

Decision making in mental health care: the caregiver's role

La toma de decisiones en la atención de la salud mental: el papel del cuidador

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Abstract

This paper sets a framework for considering ethical issues related to involuntary treatment in people with a) intellectual and developmental disabilities, b) progressive neurocognitive impairments, or c) compromised mental health from the caregiver's perspective. The different time courses for three groups of conditions are described, and potential impacts on the person affected and their caregivers in relation to decision.

While some issues for caregivers who are supporting capabilities of their loved ones to make healthcare decisions will vary, some principles apply across all groups. All caregivers need recognition and support for the roles they undertake. They need access to evidence-based, coherent and trustworthy information about available options, how to best fulfil these roles and how to look after their own health and wellbeing to best look after the person for whom they are caring.

Key words: mental health care, decision making capacity, caregivers.

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This paper is based on a talk given at the recent International Association of Catholic Bioethics (IACB) Colloquium, Promoting capabilities in persons who need support to make healthcare decisions. It aims to set a framework for considering ethical issues related to involuntary treatment in people with intellectual and developmental disabilities, progressive cognitive deterioration or mental illness, from the caregiver's perspective. It also aims to consider these ethical issues and offer some solutions. A number of questions will be discussed: What is the context for decision making? What are elements of ethical care from the caregiver's perspective? What do caregivers need?

In this paper, general principles only are provided, as countries differ in their medicolegal framework around issues of involuntary care. Also throughout this paper, the affected person is mostly called 'the person', although they may be at times a patient, client or consumer, depending on the model of mental health care applied and the stage of the person's mental health condition.

My conclusion will be that caregivers can partner with healthcare professionals in promoting capabilities in a wide range of people who need support in making healthcare decisions. The approach could vary, however, because different health conditions have different time courses and impacts on affected persons and their caregivers. For all conditions, caregivers need recognition and support for the roles they undertake and access to information about how to best fulfil these roles. They need to look after their own health and wellbeing as well as that of the person for whom they are caring.

1. What is the context for decision making?

a) Differing models of illness

Over the last century, many countries have used a *biomedical model* of health care, which concentrates on biological aspects of disease

and illness, and involves diagnosing and treating illnesses or conditions once symptoms are present. This model has centred on doctors, healthcare professionals, and hospitals who administer treatment. Here the aim is to treat individuals and their condition, with the expectation that they will return to a pre-illness state of health. Intervention focuses on biological determinants of health and less on behavioural and social determinants. This approach to medical intervention has been assisted by major advances in treatments discovered over this time (e.g., medications, medical and surgical techniques, and other forms of medical technology) and have increased pressure on hospitals and healthcare professionals to diagnose accurately and find cures or other treatments. They have also played a large role in prolonging life expectancy and increased the public's expectations about what medical interventions are able to accomplish. The biomedical model has been very successful for dealing with acute conditions but needs 'tweaking' when considering lifelong conditions or chronic illness. Contemporary medicine increasingly faces the task, not only of overcoming sickness, but also preserving health. Hence prevention and rehabilitation have increasingly important roles to play alongside curative therapies.

Caregivers are not really factored into the biomedical model. An advance on this has been the *biopsychosocial model* of health care, which looks at mental health and social systems around the individual in terms of how these impact the individual. This model is used more in mental health and rehabilitation settings and views the consumer of such services as part of a system in equilibrium. This implies that there are a number of ways the problem of illness and lack of wellbeing can be addressed. The biopsychosocial model also focuses on strengths and capacity rather than simply identifying weakness and incapacity in patients.

The *social model* is an alternative model which is more focussed on access to health care and inter-sectorial collaboration among health, government, non-governmental organizations (NGOs), and private sectors. This model considers social inequities (such as those

based on gender, culture, race, economic status or arise because of social exclusion) and behavioural determinants (as influenced by gender, culture, race or ethnicity, socio-economic status, location, and physical environment. This model seeks to empower individuals and communities and health promotion strategies. Like the biopsychosocial model, the social model considers systems and, while caregivers are not specifically considered, they are seen as part of systems. This model is more applicable to chronic disease and particularly relevant to caregivers who are working out how to engage with systems and advocate for their individual consumer or group of consumers.

