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Capacity and coercion: dilemmas in the discharge of older people with dementia from general hospital settings

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Abstract

Discharge planning of older people with dementia can present difficult ethical dilemmas to the general hospital clinician. These difficulties may be particularly pronounced for those who are moderately severely affected and for whom hazards are anticipated on discharge home. In many cases the wishes of the individual to return home may differ markedly from those of

health care professionals, carers or relatives. In order to reduce these tensions and preserve the choice of the individual as far as possible, we try to put into context a number of different issues. We discuss some of the misconceptions regarding the legal powers available in these situations, the limited and sometimes confusing issue of capacity and the role of Community Mental Health Teams in preserving autonomy and independence of older people with dementia in their own homes.

Keywords: *dementia, capacity, Mental Health Act, guardianship, elderly*

Introduction

The general hospital care of older people with dementia frequently presents difficult ethical problems. Society in general promotes the importance of individual autonomy and self-determination [1], therefore the decision-making capacities of older people, including those with cognitive deficits, must be respected for as long as possible. However, care systems also have a responsibility to protect impaired older people from risks in the event of deterioration in both decision-making capacity (see below) and functional abilities. This tension between autonomy and protection can be particularly marked in the case of older people with dementia when planning discharge from general hospital settings. There is frequently a difference of opinion between an individual and professionals, relatives or carers about the appropriateness of returning home. This conflict may create pressures to direct unwilling individuals to permanent care and questions may then be raised as to the mental capacity of the individual. It is therefore vitally important that any decision with respect to future care needs be based on ethics not expediency.

Assessment of capacity, in the main, is straightforward and a generic skill that should be acquired by workers in disciplines outside of medicine including, for instance, social workers. Capacity assessments occur routinely in many hospital settings, frequently without involvement of psychiatric services. There are, however, particular circumstances when capacity assessments in older people are not clear-cut. Difficulties arise in situations where there is a delicate balance of risks and benefits, for instance in coming to a decision on major surgical procedures or, more frequently, in matters that may have an impact on an individual's quality of life. These issues present particular challenges in patients who fall into the 'grey' range of moderate dementia. This group encompasses a very wide range of ability and disability and Old Age Psychiatrists are often called to arbitrate.

In our experience of over 2,000 referrals to a dedicated Old Age Liaison Psychiatry Service over a 4-year period, approximately 20% have encompassed some aspect of capacity ascertainment, often specifically concerning the competency of an individual to make an informed decision regarding return to their own home. It is noteworthy, however, that regional practice in this respect may vary; two previous studies report that requests for decisions regarding capacity are either uncommon [2] or are not made [3]. In our experience, hospital staff sometimes fail to differentiate between a person's *capacity* and *capability*, and the complexities of capacity judgement in this situation form only one aspect of the decision-making process. The rights of the individual to express a choice regarding their care should be considered in the light of a number of observations. These may include the severity of dementia, the presence of functional mental illness, the individual's physical state, their functional abilities, the availability of community resources as well as statutory considerations such as guardianship.

The purpose of this article is to discuss some of the practical issues and difficulties in the discharge planning of individuals with dementia, particularly where disagreement arises. Given the misunderstanding of some of the processes involved we outline some aspects of assessment of capacity as well as the limitations of legal powers. Many departments within general hospitals will have little experience of the functioning of community psychiatric resources in supporting older people suffering from dementia. Therefore we discuss how psychiatric services, where available, may interface with general hospital departments to preserve personal choice so far as is realistic and support people in their own homes.

Assessment of capacity

There are no rigid criteria, tests or rating scales that indicate whether a patient is competent or incompetent for all legal purposes. The level of capacity is a judgement that must be made in relation to whatever activity that individual is wishing to carry out or undergo. A person may be considered to be incapable of making a decision if they are unable to understand, retain or use relevant information in decision-making or communicate effectively, by whatever means. However, presumption of capacity must be the starting point of any assessment and ultimately it is the courts that decide whether an individual lacks capacity.

Physician judgement continues to be the clinical standard for determining an individual's competency. However, this type of assessment is frequently subjective, inconsistent, and an arguably idiosyncratic process [4]. There is a danger that assessment may reflect more about the physician's disposition than the patient's status and care must be taken not to underestimate the capacity of a patient in order to achieve what the doctor believes to be in the person's best interests. It must also be recognised that capacitous patients have the right to make decisions that may not be in their best interests, and clinicians have no right to impose their value systems on others. This can go against the grain; clinicians are used to helping people and it can be difficult for them to manage people who do not appear to want to help themselves.

Accurate assessment requires knowledge of the person, their social situation and cultural values, and should be

based on more than a brief interview. In practice, when reconciling the principles of autonomy and beneficence a balance must be struck between applying an inflexible standard of proof and any indication of a preference however derived. The reader is referred to the British Medical Association and Law Society report on 'Assessment of Mental Capacity' [5] for further details of definitions and assessment of capacity.

