International cooperation seminar

National Taiwan University, Taipei (College of Law + Department of Psychology) and TH Köln (Beratung und Vertretung im Sozialen Recht)



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CASE: HEALTH CARE

Paul J. (21 years old) has a severe intellectual disability and no verbal communication. He is living with his parents with whom he has a close relationship and is staying in a daycare institution from 9 am to 5 pm (Monday - Friday).

Care staff who knows him well noticed a deterioration in his behavior. In particular, they noticed that he was extremely protective of his face. They suspected toothache. However, he absolutely resisted letting anyone even come near his mouth. In attempts to find out what is wrong with him, it becomes clear that he completely resists any interference with his mouth. Later it turned out that he was indeed suffering from toothache.

Table of contents

- 1. German law of "Betreuung" (health care)
- 2. Taiwanese laws on medical treatments and patients
- 3. Legal comparison
- 4. International Law (centered on UN CRPD)
- 5. Person-centered approach



Law of "Betreuung"

German Civil Code

Medical law

1. Requirements "Betreuer" appointment

§ 1896 German Civil Code (BGB)

- (1) If a person is of full age, by reason of a mental illness or a physical, mental or psychological handicap, cannot in whole or in part take care of his affairs, the "Betreuungs-" court, on his application or of its own motion, appoints a "Betreuer" for him. ...
- (2) A "Betreuer" may be appointed **only for groups of tasks in which** the "Betreuung" is necessary....
- → In his area of responsibility, the "Betreuer" represents the person under "Betreuung" in and out of court.

Area of responsibility: Health care

2. Scope of the "Betreuung" duties of the "Betreuer"

§ 1901 German Civil Code (BGB)

- (1) The "Betreuung" includes all activities that are necessary to attend to the affairs of the person under "Betreuung" from a legal point of view in accordance with the following provisions.
- (2) The "Betreuer" must take care of the affairs of the person under "Betreuung" in a way that is according to his or her welfare/best interests.

The well-being of the person being cared for also includes the possibility of shaping his or her life according to his or her **own wishes and ideas** within the scope of his or her abilities.

ightarrow Maintain self-determination



German medical law

= Every medical treatment always means an interference with the physical integrity (Art. 2 (2) p. 1 GG) (§ 223 StGB) and requires a justification:

1. medical indication: the doctor decides on this in accordance with § 1901 (1) BGB

2. consent (medical law § 630d) of the patient who is capable of giving consent and has been informed (medical law § 630e BGB).



German medical law

An effective consent requires,

that the doctor has previously informed about the chances, risks and side effects of the treatment (informed consent) § 630e (1) BGB (§ 630e BGB)

Self-determination - doctor has duty to inform!

The information must be provided in accordance with § 630e (2) BGB:

- timely
- understandable
- verbally





Patient is capable of giving consent

- A person is capable of giving consent if he or she is able to comprehend the nature, significance and consequences of the intended medical measure and to determine his or her will accordingly.
- The basic assumption is that every adult is capable of giving consent, unless he or she is exceptionally incapable of giving consent for reasons of condition.
- = able to reason (*Einsichtsfähigkeit*) and ability to act according to the formed will (*Steuerungsfähigkeit*).
- "The effectiveness of consent doesn't depend on the patient's general legal capacity" [1].

Forced dental treatment,

especially when free will is lacking in an individual case and significant harm is imminent (§ 1906 a German Civil Code)

- Only if patient is incapable!
- Patient now refuses treatment (facts of the case).
- Serious attempt to convince patient the necessity of the treatment
- The doctor must always inform the patient and achieve voluntariness (§ 630 c para. 2, p. 1 BGB)
- \bullet Treatment complies with the patient's will as defined in § 1901 a BGB, which was determined in accordance with § 1901 b BGB
- The compulsory treatment is reasonable and appropriate for the patient (principle of necessity /principle of proportionality) if considerable damage to health is averted and there is no alternative
- = approval of the "Betreuungs-"court for compulsory medical measures according to the natural will of the person under "Betreuung"



Case – Result

Paul makes his decision independently and on his own!

Family and caregiver/nurses/doctors are bound by it.



Taiwanese laws

Taiwan Civil Code

Patient Right to Autonomy Act (PRAA)

Enforcement Rules of Patient Right to Autonomy Act

Taiwan Civil Code

Art. 14 i. To protect an adult who is not able to make a legal decision or comprehend the effect of his/her decision, the court may order the commencement of guardianship at request.

Art. 15. Complete denial of legal capacity without exceptions

Art. 1098 i. The guardian is the legal representative with full authorities

Art. 1112 When enforcing guardianship relating the ward's life, treatment, and financial management, the guardian shall respect the ward's intent.

Patient Right to Autonomy Act (PRAA) in Taiwan

Art. 4 PRAA

i. Patient's Right to be informed of the diagnosis of disease, treatment options, and the potential effectiveness and risks. Patient's Right to choose and make decisions regarding the treatment options provided by the physician.

ii. The patient's legal representative... (hereinafter, "parties concerned") may not prevent the medical institution or physician from acting on the patient's treatment decisions.

