

Beneficence and non-maleficence: confidentiality and carers in psychiatry

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The editorial considers how psychiatrists can deal with concerns relating to confidentiality that are prominent in patients and their carers. Confidentiality is paramount but there are situations when it can be breached. Some of these relate to emergency situations, others apply in less compelling circumstances. The ethical principles relating to confidentiality will be discussed. An assessment of capacity is central to the person's ability to consent/refuse information gathering or disclosure. Even when capacity is present, there are strategies that psychiatrists can use to respect patient autonomy while meeting the needs of carers. The possibility of training in negotiating these should be considered, as should advance directives.

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Confidentiality is central to communication between doctors and patients. The knowledge that information is not disclosed to others allows for mutual trust and facilitates the free disclosure of sensitive, personal and intimate information between doctor and patient. Yet, within the parameters of confidentiality there will be the necessity for the doctor to share information, in certain circumstances. In general, these will be other professionals directly involved in the care of the patient such as nurses, occupational therapists and so on. However, importantly, information may also have to be shared with those who are not mental health professionals, most commonly family members caring for the person.

The need to share information with carers has to be set against the hovering fear of litigation or of complaints to doctors' professional body. In addition, there are concerns that disclosing information will threaten the integrity of the doctor–patient relationship. Psychiatrists receive little training in how to navigate this hazardous border and have even less appreciation of the roles and rights of carers. This has led some to suggest that psychiatrists erect 'confidentiality smokescreens' as an excuse to avoid engagement with carers (Gray *et al.* 2008) and that confidentiality is frequently cited as a reason for not engaging with carers (Wynaden & Orb, 2005).

Family members are crucially important in their role as carers of those with mental illness and this is recognised in *A Vision for Change* (2006) where it states that family, friends, colleagues, neighbours and community members are important sources of support for service

users and have their own unique insight into mental ill health and the provision of mental health services. It make the following recommendation in chapter 3: 'Carers should be provided with practical support/ measures such as; inclusion in the care planning process with the agreement of the service user, inclusion in the discharge planning process, timely and appropriate information and education, planned respite care and should have a member of the multidisciplinary team to act as a keyworker/designated point of contact with the team and to ensure these services are provided' (Report of the Expert Group on Mental Health Policy, 2006). In spite of this recognition there is clear evidence internationally that close relatives feel unengaged and abandoned by mental health teams (McCrea *et al.* 2007) and that they have little opportunity to participate at any level in the delivery of mental health services (Lammers & Happell, 2004).

Ireland is no different from other countries in this regard. A study by Wilson *et al.* (2015) found that 56.3% of carers responding to an evaluative questionnaire stated that they have specifically encountered difficulties accessing information from the treating mental health team. The main reasons given were lack of patient consent (46.2%) and the unavailability (46.2%) of staff to do so. Translated nationally, such data suggests that a sizeable number of carers are likely to feel undervalued and excluded.

In addition to providing information to carers, information gathering is imperative in order to make a full assessment of a newly referred patient or one who is acutely ill and this is especially applicable in psychiatry.

As confidentiality must be respected, an ethical dilemma arises when a patient refuses to allow the gathering and/or sharing of relevant information

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from carers. The quandary is between beneficence (doing good by respecting the patient's wishes) and non-maleficence (doing no harm by failing to collect or disclose vital information) (Beauchamp & Childress, 2001). Part of the solution lies in the recognition that confidentiality is not absolute – this is recognised in the *Guide to Professional Conduct and Ethics for Registered Medical Practitioners* (Comhairle na nDochtúirí Leighis, 2009: 26–31). It can be broken against the wishes of the patient so as to protect that person, another person or the public or when instructed by a court.

Capacity and information gathering

Information may be gathered or shared with carers. The starting point is to consider whether the patient has the capacity to make decisions regarding these elements.

Turning first to information gathering, if capacity is lacking, the doctor cannot make any assumptions about the patient's true wishes and has to rely on clinical judgement and on ethical principles. The failure to interview family members (or others who may have important information) for collateral information could in certain circumstances be construed as negligent, much as a failure to carry out a blood culture on somebody with suspected septicaemia would be similarly regarded.

If the patient has capacity and refuses permission, it could be argued that in some instances the collation of information from other sources is mandatory as the veracity of the history cannot otherwise be confirmed. For instance, those who are intent on suicide may deliberately conceal this from the doctor while others might exaggerate symptoms for gain.

Family members may have important information to impart, the absence of which could have a significant impact on patient care. When gathering information about a person who either does not have capacity to consent or who has but refuses, the 'sensible person rule' must apply – 'would failure to obtain collateral information about such a patient place that person or others at greater risk than if information was obtained against the patient's wishes'. For example, a newly referred patient with agoraphobia who refuses permission to speak to their next of kin should clearly have their wishes respected as the beneficence–non-maleficence scale tips in favour of the patient. On the other hand, when a severely depressed person refuses the doctor permission to speak to a family member for the purpose of gathering collateral information, the scales may tip in the direction of non-maleficence. In other words not doing harm as a result of failure to obtain relevant information.