The previous models imply that caregivers have some agency. However, there are other models (like a *conspiratorial model*) where the consumers are seen as being simply out of step with the mainstream, and society is perceived to be conspiring to force treatment on vulnerable people. Here, caregivers consider that society has no right to stop individuals 'being themselves' but should adapt to the person rather than try to change them. At times, caregivers might have their own experience with the condition, treatment, and the health system that might lead to their being distrustful of that system.

In the past, families took care of people with disability or mental health problems. Such people were often hidden at home or placed in institutions. With the medical advances noted above, people with a range of disabilities or mental illness are living longer: they and their caregivers have a less pessimistic view of what could be done and increasing expectations regarding enhancing their quality of life. Along with this has been deinstitutionalization in the last few decades, which has increased the load on caregivers.

b) Differing kinds of caregivers imply differing roles

Variation among caregivers can include the number of caregivers a person has, quality of support, where the caregivers are placed on the caring journey in relation to the person, their expectations and

level of agreement, and whether they seem to be acting in the interest of the person to whom they give care.

There are also many types of caregivers, including nuclear and extended families, single parents, same-sex couples, foster or adoptive parents, partners, children acting as sole agents, friends, and appointed caregivers. This range of potential caring groups has evolved in the past few decades.

At the same time, the emphasis on the role of these caregivers is evolving to reflect local customs, cultures, political and judicial policies. Thus, the emphasis on caregivers' rights to commit ill loved ones to hospital or agree to treatment can vary over time and by jurisdiction. In general terms, where most jurisdictions previously stated that the 'nearest relative' had rights to appeal and complain, there are often now more formal provisions for a nominated proxy or substitute decision maker to make health, welfare and financial decisions if the person lacks the capacity to make such decisions, at the time of proposed treatment and also for persons to give directives in advance. There is also greater recognition of the balance of rights of kin versus abuse by kin, and many jurisdictions draw up boundaries and safeguards to account for this.

c) Differing points on the caregiver's journey

While consumers of mental health services are on a personal journey in grappling with their condition, so are their caregivers. In Box 1, we note the issues related to the caregiver's journey. While this is a simplification of the steps, it is important to recognize that caregivers go through different stages, although some might get 'stuck' at a particular stage.

2. Differing conditions

Here, we are considering three types of conditions that can impact the person's cognitive functioning and decision-making process:

Box 1. Stages of a caregiver's journey,
noting some typical emotions associated with these.

Stages of caregiver's journey	Associated emotions	Factors related to impact
Realizing something is wrong: May be rapid with an acute onset or gradual realization.	Worry, fear, panic.	Bewilderment.
Asking questions, coming to terms with the situation.	Bewilderment, anxiety or growing confidence, feeling valued or feeling overwhelmed, conflicted.	Depends on healthcare professionals addressing their questions, developing a plan with them, level of engagement, match of models between healthcare professionals and caregivers.
Being a proxy for the patient.		Confidence in knowing patient's needs and wishes.
Adjusting to their role and implications for their own life.	Adjustment/acceptance or resentment.	Depends on their own life and support from others.
Advocating with medical and government systems.	Bewilderment, anxiety or growing confidence, feeling valued.	Depends on their questions being addressed, developing a plan, level of engagement, match of models, degree of social support.
Possibly giving up caring role or being able to step back from caring role.	May be a sense of relief but also involves loss of value and meaning, feeling abandoned.	There is an assumption that caregivers will be relieved, but where the caring has taken up much of the caregiver's life, this can be a time of mixed emotions.

Source: Own elaboration.

1. *Intellectual and developmental disabilities*: which includes genetic disorders, congenital malformations, conditions acquired early in life, autism, learning difficulties.

2. *Progressive neurological disease*: which includes dementia, brain injury and neurological conditions (such as Parkinson's Disease and a range of intracerebral lesions).