Enforcement Rules Of Patient Right to Autonomy Act

Art. 3. In the cases when the patient has no or limited disposing capacity, his/her guardian <u>is not restricted by Article 4 of PRAA.</u>

Patient Right to Autonomy Act (PRAA) in Taiwan

Art. 5 ii. In cases when the patient has no or limited disposing capacity, is subject to an adjudication of the commencement of assistance, or unable to express ideas or understand ideas expressed by others, the medical institution or physician shall inform both the patient and the parties concerned in an appropriate manner.

Art. 6. Except for emergency cases, **consent in writing** from the patient or the parties concerned should be received prior to surgery **or invasive examinations or treatments.**

Enforcement Rules of Patient Right to Autonomy Act

Art. 5 i. Concerning consent regulated in Article 6 of Patient Right to Autonomy Act, the patient's consent shall be prioritized. When the patient does not express objection, the consent of the related party shall be granted.

ii. In cases when the patient has limited disposing capacity, in assisted declaration, or has significant deficiency in ability to express will, in addition to the patient's consent, the consent of the related person shall be obtained.

iii. If the patient has no disposing capacity, unconscious or unable to express his wishes clearly, consent should be obtained from the person concerned.

Case – Result

The guardian can decide against the patient's will!

Only the consent of the guardian is required, even though it goes against the patient's will.

Legal Comparison

Taiwan	Germany
Incapacitation - complete denial of legal capacity without exceptions (= incapable of giving consent)	The basic assumption is that every adult is capable of giving consent, unless he or she is exceptionally incapable of giving consent for reasons of condition. (exception: reservation of consent)
The guardian is the legal representative with full authorities	The "Betreuer" is the legal representative with limited authorities
No areas of responsibility	Areas of responsibility (principle of necessity)
The consent of guardian is valid	The consent of the patient is valid



International law Central aspects of the UN CRPD

The States Parties to the present Convention,

(c) Reaffirming the universality, indivisibility, interdependence and interrelatedness of all human rights and fundamental freedoms and the need for persons with disabilities to be guaranteed their full enjoyment without discrimination.

Article 3 - General principles

1. Respect for human dignity, individual autonomy, including the freedom to make decisions, and independence;...



International law Central aspects of the UN CRPD

Article 12 - Equal recognition before the law

...(4) States Parties shall ensure that all measures that relate to the exercise of legal capacity provide for appropriate and effective safeguards to prevent abuse in accordance with international human rights law. Such safeguards shall ensure that measures relating to the exercise of legal capacity respect the rights, will and preferences of the person,...

Comment from the perspective of CRPD

- 1. In the name of **equality** before the law, we should seriously consider whether ignoring one's will and legal capacity is correct.
- 2. Taiwanese Civil Code declared a person to be denied of legal capacity, and many other law denies a person's capacity based on this classification
 - \rightarrow problem
 - (1). too rigid without flexibility based on cases
 - (2). the system focusing on property protection may not be suitable for person-related decisions because the criteria and factors concerned are different

Comment from the perspective of CRPD

Suggestions for law amendment

- Use the concept of mental capacity, instead of disposing capacity
- Mental capacity: capacity to give consent while understanding the consequences, and thus differs case by case
 - →If Paul understands the consequence and insists on his decision, his decision should be respected, unless it will cause irreversible harm to his property or life

What options for action do the "Betreuer" and guardian have?

Promotion of self-determination

... "In attempts to find out what is wrong with him, it becomes clear that he completely resists any interference with his mouth."...

SUPPORTED DECISION MAKING



Inform the patient about dental pain and pointing out the consequences

Support him in his decision-making process:

- protect Paul's right to self-determination, wishes and ideas
- communication
- experience
- involve the family as a resource mediator
- knowledge

SELF-DETERMINED DECISION OF PAUL

→ Establish and support capacity to act



Person-centered approach

A) How do we talk to Paul (preparation)?

creating optimal general conditions - basis: good relationship

B) How can we inform and consult him (content)?

Communication principles:

- always address Paul directly
- ask questions in different ways
- use easy or simplified language
 - → age-appropriate, empathetic, sufficient time management, non-directive
- reassure and check what he has understood
- repetition of the procedures



Action plan: before decision making

describe observation of Paul's behavior

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ask about the pain:

Do you have toothache? Are you sick?

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wait for Paul's feedback

(give him enough time to answer)

Fif necessary,

ask faul if he would like to involve his family that we can know more about him!

Specify symptoms With help of:

- Communication board
- role plays
- pictures or videos



Health Care Communication Board

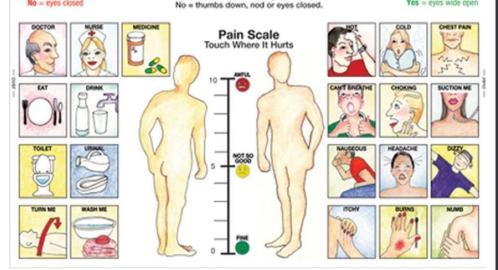
For Medical, Physical and Emotional Information

INSTRUCTIONS: Have patient touch pictures to request wants and needs.

