

Empfehlungen für die Implementierung von Odysseus-Verfügungen

aus einer internationalen Perspektive

Matthé Scholten¹, SALUS Forschungsgruppe^{1,2}, et al.

¹ Institut für Medizinische Ethik und Geschichte der Medizin

² Klinik für Psychiatrie, Psychotherapie und
Präventivmedizin, LWL-Universitätsklinikum

Ruhr-Universität Bochum

I. Hintergrund

Hintergrund

- Odysseus-Verfügungen bringen nicht nur Chancen und Vorteile mit sich, sondern auch Risiken und Herausforderungen
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Ziel

- Empfehlungen zur Überwindung der Herausforderungen und zur Minimierung der Risiken von Odysseus-Verfügungen zu entwickeln
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II. Methodik

Systematisches Review

Self-binding directives in psychiatric practice: a systematic review of reasons



Lucy Stephenson, Astrid Gieselmann, Tania Gergel, Gareth Owen, Jakov Gather, Matthé Scholten

Self-binding directives (SBDs) are an ethically controversial type of advance decision making involving advance requests for involuntary treatment. This study systematically reviewed the academic literature on psychiatric SBDs to elucidate reasons for and against their use in psychiatric practice. Full-text articles were thematically analysed within the international, interdisciplinary authorship team to produce a hierarchy of reasons. We found 50 eligible articles. Reasons for SBD use were promoting service user autonomy, promoting wellbeing and reducing harm, improving relationships, justifying coercion, stakeholder support, and reducing coercion. Reasons against SBD use were diminishing service user autonomy, unmanageable implementation problems, difficulties with assessing mental capacity, challenging personal identity, legislative issues, and causing harm. A secondary finding was a clarified concept of capacity-sensitive SBDs. Future pilot implementation projects that operationalise the clarified definition of capacity-sensitive SBDs with safeguards around informed consent, capacity assessment, support for drafting, and independent review are required.

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Department of Psychological Medicine, Institute of Psychiatry, Psychology and Neuroscience, King's College London, London, UK (L Stephenson PhD, T Gergel PhD, G Owen PhD); Institute for Medical Ethics and

Empirische Forschung mit Stakeholdern

- DE: Ruhr-Universität Bochum
- NL: VU-Universität Amsterdam
- UK: King's College London

References	Sample	Data collection	Data analysis
Hindley et al. [32]	932 persons with bipolar	Online survey	Quantitative
Stephenson et al. [33]	10 persons with bipolar, 3 relatives, 19 professionals; 5 service user-led organizations, 5 mental health clinical teams	Focus groups; consultation process	Qualitative
Gergel et al. [34]	565 persons with bipolar	Online survey	Qualitative
Potthoff et al. [35]	6 persons with bipolar, 6 relatives, 5 professionals, 5 researchers	Focus group; semi-structured interviews	Qualitative
Stephenson et al. [36]	17 persons with bipolar, 14 relatives, 18 professionals	Semi-structured interviews	Qualitative
Van Melle et al. [37]	7 service users, 14 professionals	Semi-structured interviews	Qualitative
Werning et al. [38]	225 persons with bipolar, 105 relatives, 45 professionals	Online survey	Quantitative

Experten Konsensprozess

- Bioethik, Medizin, Pflege, Philosophie, Psychiatrie, Psychologie und Sozialwissenschaften
 - gelebte Erfahrung und klinische Erfahrung
 - DE, NL und UK
-
1. Regelmäßiger Austausch
 2. Brainwriting-Veranstaltung mittels Miro
 3. Austausch auf dem SALUS Midterm Symposium
 4. interaktives online Dokument
 5. mehrere Feedbackschleifen

Chancen und Risiken

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Corresponding author:

Matthé Scholten;

Email: matthe.scholten@rub.de

Opportunities and challenges of self-binding directives: A comparison of empirical research with stakeholders in three European countries

