CONSENSUS CONFERENCE
ON THE SPECIAL CARE UNIT FOR BPSD
SCU-B

RECAGE Project (GA No: 779237)
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ETHICAL ISSUES PERTAINING TO THE SCU-B

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Some general premises

→ **Legal capacity:** ability to effectively carry out general legal transactions independently. The precondition of this is to develop and express a free will. Every adult is considered capable of this capacity, i.e. decide for her/himself until the capacity is disproven (hence: a diagnosis of dementia by itself doesn't necessarily entail lack of legal capacity). Although there is no universally agreed definition of legal capacity, most (Western) cultures agree on this concept.

→ **Capacity to consent:** every subject with legal capacity has the capacity to consent, but a subject lacking legal capacity still may be able to give consent, if he or she can understand the nature, significance and scope (risks) of a specific measure within the framework of adequate information. The procedure to arrive at this is called **"informed consent" (IC)**.

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SURROGATE DECISION-MAKING

When a patient lacks decision-making capacity, *recourse to a surrogate decision-maker is the rule.* At best, she is a guardian appointed by the law, but often is the next-of-kin. The challenge then becomes: what standard should she/he adhere to?

Three ordered principles to guide surrogate decision-making:

→ **Advance directives**

→ **Substitute judgement**

→ **Best interest**

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SURROGATE DECISION-MAKING

Advance directives principle

According to it decisions should be made in accordance with the patient's advance directive (when it exists) with instructions that relate to the decision at hand.

Unfortunately, despite great efforts to increase the use of advance directives, most patients do not have one when they are incompetent to make their own decisions.

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SURROGATE DECISION-MAKING

Substituted judgment principle

This means that the surrogate should attempt to make the decision the patient would have made if she had been competent in the circumstances that obtain. However, some caution is needed because some studies have shown that family members frequently are mistaken in their judgments about patients' wishes, not to mention the financial constraints related to the decision to make.

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SURROGATE DECISION-MAKING

Best interest principle

It is defined as the best possible outcome for patient in a given situation, the outcome that provides the most benefit to the patient. The values of the patient must be taken into account as well as what legal scholars call her/his **natural will.**

In fact, even if the person is incapable of acting with full responsibility, that does not mean that she/he has no will: she/he can still express her wishes and strivings, she/he may want to move around, accept or refuse a medical procedure, etc.

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ETHICAL ISSUES OF THE SCU-B

The major ethical problem as regards the SCU-B is **consent to treatment.** The reason for this is clear: many persons with dementia lack the ability of giving their IC and this raises the problem of the ethically proper decision-making. How to tackle this challenge?

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COMMON CLINICAL SITUATIONS

a. at admission to the unit, when the patient is unable to give direct IC and is admitted on the ground of the consent given by the surrogate decision-maker (legal guardian or closest relative) and, even though unable to give IC, clearly manifests her opposition to hospitalisation
b. during the stay, when the patient repeatedly asks to be discharged home, tries to find exits discovering that the doors are closed, and doesn't receive honest answers
c. during the stay, when she/he doesn't comply with the requirements not to stand because of impaired balance and risk of falls.

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WHAT RESPONSES?

In these scenarios the usual answers of the caring staff are acts of **“benevolent coercion”**: e.g.

. *admitting the patient despite her/his opposition,*

. *detaining her/him in a closed ward*

. *start antipsychotics therapies* and, sometimes,

. *resorting to mechanical restraints.*

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COERCION AND BENEVOLENT COERCION

The definition of ***coercion*** proposed by the German Ethics Council, is "overriding another person's will" whilst the definition of ***benevolent coercion*** is "the same, if performed with the intention of preventing the recipient from harming her/himself, that is if it is conceived as being helpful to her/him… When determining whether overriding another person's will amount to coercion, it is immaterial whether or not will is fully responsible. Overriding someone's natural will also constitutes coercion".

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WHAT COERCIVE MEASURES?

- Sometimes the admission itself to the Unit, when the patient was not previously informed by relatives, not to mention frank deception (e.g. when the patient comes to the Unit thinking that she/he is going to a simple visit)
- The mere stay in a Unit with locked doors and no exit available
- The interruption or loosening (albeit transient) of the relationships with the family

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WHAT COERCIVE MEASURES?

- The use of antipsychotic medication to restrain patients with chemical means
- Mechanical restraints, ranging from bedrails, bedside tables, removing walking frames or other physical aids
- Finally, moving from the SCU-B directly to a nursing home can be highly stressful, and may be in contrast with a previous advance directive stating the refusal to be admitted to a hospital or to a nursing home, but this refusal must not be respected when admission to a nursing home may be the sole possible solution.

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The main question is: to what extent may carers override patients' will?

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Our tentative statements

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1. INFORMED CONSENT

- If the person is able to give direct IC, there are no problem for admission, but if she/he changes advice, she/he must obtain discharge
- If the person is not able to give IC, consent is given by the legal guardian (if there is one) or the next of kin according to the strongest possible standard

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2. INFORMED CONSENT

- However, if the person either at admission or during the stay shows ***clear dissent*** and is not amenable to agree, despite gentle effort from the caring staff, the problem must be discussed with the surrogate decision-maker, trying to clarify (possibly) contrasting interests between her/him and the person and attempting to reach a shared decision
- Should a shared decision not be attainable or would a surrogate not be available, an urgent recourse to the relevant Ethics Committee is recommended

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3. COERCIVE MEASURES

- **Antipsychotic drugs: very strict criteria must be followed** and as a rule *only as a second line approach*, after a serious trial with non-pharmacological therapies.
- **Avoiding mechanical restraints** is the first principle to follow and much can be done, in the framework of a SCU-B, in this direction
- **Staff education and training**: all carers should be able to listen to the patient and to consider abnormal behaviours often as the sole modes available to the patient to manifest her needs.

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Thanks for your attention!

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