If unable, caregiver touches pictures and gets yes/no response from patient.

Yes = thumbs up, nod, or eyes wide open;





Steps to supported decision making

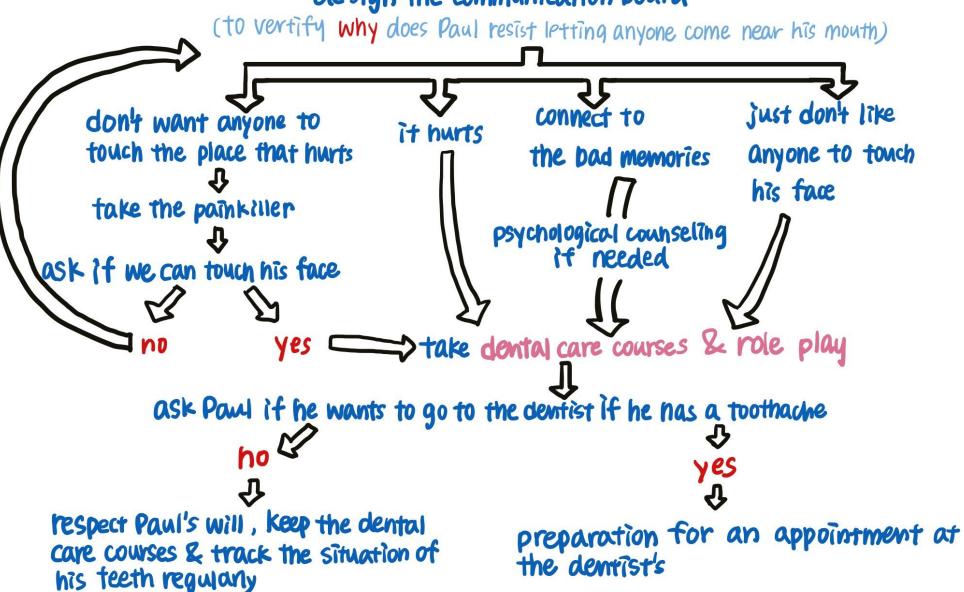
If necessary, ask Paul if he would like to involve his family/relatives (transparency):



- identify Paul's motivation behind resisting interference to his face
- request information about his previous reaction to illnesses in general
- ask about the condition of his teeth in the past
- inquire about Paul's experience regarding visiting the dentist
- clarify if he wishes to have company at the dentist

Action plan: after we know Paul's situation

design the communication board



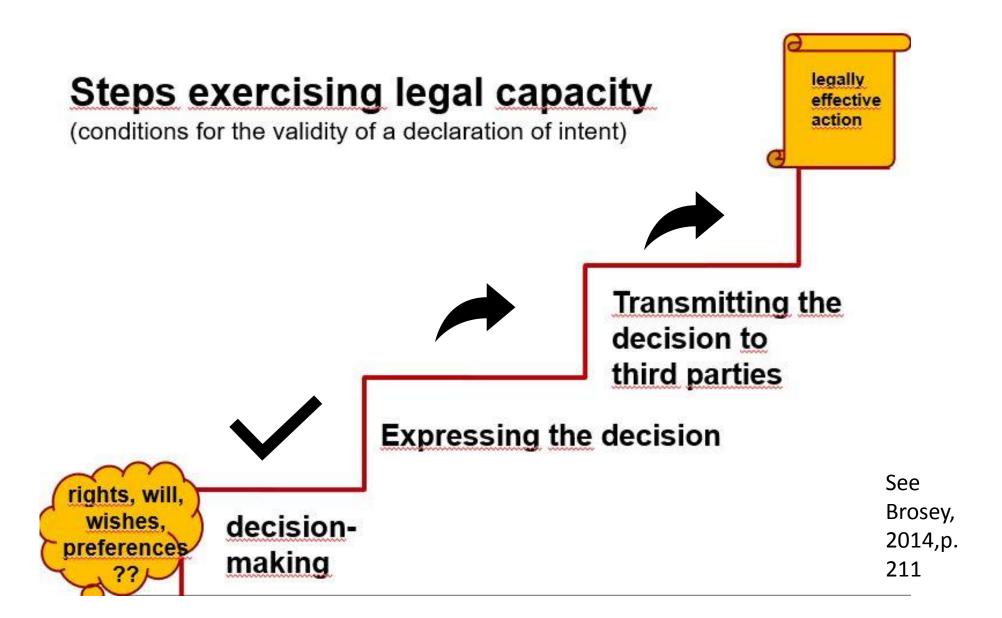
Preparation for an appointment at the dentist:





- explain to him the suspected cause of his pain and the recommended solution (→ pain relief)
- describe the consequences of early and delayed treatment
- gradual rapprochement (e.g. first appointment: visit to the dental practice second appointment: dentist will just inspecting the tooth third appointment: dental treatment)

→ Give Paul time to make a decision by himself!



"thankyoufor your AMENTION "