Matthé Scholten¹, Simone A. Efkekmann², Mirjam Faissner², Marleen Finke¹, Jakov Gather^{1,2}, Tania Gergel³, Astrid Gieselmann^{1,4}, Lia van der Ham⁵, Georg Juckel², Laura van Melle^{5,6}, Gareth Owen³, Sarah Potthoff¹, Lucy A. Stephenson³, George Szmukler³, Astrid Vellinga⁷, Jochen Vollmann¹, Yolande Voskes⁵, Anna Werning² and Guy Widdershoven⁵

¹Institute for Medical Ethics and History of Medicine, Ruhr University Bochum, Bochum, Germany; ²Department of Psychiatry, Psychotherapy and Preventive Medicine, LWL University Hospital, Ruhr University Bochum, Bochum, Germany; ³Institute of Psychiatry, Psychology and Neuroscience, King's College London, London, UK; ⁴Department of Psychiatry and Psychotherapy, Charité Campus Benjamin Franklin, Berlin, Germany; ⁵Department of Ethics, Law and Humanities, Amsterdam UMC, Vrije Universiteit Amsterdam, Amsterdam, The Netherlands; ⁶GGZ inGeest, Amsterdam, The Netherlands and ⁷Mentrum/Arkin, Amsterdam, The Netherlands

Abstract

Background. Self-binding directives (SBDs) are psychiatric advance directives that include a clause in which mental health service users consent in advance to involuntary hospital admission and treatment under specified conditions. Medical ethicists and legal scholars identified various potential benefits of SBDs but have also raised ethical concerns. Until recently, little was known about the views of stakeholders on the opportunities and challenges of SBDs.

Aims. This article aims to foster an international exchange on SBDs by comparing recent empirical findings on stakeholders' views on the opportunities and challenges of SBDs from Germany, the Netherlands, and the United Kingdom.

Method. Comparisons between the empirical findings were drawn using a structured expert consensus process.

Results. Findings converged on many points. Perceived opportunities of SBDs include promotion of autonomy, avoidance of personally defined harms, early intervention, reduction of admission duration, improvement of the therapeutic relationship, involvement of persons of trust, avoidance of involuntary hospital admission, addressing trauma, destigmatization of involuntary treatment, increase of professionals' confidence, and relief for proxy decision-makers. Perceived challenges include lack of awareness and knowledge, lack of support, undue influence, inaccessibility during crisis, lack of cross-agency coordination, problems of interpretation, difficulties in capacity assessment, restricted therapeutic flexibility, scarce resources, disappointment due to noncompliance, and outdated content. Stakeholders tended to focus on practical challenges and did not often raise fundamental ethical concerns.

Conclusions. Stakeholders tend to see the implementation of SBDs as ethically desirable, provided that the associated challenges are addressed.

Empfehlungen

Implementation of self-binding directives: recommendations based on expert consensus and input by stakeholders in three European countries

Self-binding directives (SBDs) are psychiatric advance directives including a clause in which mental health service users give advance consent to involuntary hospital admission and treatment, and grant mental health professionals permission to overrule anticipated treatment refusals during future mental health crises^{1,2}. They are also known as “Ulysses contracts” or “Ulysses arrangements”.

SBDs can enable people with mental disorders which involve fluctuating mental capacity and regular treatment refusals during crises (e.g., psychotic and bipolar disorders) to stay in control of their life and treatment¹. During episodes, these people may make decisions that are incompatible with their deeply-held values, convictions and preferences. Such decisions regularly involve refusal of hospital admission or treatment and can have far-reaching consequences. By enabling service users to authorize professionals to overrule such refusals, SBDs are essential to advance care planning in people with psychotic or bipolar disorders.

While potential ethical benefits and risks of SBDs have been discussed extensively in the ethics and legal literature, little was known about stakeholders’ views on the opportunities and challenges of SBDs until recently. Recent studies conducted in Germany, The Netherlands and the UK reveal that stakeholders perceive promotion of autonomy, avoidance of harm, possibility of early intervention, improvement of the therapeutic relationship, and involvement of trusted persons as opportunities of SBDs³⁻⁹.