In situations where capacity is not clear-cut, complex and challenging decisions may arise, which should ideally be made in the light of a multidisciplinary assessment and after consultation with next-of-kin or carers. Disagreements may occur, and anyone assessing capacity needs to be mindful of any conflict of interests. The general practitioner may actually be the professional best suited to assess an individual's capacity although a psychiatric opinion may be more helpful in complex situations. For instance, where there is a high degree of perceived risk or where there is a comorbid functional mental illness. Practically, when deciding whether someone is capable of making an appropriate decision about their future care, account must be made of the individual's insight and awareness of their care needs as well as their willingness to accept support in the light of these. Decisions regarding the appropriateness of guardianship may be influenced by these observations.

Legal powers

Guardianship is discussed at this point since the use of the Mental Health Act (MHA) 1983 [6] to facilitate patient placement is frequently misunderstood or overemphasised. It is noteworthy that issues regarding guardianship will ultimately be replaced by the provisions within the Draft Mental Incapacity Bill discussed below (view at www.lcd.gov.uk/menincap/legis.htm). Carers (and sometimes clinicians) often assume that psychiatrists have powers to remove individuals and deposit them wherever is felt to be appropriate under some type of legal aegis, whenever a degree of individual risk is evident. However, the purpose of Guardianship (section 7 MHA) 'is to enable patients to receive care in the community where it cannot be provided without the use of compulsory powers' [7] and to provide a limited form of personal control in order to help improve the welfare of the patient. Guardianship was originally intended to be the community care equivalent of compulsory admission. The grounds and procedures are quite similar and in general should be used to facilitate a comprehensive package of care. In the case of civil guardianship the application is made by an approved social worker or nearest relative and founded on the recommendations of two doctors who provide a clinical description of the patient's mental condition and explain why he or she cannot be cared for without the powers of guardianship. The implication is that the order is something to be avoided unless it is clear that the patient will not accept care without it. The proposed guardian may be any social services authority or a private individual.

The Mental Health Act specifies three powers to the guardian: (i) to require the patient to reside at a specific place; (ii) to require the patient to attend at specified places for medical treatment, occupation or training (without the authority to use force to secure such attendance); and (iii) to require access to the patient at their place of dwelling to any doctor, social worker or other specified person [7]. Guardianship, itself, lasts initially for 6 months but may then be renewed for a further 6 months and then a year at a time. The responsible medical officer (RMO) (or nominated deputy) must examine the patient within the last 2 months of the period and report to the guardian and social services if the grounds for guardianship remain. The RMO may also discharge the patient at any time.

A 'Guardianship panel', often comprising senior social workers in a locality, with a power to veto the submission, reviews applications for guardianship. Thus, realistically, for an application to proceed there has to be no viable alternative other than detention under the Mental Health Act. Therefore, institution of, or modification to a social care package with increased community supervision should be pursued if at all viable. In practice there is marked regional variation in the application of Guardianship [8] and it is uncommonly used in the context of imposing permanent placement from general hospitals. However, in one series elderly female patients with organic brain diseases were the group most likely to be subject to the order, mostly to facilitate community care or admission to residential care [9]. Although Guardianship has a number of drawbacks and in certain instances may be rendered 'toothless', there are some cases where its application may be considered appropriate.

The Draft Mental Incapacity Bill was published in June 2003 in order to clarify some of the uncertainties in decision-making and provide safeguards for adults who have lost capacity by way, for instance, of dementia. The bill will replace the powers invested in section 7 of the Mental Health Act and those in the Enduring Power of Attorney Act. The document emphasises that capacity should be decision specific and retains the principle of acting in an individual's 'best interests'. Clause 6 of the bill provides for a 'general authority' which empowers carers, professional or informal, with the legal powers to offer basic care and facilitate services where there is no explicit consent by virtue of incapacity. Clause 8 defines the powers of the Lasting Power of Attorney (LPA). This authorises the LPA to make decisions that govern an individual's personal welfare. How this legislation will affect discharge planning or requests for capacity assessment is not clear. It is, however, worth bearing in mind that there are potential dangers inherent in this as the appointment of an LPA may paradoxically result in the limitation of personal choice, perhaps even with best intentions, for instance, in guiding individuals prematurely to permanent care where alternatives could possibly be pursued.

The role of psychiatric services

There are a number of different models of multidisciplinary community team working and a detailed discussion of these is beyond the scope of this discussion. Generic community mental health teams (CMHTs) remain a prevailing model of psychiatric practice, and reference is made to them, although

we acknowledge that different localities may operate in different ways. Psychiatric services have three main roles to play in the assessment of capacity. The first is to educate other professionals in the essentials of capacity assessment, in order that clinicians are able to assess capacity in straightforward cases; secondly, to provide specialist input in more complex cases; and finally to provide information on the range of services available to support older people with dementia, so that the degree of risk is accurately understood by staff involved in discharge planning.

