



Web-based support for daily functioning of people with mild intellectual disabilities or chronic psychiatric disorders: A feasibility study in routine practice



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ABSTRACT

Background: People with mild intellectual disabilities or chronic psychiatric disorders often experience challenges in important aspects of life and need support in daily functioning. In this study, we examined the feasibility of a web-based program enabling professional support of patients with chronic conditions in their daily functioning. **Method:** A triangulated research method was applied involving a combination of the results of semi-structured interviews and standardized questionnaires. We conducted face-to-face interviews with clients ($n = 11$) and telephone interviews with coaches ($n = 10$) on their initial experiences with the program. In addition, clients took an online pre-test ($n = 39$) – post-test questionnaire ($n = 30$) which measured quality of life, empowerment, mastery, social cohesion and satisfaction with care. Clients and coaches both received a questionnaire to report on the perceived usability of the program.

Results: Clients and coaches used the program and were positive about this new way of communicating. Clients were pleased that they could contact the coach at any time and experienced increased control over the support they received. Coaches reported positive effects on the levels of independence among clients, saved time and experienced greater flexibility in their scheduling. The implementation of the program did not lead to changes in quality of life, empowerment, mastery, social cohesion or satisfaction with care. Clients and coaches reported that the usability of the MPC could be improved through the use of an enhanced Internet connection.

Conclusion: The initial results of the use of web-based support for this client population seem promising and justify further research on online support for clients with mild intellectual disabilities or chronic psychiatric disorders.

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1. Introduction

People with intellectual disabilities or chronic psychiatric disorders (MID-CPD) face many challenges in important aspects of their life, including daily functioning, physical health constraints, social isolation and limited financial resources (Pratt, 2012; Verdonschot et al., 2009). When people with MID-CPD live independently or semi-independently in the community, they often need support with tasks related to daily functioning in order to meet their personal needs (Perkins and Burns, 2001; Thompson et al., 2009). Such personalized support is often provided by professional coaches who visit clients at their homes. Coaching aims to give clients the skills they need to attain

a high level of independent daily functioning and improve their quality of life and social functioning (Slevin et al., 2008). With this in mind, coaches generally aim to empower their clients. Empowerment has been defined by Rappaport (1987, p.122) as ‘a process, a mechanism by which people, organizations, and communities gain mastery over their affairs’. Through focusing on empowerment, the coach accentuates personal rights and potential, rather than focusing on impairments. Available studies, although limited in numbers, show that providing personalized support at home may lead to improved personal functioning and quality of life among clients with MID-CPD (Siskind et al., 2012; Young et al., 1998). Recently, this kind of support has also been provided remotely, supported by web-based technologies. These new technologies may offer a new, more efficient type of support for MID-CPD clients, while maintaining quality of care levels.

The overall use of Internet interventions in mental health care is rapidly expanding (Andersson et al., 2014; Lal and Adari, 2013). A number

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of interventions aimed at the prevention and treatment of common mental disorders have been developed, delivered via Internet and have proven to be effective when compared with non-intervention or face-to-face treatments (Andrews et al., 2010; Richards and Richardson, 2012). Directing individuals with psychological problems to Internet interventions may reduce costs, facilitate access to help and boost empowerment and self-management skills (Musiat and Tarrrier, 2014; Samoocha et al., 2010; Smit et al., 2011). Most e-Mental-Health research has focused on the development and (cost) effectiveness of therapeutic (guided and unguided) self-help interventions to reduce or overcome symptoms of common mental disorders such as anxiety, depression, substance abuse (Lal and Adari, 2013) and co-morbid disorders such as diabetes and depression (Van Bastelaar et al., 2011). Online support for daily functioning for the broad MID-CPD target group remains the exception in terms of both research and service provision. In contrast, studies on the evaluation of online support in daily functioning for clients with (chronic) physical conditions such as diabetes or cardiac problems are widely available and show positive results in relation to health outcomes and costs (Purcell et al., 2014; Takahashi et al., 2012; Verhoeven et al., 2007).

