seedhouse argues that health is not simply the absence of disease but the ability to achieve one's human potential. He proposes four foundations that are essential to this definition of health: basic needs (e.g., food and shelter), access to information, the ability to understand and use information, and support from others. Clearly, these proposed foundations are consistent with the aspirations of supported decision-making and mental capacity assessment. In *Ethics: The heart of healthcare* (2009), Seedhouse proposes that healthcare is ultimately a moral activity; he argues that ethics is subjective and personal and cannot be reduced to objective principles. According to Seedhouse, to practise ethically, practitioners need to reflect deliberately on their actions and goals, and what they are attempting to achieve in healthcare; they need to make a commitment to thinking about the purpose of their practice.

This approach promotes a more concrete type of ethical thinking than Principlism, and proposes practical tools that practitioners can use to help them reflect ethically about their daily work. One of these tools is the Ethical Grid (Seedhouse, 2009, pp. 142-174), which can be used by practitioners to help them to explore the ethical considerations associated with any healthcare decision or challenge. Seedhouse suggests the Ethical Grid can be used as a structure for personal or group reflection, for example during team meetings or case discussions. The grid includes four different layers containing different boxes with written labels; these labels correspond to the different aspects of an ethical dilemma that need to be considered. The layers relate to the core foundations for health (including the creation and respect for autonomy), to practitioners' professional duties (similar in content to the bioethical principles discussed above), to the outcomes of healthcare interventions (the relative benefits for different groups of people), and also to external considerations (e.g., legal constraints and resource availability). Exploration of the different boxes across the layers is designed to prompt more comprehensive reflection about a dilemma than use of bioethical principles alone. Thus, in respect to supported decision-making and mental capacity assessment, this approach has the potential to support practitioners to reflect

on the complex, multifaceted nature of this area of practice when attempting to solve the ethical dilemma.

A solution to the clinical and ethical challenge: The *Mental Capacity Assessment Support Toolkit* (MCAST)

As part of a research fellowship funded by the National Institute for Health Research (NIHR), I developed a practical solution to this clinical and ethical challenge, a toolkit designed to facilitate mental capacity assessment and supported decision-making and enable the multidisciplinary team to improve their practice, particularly when working with people with communication disability. I developed the *Mental Capacity Assessment Support Toolkit* (MCAST) in partnership with multiple stakeholders: health and social care practitioners; experts in mental capacity assessment, communication assessment and tool design; service users with communication difficulties secondary to stroke and dementia and their family members.

This multidisciplinary project employed a user-centered design methodology. User-centered design places the users of novel healthcare products and services at the heart of the design process (Rekha Devi, Sen & Hemachandran, 2012). The design specification for the toolkit was based on a review of existing research evidence and case law (Jayes, Palmer & Enderby, submitted) and on data collected during interviews with practitioners who carry out mental capacity assessments (Jayes, Palmer & Enderby, 2016). The practitioner, expert and service user groups were invited to review the initial iterations of the toolkit components. Their feedback was used to improve the design. This iterative cycle continued until a prototype toolkit was suitable for feasibility testing in clinical practice.

The MCAST includes three main components:

1. a Support Tool, which helps practitioners to prepare, complete and document any mental capacity assessment;
2. a Communication Screening Tool, which a practitioner from any discipline can use to identify if a service user has a communication support need and how to address that need (whether to refer to speech and language therapy or use simple strategies and resources to support the person to understand and talk about the decision);
3. a Resource Pack of accessible information resources, that can be used to help staff to talk to service users about decisions relating to leaving hospital, dysphagia, or medical procedures.

The toolkit is designed to promote person-centered care, by increasing practitioners' awareness of the right of service users to make decisions and to receive support to do this. Therefore, it is hoped that its use may help to change paternalistic

attitudes to decision-making and bring about cultural change. By providing methods to enable non-speech and language therapists to identify and support service users with communication needs and understand the role of the speech and language therapist better, the MCAST aims to propose a practical solution to the challenge of competing demands on limited speech and language therapy resources. The MCAST was evaluated positively during initial feasibility testing and its design is being finalized in order to support its further evaluation and implementation.

Conclusions

This paper has discussed the challenges associated with supported decision-making and mental capacity assessment. Many Western healthcare systems promote active patient involvement in decision-making and patient-centered care as fundamental to ethical and effective service delivery. However, issues arising from the complexity of this clinical activity, the inferior quality of current practice, cultural and attitudinal factors and resource limitations mean that service users are not always offered opportunities or support to make decisions. Patients with communication disabilities need support to engage in decision-making and speech and language therapists are uniquely placed to provide this support.

Speech and language therapists may find themselves facing an ethical dilemma when attempting to provide such support using limited resources. Engagement with ethical reasoning can help practitioners to reflect on this area of practice and to identify ways to meet these challenges. More practical approaches to ethical reasoning, like those proposed by David Seedhouse, may be particularly beneficial. Ethical reasoning might be especially useful at times when resources are limited and clinical priorities change, for example during periods of financial austerity. The MCAST was developed in the UK as a practical, resource-smart solution to this particular ethical dilemma. The toolkit has the potential to both facilitate and improve practice and to provide greater access to decision-making for people with communication disability.

Migliorare la pratica nel supporto al processo decisionale e nella valutazione delle capacità cognitive. Un imperativo etico per i logopedisti

Sommario

Gli attuali modelli di pratica basata sulle evidenze si fondano sul coinvolgimento di pazienti/utenti nelle decisioni che riguardano la loro assistenza sanitaria. Nel Regno Unito (UK), i regolamenti e la legislazione inerenti all'assistenza sanitaria richiedono al personale sanitario di fornire supporto al processo decisionale e, se necessario, di effettuare una valutazione delle capacità cognitive per verificare che gli utenti siano in grado di prendere decisioni informate. Le persone con disabilità comunicative possono avere delle difficoltà a comprendere, a pensare e a parlare delle decisioni e possono avere bisogno di supporto comunicativo. In questo articolo, vengono discusse le attuali sfide associate alla valutazione delle capacità cognitive e al processo decisionale supportato. Si suggerisce che i professionisti dell'assistenza sanitaria dovrebbero guardare al di là degli imperativi legali e procedurali per considerare le fondamentali etiche della propria pratica, quando affrontano queste sfide. Sono messi a confronto due approcci concettuali al ragionamento etico e si descrive una soluzione pratica alla sfida clinica: lo sviluppo del MCAST, un kit di strumenti per supportare staff multidisciplinari nella valutazione delle capacità cognitive e per fornire supporto agli utenti con disabilità cognitive durante il processo decisionale.

Parole chiave

Pratica basata sulle evidenze, Processo decisionale, Valutazione delle capacità cognitive, MCAST, Logopedia.

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