3. *Mental illness and addiction*: which includes acute conditions (delirium, intoxication, responses extreme stress and trauma); mood disorders (depression, mania, bipolar disorder), psychotic disorders (mainly schizophrenia, bipolar disorders); eating disorders; addiction (nicotine, drugs, gambling, prescribed or unprescribed medications, alcohol).

a) *Differing types of involuntary decision making*

This is not intended to be a full review of the various legal requirements for involuntary detention and treatment and implications

Box 2. Comparison of the three types of conditions and their implications for carers.

Life stage of onset	Implications	Impact on caregiver
Intellectual and developmental disabilities.		
<ul style="list-style-type: none"> – Present from birth/ childhood (congenital or environmental conditions, developmental delay, autism, result of childhood illness). – May be stable, or fluctuating with functional decline. 	<ul style="list-style-type: none"> – Large impact on development, education, social skills. – Response will vary with: <ul style="list-style-type: none"> • Amount of support available (family/friends/ health care/other support systems). • Culture (shame or acceptance). • Level of understanding. • Caregiver's sense of agency. 	<ul style="list-style-type: none"> – Feelings of guilt, sadness, pity, anger (difficult to own). – Parents might feel blame or feel blamed (and hence, might overcompensate). – Parents are more likely the sole caregivers. – Caregivers might have a sense of meaning or feel entrapped. – Support is more available for some conditions than others. – Caregivers and clinicians might become inured to possible improvements.

Progressive neurological disease.		
<ul style="list-style-type: none"> – Arises in adulthood/ older age or end of life conditions. – Issues of ongoing cognitive decline, including dementia, coping with disability. – Other conditions, e.g., depression, delirium, psychosis could arise as part of the deterioration. – May be fluctuating or steady decline. 	<ul style="list-style-type: none"> – Personality and coping styles have developed and will shape coping. – Caregiver's response will be more predictable but still is related to the same issues as for persons with intellectual and developmental disabilities. – Caregivers should be encouraged to discuss the person's views on dealing with their progressive decline (including end-of-life issues) while they have decision-making capacity. 	<ul style="list-style-type: none"> – Feelings of anxiety, sadness, pity very much linked to quality of relationship. – Embarrassment with behaviours. – Anger, particularly if self-inflicted or occurring at a time when caregiver had different plans (e.g., travel or retirement). – Parents might have a role but partner, children (where present) are more likely to be involved. – Caregivers might have a sense of meaning or entrapment, but know this is a time-limited commitment.
Compromised mental health and addiction.		
<ul style="list-style-type: none"> – Arising over lifespan: • Mood changes: depression, mania, bipolar disorder. • Psychotic disorders (early psychosis, schizophrenia, bipolar disorder, drug-induced psychosis). • Acute states: delirium, intoxication, responses to extreme stress and trauma. • Episodes tend to be episodic. 	<ul style="list-style-type: none"> – Personality and coping styles have developed and will shape coping. – Caregiver's response will be more predictable but still related to the same issues as above. – The temporary nature should allow for discussion of issues and advance planning for further episodes on recovery. 	<ul style="list-style-type: none"> – Feelings of fear, anxiety, shame, embarrassment, bewilderment. – Inadequacy. – Anger, towards person, particularly if condition is seen as self-inflicted. – Acute episodes can be very confronting and frightening for carers. – Parents may have a role but family (partner, children) more likely to be involved. – Carer's role is anticipated for temporary deterioration in mental health.

Arising in teens/young adults.		
<ul style="list-style-type: none"> • Eating disorders. • Addiction: nicotine, drugs (un/prescribed, alcohol, gambling). • Personality disorders. 	<ul style="list-style-type: none"> – Conditions arising in this age group will impact the person's personality, maturation, social network, and capacity to make decisions. – The temporary nature should allow for discussion of issues and advance planning for further episodes on recovery. 	<ul style="list-style-type: none"> – Parents are still likely to be important as caregivers. – These disorders can leave parents and partners feeling helpless and afraid.
Arising in older adults.		
<ul style="list-style-type: none"> • Melancholic depression (often due to cerebrovascular disease). • Long-term effects of chronic mental illness and addictions, often associated with poor physical health. 	<ul style="list-style-type: none"> – Conditions arising later in life occur when a person's personality and decision-making capacity is more evident, and it is easier to determine the person's wishes. 	<ul style="list-style-type: none"> – Carers more likely to be a partner, children, friends or paid caregivers.