In many instances, provided the patient has capacity, a simple explanation that the purpose of such a meeting

is out of concern for his/her well-being might be reassuring enough for permission to be granted.

Capacity and information sharing

Information sharing is a little more complex than information gathering. Confidentiality is not binary as there are different types of information to be shared (general and specific) and differences in the extent of sharing (broad or 'need to know'). The extent of information sharing depends also on the setting in which information is being passed on as this is likely to be different when the patient is an in-patient in the throes of treatment by comparison to that given at the time of discharge.

Slade *et al.* (2007) draw a distinction between general and specific information, whereas Pinfold *et al.* (2004) identifies three types. General information is that which is in the public domain on mental health problems, available treatments or resource directories for local services; personal information consists of the specific diagnosis, medication prescribed or the care plan; sensitive personal information refers to information such as HIV status, history of sexual and emotional abuse, or views on relationships with family members. A way forward when a person, with or without capacity, refuses consent to share information with others is for general information to be passed on, while regularly re-evaluating shifts in the level of permission being granted and in the extent of the person's capacity.

Specific information about treatment, follow-up and individual relapse signatures requires the permission of the patient (assuming he/she has capacity). However, frequent misunderstandings arise because of a lack of appreciation of the confidentiality and information needs of the respective parties. Patients may worry that sensitive personal information of the kind described by Pinfold *et al.* (2004) will be passed on, whereas carers will ordinarily wish to know about diagnosis, prognosis, treatment, follow-up arrangements and risk issues so as to maximise the benefits of treatment. Clarity on this will often lead to agreement between the parties.

For an individual who does not have capacity, imparting specific information to carers is based on clinical judgement and, at minimum, should be on a need to know basis.

Problem carers

Are there situations where relatives could be denied information about the patient? Sometimes the family, either in the whole or as individuals, may be detrimental to the health and well-being of the patient. For example, families that are sexually, physically or

emotionally abusive should only be provided with limited information with the patient's permission and even then it might be justifiable to withhold any details concerning the person's illness. Other carers are over-involved, not through any obvious family pathology but, because of a misguided fear for their well-being. Examples include the parent who refuses to allow their adult child to return to education through fear that the 'stress' of this will cause a relapse or the parent who insists on sitting in on every out-patient visit.

The concept of high 'expressed emotion' in the families of those with schizophrenia and other serious mental illnesses (Brown *et al.* 1972) is well recognised and has three elements: emotional over-involvement, criticism and hostility. The difficulties posed by over-involved or hostile carers are recognised in *A Vision for Change* (2006) in the comments such as 'Service users and carers are not interchangeable: Service users can often be made to feel disempowered by well-meaning carers, and in some instances may be in direct conflict with carers. Users and carers should not be considered as a homogenous group'. The complexities faced by doctors when communicating with such families are real and require particular skills. Yet, the problems posed by a minority of carers should not cloud the over-arching needs of the majority, who deserve and probably have a right to certain basic information about the person they are caring for.

The way forward

Between no disclosure and total disclosure there is leeway to engage with both the patient and their carers while respecting the over-arching principle of confidentiality balanced against the vital involvement of carers.

The confidentiality rule does not extend to refusing to take telephone calls or neglecting to respond to communication from carers expressing concern. Practices such as these would create an inappropriate barrier that would compromise patient care. Listening is not precluded by confidentiality, even when a capacitious patient refuses consent to share information. In these circumstances that not only must the doctor listen to carers' concerns but if they are grave enough the doctor should act on these concerns.

The possibility of advance directives in respect of confidentiality is one that could be considered. When patients are well between episodes of illness, the limits and extensions of confidentiality could be discussed and recorded in their medical records. The extent to which these would be binding law is unclear but, provided they are reviewed regularly to identify changes in the relationship between the patient and their carer, the good will of the treating doctor would be

in no doubt. Arguably, this would afford significant protection for the doctor faced with a complaint or litigation in respect of confidentiality.

Confidentiality is clinically and ethically challenging and as we deal with increasingly complex psychiatric illnesses and an informed public, the time may have come for specific training in responding to confidentiality issues (Steiberg *et al.* 2012). Managing confidentiality should not be cast as a competition between patients and carers (Chatzidamianos *et al.* 2015). When faced with a dispute or dilemma involving a patient and the information that we believe a carer should be given we should consult with colleagues and with textbooks of ethics and document carefully in the patient's records the issues and concerns. Just saying 'no' to a carer isn't good enough.

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Conflicts of Interest

None.

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