

Clinical decision making and outcome in routine care for people with severe mental illness (CEDAR, Project No. 223290)

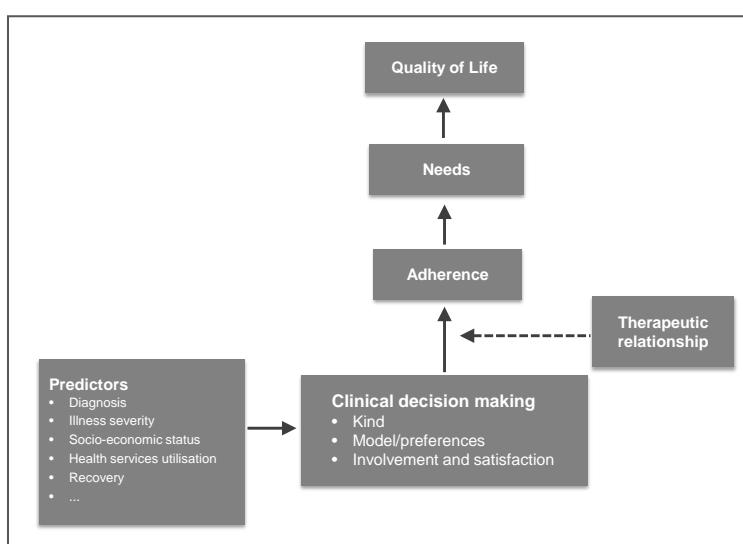
Publishable summary report

Main objectives

Clinical decision making (CDM) in chronic conditions such as severe mental illness (SMI) has to take into account that treatment focus is on long-term disease management, a high number of decisions have to be made frequently, often together with more than one service provider and/or carers, and that patients in general are highly knowledgeable about their illness. There is a lack of knowledge on CDM and its outcome in the care for people with severe mental illness. The most salient approach (i.e. both clinically relevant and crucial for clinical governance) would be a focus on what level of participation a patient wants in their care, and whether a good match between desired and experienced level of participation has any impact on treatment satisfaction or outcome.

Furthermore, quality of CDM in the care of people with SMI has yet to be studied from an international perspective which would yield insights into similarities and differences of CDM among different countries and mental health service systems.

The CEDAR study addresses those challenges. The main objective of this multi-centre prospective observational study is to develop a methodology to assess the scope and quality of clinical decisions in the care of people with SMI from both the patient and clinician perspective, and to specify how and to what degree CDM in routine care affects patient behaviour and short- and long-term treatment outcome. The figure below shows the model to be tested in the CEDAR study in 6 European cities (Ulm/Germany, London/UK, Naples/Italy, Debrecen/Hungary, Aalborg/Denmark, and Zurich/Switzerland).



Results

Phase 1 (04/09-06/09): Instrument development: Three instruments with parallel patient and staff versions each were developed to assess key aspects of clinical decision making in the routine care of people with severe mental illness: (i) *Clinical Decision Making Style (CDMS)*: To assess nature and stability of CDM style (with the subscales “Participation in Decision Making” and “Information”) at baseline and at one-year follow-up; (ii) *Clinical Decision Making Involvement and Satisfaction (CDIS)*: To assess at bi-monthly intervals involvement in (“active” vs. “shared” vs. “passive”) and satisfaction with CDM; (iii) *Clinical Decision Making in Routine Care (CDRC)*: To measure at bi-monthly intervals context and content of CDM. Instrument development followed state-of-the-art recommendations for the development, translation and cultural adaptation of measures and yielded feasible instruments in five languages showing adequate psychometric properties.

Phase 2 (7/09-09/12): Main study: A comprehensive prospective study with 6 measurement points over one year was carried out in six European countries (DE, UK, IT, HU, DK, CH) in order to examine the effect of clinical decision making on outcome. Data collection and check for the main study was completed in July 2012 (N = 588 patients, N = 213 staff). Patients were in their early forties on average, half of them were female, and mean duration of mental illness was more than 12 years. Main themes of clinical decision were medication, social issues, and psychosocial treatments. Both patients and staff indicated shared as their preferred style of participation in decision making. Desire for information was predominantly high in patient report, and mostly moderate in the view of staff. Satisfaction with the way the last decision was met was predominantly high in patients, and mostly moderate in staff, while involvement was mainly rated as shared by both. Unmet needs (outcome) significantly decreased over one year, and change in unmet needs was affected by clinical decision making style and with the satisfaction with how the actual treatment decision was made.

Recommendations

- (1) Three new measures (CDMS, CDIS, CDRC) are available in Danish, English, German, Hungarian and Italian, and are suitable for use in clinical practice and research studies.
- (2) The content, structure, and process of clinical decision making in people with severe mental illness is amenable to empirical investigation. Future research involving the measures developed in this study can aim to understand the relationship between psychosocial interventions and clinical decision making.
- (3) Decision making style and content in treatment session both impact on patient outcome. Future interventions should specifically characterise and influence staff and patient attitudes and behaviour in relation to decision making in clinical practice, in order to foster decision making on the basis of a cooperative bond between patient and staff.