Source: Own elaboration.

for decision making. There may be temporary uses of involuntary decision making, such as invoking legal regulations for purposes of involuntary assessment and involuntary treatment for mental and medical conditions or temporary guardianship. Any of these could occur if the person is in the throes of an acute episode of mental illness (e.g., schizophrenia, severe depression or bipolar disorder), temporarily affected by intoxication or overdose and during times when the person has cognitive impairments and behaviours that challenge related to a medical illness. The nominated next of kin or other family members and caregivers are likely to be involved in these decisions. Involuntary detention and treatment might be followed by a community treatment order, which mandates follow up after discharge.

For enduring or worsening conditions, there might be need for ongoing guardianship which might include making decisions for persons who are assessed to lack decision-making capacity in areas such as finance, accommodation, medical or psychiatric interventions. Usually family members are nominated as guardians unless they themselves decline or are deemed unfit, unsuitable or unavailable.

b) Differing levels of support and interest by caregivers and clinicians

It is worth noting that not all caregivers are helpful and supportive towards family members who might have some capabilities for making healthcare decisions. What if caregivers are abusive or neglectful towards the person? What if caregivers exacerbate the person's problems or undermine treatment and support? What if caregivers exert 'undue influence' by answering for the person, talking over and/or ignoring them, preventing access to or use of services? What if they act for own interests rather than those of the affected person? Where this is recognized, there are usually mechanisms for dealing with the situation, as long as it is brought to light.

On the other hand, the same issues can arise with healthcare professionals, and again, these need to be addressed. This is more likely to occur in 'total institutions' without adequate external governance processes.

3. The elements of ethical care from the caregiver's perspective

Some of the general principles in decision making across all types of conditions or illnesses include: a) even when unwell, people can contribute to making decisions and provide assent or limited consent, b) in their supportive role, caregivers need to be clear about what areas are important for affected person; it is best to

appoint someone who can speak for the person, understands the person's view and seems to have the patient's interest foremost; c) there are decision-making steps that can be used, with some general and some condition-specific issues, and d) the decisions need to be realistic and achievable.

In considering how best to support capabilities of those who need support from caregivers to make health care decisions, it is important also to address five elements of ethical care. These have been described as attentiveness, responsibility, competence, responsiveness, and care for self (1).¹ The first four operationalize what many clinicians gauge intuitively, while the fifth, which is also important, can be easily overlooked by medical staff and caregivers alike.

It is helpful to check carers' understanding, expectations, experience, and the model of care they are operating with. There might or might not be a 'fit' between the model of care of clinicians and caregivers, and importantly, not all healthcare professionals might use the same model, and might or might not be aware of these differences. This can result in conflicting messages being delivered to caregivers. Even when there are other people involved in a person's care, it often falls back on the person's family because family members are generally still around when no one else is available.

In turn, caregivers can more easily provide respectful care, including supporting decision-making capabilities, if they have a clear role and are respected by others and themselves. To do this, they need access to reliable sources of information from clinicians, support groups, credible internet and local information.

However, caregivers are human, and family members often have mixed emotional responses (e.g., relief, guilt, anger, sadness, worry, stress) when dealing with their relative in situations occasioning involuntary treatment, especially if the situation is enduring and they have a difficult relationship with healthcare professionals. This can lead to situations of high emotion. At times, this is complicated by the fact that relationships with caregivers have been frayed or frac-

tured prior to the acute episode. Particularly in the case of some mental illnesses, the family and friends have lost contact with the person for a variety of reasons (e.g, they don't trust the person, they have been hurt by them or feel afraid due to delusional thoughts involving them, they have been the source of trauma or been seen as 'stifling'). In the case of long-term disorders, they may be worn out if they have insufficient respite or support. However, where the affected person has been missing engaging with family members, an involuntary admission might be a chance for them to reconnect with their family.