The lack of online developments in the field of support for the specific MID-CPD group can be explained by a number of barriers which are linked to characteristics of this target group. One explanation is that MID-CPD clients are often characterized by a low social economic status which constitutes a barrier to Internet use and the acquisition of a personal computer (DiMaggio et al., 2004). Another possible barrier is that MID-CPD clients often experience impairments in information processing, learning new information and concentration, which complicates the acquisition of new skills (Sadock and Sadock, 2005). Furthermore, the use of web-based devices such as webcams and microphones may be problematic for clients with CPD who experience delusions (Bell et al., 2005). For these reasons, it was long understood that personal computer or Internet use was beyond the capacities of MID-CPD clients. However, in the Netherlands and other North Western European countries, Internet penetration is remarkably high and almost complete (Warf, 2013). Internet use rates among people with MID-CPD appear to be increasing as well (Khazaal et al., 2008; Tanis et al., 2012). A recent study in the Netherlands even found that people with lower educational levels and people with physical or mental disabilities which prevent them from working, use the Internet more often than people with high levels of education and those in employment (Van Deursen and Van Dijk, 2014). The researchers investigated Internet use in leisure time. The results show that people with a disability and people with lower education use the Internet for more hours a day than higher educated and employed persons and are more likely to use the Internet for gaming and social interactions. Conversely, people with higher education use the Internet more often for personal development and information seeking. Nowadays, it appears that there are no computer- or Internet use barriers for the MID-CPD group in the Netherlands and professional support can be provided online.

Hulsbosch et al. (2011) investigated the effects of an online support system that enabled videocalling between clients with chronic psychiatric disorders and their coaches in a randomized controlled trial. Online videocalling was combined with care as usual (face-to-face contact) to support clients in their daily functioning. Clients who received online support showed stable clinical outcome measures such as quality of life and social and psychological functioning. They also rated their satisfaction with care over the study period higher compared with clients who received care as usual ($\beta = -2.750, p = 0.03$). In a small pilot study, Taber-Doughty et al. (2010) compared face-to-face support with support via online videocalling on the independent performance of adults with intellectual disabilities as they completed household tasks. Results indicated that clients who were supported through videocalling had a higher degree of independent performance than those who were not supported in this way. Although initial results seem thus promising, much more research is needed in this area.

In the present study, we focus on the MPC, an online program that enables online communication between MID-CPD clients and their coaches. Coaches offer support when clients experience problems in daily activities as financial administration, housekeeping tasks, social activities or arranging appointments with health professionals and through the MPC clients can receive this support online. One of the core functionalities of the MPC is secured videocalling. This enables clients and coaches to communicate in a way face-to-face on a distance. Furthermore, it contains a personal logbook for the client, messaging for clients and coaches, the client dossier and information. The main objective of the study is to evaluate the feasibility of using the MPC in a regional institution for supported living in the Netherlands. We describe the characteristics of the program and explore the initial experiences of patients and coaches with the program on the basis of qualitative interviews. We also report data on a pre-test – post-test survey which measured the main goals of support for daily functioning for this client group: quality of life, empowerment, mastery and social network. In addition, we measured the usability of the program and satisfaction with care.

2. Methods

2.1. Study design

We performed an uncontrolled feasibility study, in which we applied a triangulated research method to assess the experiences of clients and coaches with the MPC through semi-structured interviews and online questionnaires. Methodological triangulation refers to the use of more than one study method to answer a research question in order to increase confidence in the results (Denzil, 1970). Clients were invited for face-to-face interviews, and telephone interviews were held with coaches. Clients received a questionnaire on two occasions: first, a baseline assessment and then a follow-up measurement three months later. Coaches and clients each received one questionnaire about the usability of the program. The study protocol was approved by the Scientific Committee of the EMGO + institute and by the Internal Ethical Committee of the VU Psychology and Education faculty.

2.2. Participants

Participants were clients with mild intellectual disabilities or severe chronic psychiatric disorders such as psychotic disorders, schizophrenia, personality disorders and mood disorders. They received professional support in their daily functioning at home from professional coaches in a regional institution for supported living in the Netherlands. Coaches selected clients who were able and motivated to work with the program.

2.3. Study procedure

Clients who were using or subscribed to the MPC ($n = 162$) received a description of the study and an informed consent form via mail and e-mail. Clients could indicate on the informed consent whether they were willing to participate in a face-to-face interview or/and the questionnaires. After submitting the informed consent form by mail, the participants received a link to the first web-based questionnaire. A link to the second web-based questionnaire was sent three months later. Participants received a gift voucher for their contribution (€10 per interview or questionnaire). Coaches who used the program ($n = 44$) were also invited to the study. They were informed via e-mail about the research, received a link to the questionnaire and were invited to participate in a telephone interview.

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