Those who represent an intermediate risk pose the greatest dilemmas when planning discharge from a general hospital. They are more likely to be of advanced age, have some physical dependency, moderate cognitive impairment, variable powers of communication, patchy competency, and some behavioural or psychiatric manifestations of dementia such as wandering or psychotic symptoms. They frequently express the wish to return home but often have no insight into their level of dependency and there may be varying concerns regarding safety in the home. For these people, a general hospital admission can be the determining event that precipitates the decision to make plans for permanent care, but if general hospital staff have better knowledge of community services they may be more prepared to discharge home even where there is a significant element of risk.

Psychiatric assessment is often useful in these situations. Expert psychiatric knowledge can help to ameliorate specific problem behaviours that may confound discharge, as well as providing information on the available community resources and whether discharge is tenable in the presence of appreciable risks. In addition, a specific behavioural difficulty may be improved by a period of in-patient assessment in an acute psychiatric facility or through access to Intermediate Care beds and facilities. This input is facilitated by the establishment of general hospital-based liaison psychiatry services for older people, which provide a prompt assessment service together with educational programmes for general hospital staff [10]. Where such services exist, the core skills of general hospital staff in the management of common psychiatric conditions are improved. Unfortunately, liaison psychiatry services for older people are far from universal, meaning that many general hospitals struggle with these core competencies [10].

If individuals with dementia wish to stay in their own homes then this ought to be considered as a serious option. Assessment of a person's needs and how they may be met must be holistic and ongoing, producing a flexible care package that mitigates for as many of the risks as possible. In a proportion of 'grey' cases a pragmatic course of action may be to attempt discharge with a comprehensive social care package and, where possible, adequate community observation from the community teams. Relatives and carers of people with dementia may have understandable and overwhelming concerns, and close attention needs to be paid to these anxieties, with discharge home requiring careful negotiation.

Involvement of psychiatric services in the form of CMHTs together with liaison psychiatry services, where they exist, can facilitate the successful return of a person with moderate dementia to their own home. Contact should be made early, as the psychiatric teams may already have close involvement. Psychiatric services work in conjunction with other agencies to support people with dementia and their carers and should dovetail with initiatives such as intermediate care and joint care management. CMHT members are experienced in monitoring mental state and cognition and may predict and manage behavioural or other problems. They may also facilitate appropriate respite and hospital admissions, or permanent placement should this be indicated. Supervision from the CMHT should be appropriate to the needs of the person with dementia or their carers. This may range from regular visits or telephone contact to more intense nursing and therapy at home or in a psychiatric day hospital, and may be a means of introducing the concept of a social care package where this is initially refused.

Discharge planning must, of course, include other health and social care professionals before the day of discharge and the day set for discharge must take account of community services available. Good communication between members of the teams involved, including local community resources, may be critical in ensuring successful discharge. Inevitably there will be instances when there is no alternative other than transfer to permanent care. On these occasions the input of the psychiatric teams may be useful in the choice of facility, whether specialised or otherwise, as well as the utility of provisions under the Mental Health Act.

Clearly, not all localities have highly developed or responsive psychiatric services for older people; however, the principles and the mindset of promoting choice and (managed) risk taking in order to uphold this should be the same. Even without direct support of psychiatric teams we would advocate a rapid transfer home when this is requested and at all feasible, with a robust care package and increased surveillance from primary care professionals and social services.

Conclusions

In planning discharge of people with dementia, the most difficult dilemmas frequently relate to those who suffer from a moderate degree of dementia. Careful planning with seamless discharge arrangements as well as offering imaginative schemes for ensuring older people are adequately prepared for at home may be effective in preventing readmission and help preserve an individual's autonomy and independence. Guardianship under the Mental Health Act, where appropriate, should be employed to facilitate the community care of patients and not as a means of directing unwilling individuals to institutions. Although there is a role for legal guardianship in the protection of more severely demented patients, or in those with complex mental heath or physical needs, the application of guardianship, especially when it is unwarranted, may deprive individuals of their most basic civil liberties. In any event, the presence or absence of capacity is frequently a secondary issue and its absence should not be used as a justification for disregarding individual choice. We would advocate the participation of the older person and their families in assessment, care

planning and evaluation, and after discharge seek regular feedback on appropriateness of care. Early involvement from the community or hospital-based mental health teams is often paramount. These services may not exist, or may not provide adequate input to general hospital wards. If this is the case, commissioners and providers should work together to ensure that this important gap in service provision is filled. Consideration of individual choice, acknowledging and mitigating risk where possible with the promotion of early discharge of people with dementia when at all realistic has a number of potential benefits. Even in the presence of active hospital rehabilitation it will serve to promote personal choice and person-centred care, minimise the corrosion of functional abilities during hospital admission, reduce lengths of stay, diminish the numbers of delayed transfers of care and possibly ease the unsustainable demand for residential and nursing home placements.

Key points

- Capacity and capability should be considered when gauging suitability of home discharge.
- Legal powers are designed to facilitate community care, not to direct unwilling individuals to residential or nursing facilities.
- Psychiatric services are expert in risk management of older people with dementia and should be involved in discharge planning in complex cases.
- General hospital-based liaison psychiatry services can speed up assessment and provide education.
- General hospital staff should be prepared to take managed risks together with psychiatric colleagues.

Conflicts of interest

None.

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