Potential barriers to caregiver involvement in supporting health-care decision making include lack of adequate caregiver support, lack of health service provider resources, and patients who are seen as being too dangerous and/or erratic to be involved in the process.

4. What do caregivers need?

Box 3 has a story from a caregiver's viewpoint. This illustrates some of the difficulties and mixed emotions associated with being a caregiver in acute episodes of mental illness. A recent Australian study (2) interviewed 19 family members who had a family member involuntarily detained mostly for a psychotic illness. This is usually a very stressful time for caregivers who are searching for answers and adjusting to the realities of their affected member's condition. They noted four critical elements that assisted the families in providing recovery-orientated support, which include:

1. Ensuring that the caregivers had confidence that their relative was safe and receiving good care;
2. Families being informed of their relative's progress;
3. Enabling access to information, and
4. Working in partnership with the families.

Box 3. A carer's perspective.

Johan is 35-year-old man (married for 3 years, with no children), with a Master's degree who has had a series of high profile jobs. His family's report (below) notes that he had been 'emotionally up and down' and made some impulsive personal and business decisions in the past but had always managed to extricate himself due to his high intelligence and personal charm. However, in the past three months, he has been very irritable and sleeping very poorly and was fired from work for rudeness after several warnings. His friend has been giving him cannabis and cocaine 'to settle him down', but he became increasingly erratic and aggressive, and has accused wife of infidelity.

His wife is despairing and approached her Mother-in-law for help. They eventually called the community's Acute Mental Health Team, leading to involuntary admission in a mental health facility under the local Mental Health Act. Johan was diagnosed with a Manic episode as part of Bipolar Disorder. After release, he has stopped all medication, been smoking cannabis daily and become much more erratic. His wife has now left the country, and he has been evicted from their home. Johan does not want to his mother 'to interfere with his care' but does want to live with her now that he is destitute. Below, is her view.

I never realized it was an illness. He was bright, a bit eccentric erratic, it never got called that. There are lots of examples of him getting into a shit-load of trouble. He saw a counsellor a couple of times... He is very smart, with degrees in business and accounting He talked us into starting a business. Looking back he shut himself away and depressed, and at other times, he was high. Business went from 2003-2007. He feels guilt at losing hundreds of thousands of dollars: in 2007 the business folded, but then talked his way into a prestigious Master's Course (talked the Dean into it a week before it got started).

After that, he went to Asia, where he slumped, sounded very down. He returned to Sydney, Oct/Nov 2017, started acting erratically, cut off all contact, wife distressed, came to me for advice. We rang the hospital: They said what do you want to do? We were given options, but we weren't really aware of the consequences and know the staff were wanting us to make decisions. They were asking me, is he a danger to self? Others?

It was hard to know the right thing to do, and we were afraid about this getting around. We asked the medical staff to come and visit. After he was taken to hospital in handcuffs and detained as an involuntary patient, he attended Magistrate's hearing a week later. He was more settled by this stage, but far from recovered. He was discharged as his friend had vouched for him at the Tribunal. His wife was worried about his behaviour, he was blaming her for having him locked up. They met up in an open place. He was volatile and frightening. It was a disaster. His wife was frightened for his safety and her own.

I went back to the mental health service and asked, «What can we do?» They said they would visit and let me know before they went. They did visit but they didn't let me know until later and no one answered his door. This is doing more harm than good.

I later found him in my garden in an appalling state. He hadn't taken any medication for days, his landlord had thrown him out, he moved in with me. He was very depressed and remorseful. He gets irritable if any of this is discussed. He did go to another clinic and got some useful help (psychiatrist and psychologist) but he is still struggling and has lost everything. He has increased tobacco use and still smoking THC. If I tell anyone about my concerns, he is likely to find out and will get very angry. I can't go through the whole process again and don't want to get him offside as he has no one else. I also want the best for him and his future. You feel very alone, don't know whom to ask. It is a huge responsibility to live with.