Perceived challenges include lack of awareness and knowledge of SBDs, lack of formal support for SBD completion, undue influence during the drafting process, inaccessibility of SBDs during crisis, lack of cross-agency coordination, problems of interpretation of SBD content, difficulties in mental capacity assessment, restricted therapeutic flexibility due to narrow SBD instructions, infeasibility of SBDs due to scarce resources, disappointment due to non-compliance with SBD instructions, and outdated SBD content³⁻⁹.

Stakeholders who participated in these studies tended to see the implementation of SBDs as ethically desirable, provided that the above-mentioned challenges are addressed through the implementation of appropriate safeguards. Based on suggestions made by stakeholders and a structured expert consensus process among authors, we have derived the following recommendations for the legal and clinical implementation of SBDs.

Legal regulation. The implementation of SBDs requires legal provisions stating clear criteria for the validity, content, activation and revocation of SBDs. There should be an expedited procedure for arranging involuntary hospital admission and treatment based on an SBD to enable early intervention.

Authorization by an independent party. Involuntary hospital admission and treatment based on an SBD must be authorized by an independent party. The authorization can take the form of a prospective approval or a retrospective review by a judge, a second opinion by an independent medical specialist, or another

IV. Ergebnisse

Rechtlicher Rahmen

- Einen rechtliche Regelung für Odysseus-Verfügungen sollte geschaffen werden
 - Gültigkeitskriterien
 - inhaltliche Anforderungen
 - Kriterien für die Umsetzung
-

Bewusstsein und Kompetenz

- Bewusstsein sollte geschaffen werden, z. B. mittels Flyer, Informationsblätter, Online-Informationen und Kampagnen in traditionelle und soziale Medien
 - Kliniker sollten geschult werden
 - Fortbildungen und Fortbildungsmaterialien sollten entwickelt werden
-

Zielgruppe

- fluktuierende Einwilligungsfähigkeit
 - Tendenz, eine Krankenhausaufnahme und Behandlung während der Krise abzulehnen
 - Remission der Symptomatik zwischen Episoden
 - Erfahrung mit Unterbringung und Zwangsbehandlung
 - gute Krankheitseinsicht
-

Erstellung

- Unterstützung bei der Erstellung
 - Aufklärungsinformationen
 - Erwartungsmanagement
 - Involvierung von Angehörigen bzw. Vertrauenspersonen
 - Moderation durch eine neutrale Partei (z. B. Genesungsbegleiter*in)
-

Inhalt

- Umständen, unter den eine Unterbringung bzw. Zwangsbehandlung angeregt werden muss
- Präferenzen bezüglich der Unterbringung und Behandlung
- Umständen, unter den die Unterbringung bzw. Zwangsbehandlung abgebrochen werden muss

- Kontaktdaten der Vertrauenspersonen
- Unterschriften der Beteiligten (Trialog)

- Optional: selbst definierte Indikatoren für Einwilligungsunfähigkeit

Umsetzung

- Auffindbarkeit und Zugänglichkeit der Odysseus-Verfügung muss garantiert werden, z. B. mittels einer datenschutzkonformen digitalen Infrastruktur
- **Anwendungskriterien:**
 - die im Dokument beschriebenen Umständen sind aufgetreten
 - die Person ist nicht einwilligungsfähig
 - eine richterliche Genehmigung liegt vor

Umsetzung und Evaluation

- Die Unterbringung und Zwangsbehandlung müssen gemäß den Angaben in der Odysseus-Verfügung durchgeführt werden
- Nachbesprechung: Waren die Unterbringung und Zwangsbehandlung in Übereinstimmung mit den Angaben in der Odysseus-Verfügung?

V. Fazit

Fazit

- Die Risiken und Herausforderungen von Odysseus-Verfügungen können mittels geeigneter Schutzmaßnahmen und einer sorgfältigen Implementierung überwunden und minimiert werden.
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Danke!

Mehr Information

matthe.scholten@rub.de

www.bochum-salus-project.com

GEFÖRDERT VOM



Bundesministerium
für Bildung
und Forschung

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