

CONFERENCE ABSTRACT

Client-accessible records contribute to experienced autonomy in 'care for youth'.

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Introduction: Worldwide, patient-accessible health records are gaining popularity, contributing to, among others, patients' autonomy. Since autonomy is an important aim in the Dutch transformation of care for youth, three organizations developed a client-accessible record as an instrument to enhance their client's autonomy. We investigated how a client-accessible record was received by its users and whether it contributes to autonomy among youths and their parents.

Methods: A mixed methods design was used to measure autonomy and the process indicators acceptability, adoption, appropriateness and fidelity. Autonomy was assessed with self-constructed surveys among professionals and clients, measured at baseline and in follow-up. Change in autonomy was tested using independent-sample T-tests. To evaluate the process, project meetings were recorded and analyzed qualitatively. Focusgroup interviews with clients and professionals deepened understanding of autonomy and process indicators.

Results: Preliminary analyses of the survey among 914 parents and 89 youths show an improvement in experienced autonomy among both groups. This improvement was stronger when respondents had actually accessed their client record. In focusgroups, parents reported that transparency of the client record was the most important benefit and enhanced their trust in professionals. Professionals said that parents acted more autonomous. They took a more active role in planning appointments, gave more feedback on visit notes and corrected mistakes. Youths especially appreciated having control over who accessed their client record.

The process evaluation showed high acceptability scores among clients, independent of demographic features. However, adoption appeared to be lower among lower educated Respondents.

Conclusion: A client-accessible youth health record bears potential to enhance a client's autonomy. More research is needed to explain the contradiction between acceptability and adoption outcomes.