They concluded that «family wellbeing is improved when they feel part of a supportive team» and recommended that families should have ready contact and access to information about their relative and that it was important for healthcare professionals to «acknowledge families relationships, expertise, and understanding of their family member».

As part of the elements of ethical care, including supporting decision-making capabilities, caregivers also need to be given the opportunity and encouragement for self-care of patients as well

as themselves. A recent Australian study used The Optimal Health Program, a series of modules offered to patients and caregivers to address caregivers' concerns and to enhance patients' self-efficacy in crisis and maintain wellbeing, while helping them gain a better understanding of the healthcare system and their own treatment. This Program has been used for people affected by a stroke and their caregivers (3). Similar interventions aimed at promoting caregiver welfare have been important in supporting families with a member with dementia. They are less common for families with a member with mental illness.

In general, caregivers seek to be and should be involved in shared decision making with healthcare professionals to support the person to whom they both provide care. Elwyn et al.'s paper provides a 3-step model for shared decision making: 1) introducing choice; 2) describing options, often by integrating the use of patient decision supports, and 3) helping patients explore preferences and make decisions. This involves a process where both caregivers and clinicians work with the person to make decisions based on 'what matters most' to the person (4). This process is also shared in Gawande's book about dealing with end-of-life issues (5).

Some other models for enhancing caregivers' support of family members worth noting include the family-focussed recovery practice, which is used to support the family to better assist their relative with compromised mental health in recovery, and secondly to address the needs of the family members themselves (6). A family-focussed recovery framework is needed to assist service planners, practitioners, family members and those with mental health needs and should be embedded within practice guidelines. There has also been success in teaching families to use a problem-solving approach (Family Problem Solving Therapy) to improve family function, particularly in dealing with crisis situations (7).

These are some suggested areas where reliable information would benefit caregivers in supporting family members with compromised mental health:

1. Specific conditions of relevance to them (including delirium).
2. Whom they are dealing with and how to get the best out of medical interactions (e.g, how to make best use of a case conference, ward round, and/or interview with a new clinician).
3. How to deal with crises and relapses.
4. How to work as a team and engage family problem-solving.
5. How to be an advocate.
6. how to be a proxy or substitute decision maker; use of a «Best Interest Checklist».¹
7. Access to support groups on the condition(s) of relevance.
8. Information about self-care and respite.

Of note, the World Health Organization (WHO)'s (8) *iSupport* manual for caregivers of people with dementia addresses many areas mentioned above. It includes five modules, namely: a) introduction to dementia; b) being a caregiver; c) caring for me as a caregiver; d) providing everyday care; and e) dealing with behaviour changes.

There is not a corresponding manual for people caring for someone with compromised mental health, but due to the great diversity and range in severity of mental health conditions, developing such a manual might not be so simple. There are organizations giving support to caregivers of persons with specific disorders such as psychosis, eating disorders and depression. These are too numerous and diverse to specify here, but advice contained in such manuals are often not sufficient for caregivers dealing with acute, emotionally charged situations, such as the example cited below in Box 3.

Conclusion

Some cultures and societies have looked to care by extended families. In other cultures and societies, institutional care is still preferred

for people with intellectual and developmental disabilities, progressive neurological disorders, compromised mental health and addiction. There is now, however, less access to institutions and smaller, more diverse families. At the same time, there has been greater interest in transparency in health care and access to information. These changes have placed more focus on a smaller number of caregivers, with the result that the caregiver's role, along with definitions and medico-legal implications, has been evolving.

The three groups of conditions mentioned have different time courses and impacts on the person involved and their caregivers. Approaches to caregivers to caring and supporting capabilities of their loved ones to make healthcare decisions, therefore, can vary among these conditions. However, some principles apply across all groups: caregivers need recognition and support for the roles they undertake and access to information about how to best fulfil these roles. They need to look after their own health and wellbeing as well as that of the person for whom they are caring.

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