

# Personal control in rehabilitation: An internet platform for patients with schizophrenia and their caregivers

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## ABSTRACT

In order to facilitate optimal quality and continuity of care and self-management of patients with schizophrenia, Personal Control in Rehabilitation (PCR) has been developed, a comprehensive internet-based platform. PCR aims to reach patients with schizophrenia or related psychotic disorders and their (in)formal caregivers. It provides caregivers and patients with a kind of dashboard giving them (tailored) information about the physical and psychosocial situation of the patient, their compliance with treatment, and facilitates optimal self-management for patients. With the use of PCR, informal caregivers have access to information about treatment and can consult formal caregivers, formal caregivers have easy access to the multidisciplinary guideline schizophrenia and to the regional care plans. Patients and their formal and informal caregivers completed questionnaires about empowerment, quality of life, quality of care and workload before the introduction of PCR and nine months later. A sample of them also participates in focus group discussions about the usefulness and usability of PCR and bottle necks in using the platform. Response to the questionnaires, especially at followup, was not adequate for statistical analyses of its results. Therefore, the focus of this paper is on the process evaluation of the implementation of PCR in two large mental health organisations in the Netherlands. Data for this evaluation are results of a number of open questions of the questionnaire and results of the focus group discussions. In these discussions, 19 patients, 12 informal caregivers, 33 formal caregivers and three managers participated. Preliminary results of this study show that the implementation of PCR is feasible and patients, formal and informal caregivers were satisfied with the use of PCR and frequently used PCR to communicate, make appointments, give feedback and look for information

about their disease and its treatment. PCR is considered as a help in reaching more self-management by patients, to facilitate communication between patients and caregivers, and to match treatment and support. It seems useful also for other patient groups and their (in)formal caregivers like patients with depression, autism and addiction disorders.

**Keywords:** Schizophrenia; Self Management; Internet Platform; Disease Management

## 1. INTRODUCTION

Schizophrenia and related psychotic disorders are major psychiatric disorders. Incidence of schizophrenia and related psychotic disorders is estimated to be 1.5 per 10,000 inhabitants, with a life time incidence of 1% [1]. This corresponds with 24,000 new cases each year in the Netherlands. Schizophrenia has a high burden of disease, causing limitations in psychological functioning and social participation and has great impact on patients, their relatives and society. Symptoms are extremely heterogeneous and variable among and within patients and psychotic relapse frequently occurs [2]. Moreover, the costs of treatment of and care for patients with schizophrenia are very high [3] and there is a growing demand for cost-effective interventions [4]. The high costs of schizophrenia care (500 million a year in the Netherlands) are influenced by the ineffectiveness of available interventions, large amounts of time spend travelling, the amount of face to face contacts and the number of no-shows.

People with schizophrenia generally participate on moderately low levels in society, experience unfulfilled needs for rehabilitation and are socially isolated [5]. They are long-term dependent on mental health care, but many withdraw from treatment and the use of medication. Patients don't have access to sufficient information to understand, influence and control their problems (self-management). Self-management entails active participation of patients in their treatment and rehabilitation and is

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crucial for good integrated care, recovery of social functioning and well-being [6,7]. Increased of empowerment has shown to be associated with improved quality of life, recovery and social integration [8,9]. Research has shown that the use of relapse prevention plans by patients helps with their understanding of their mental health problems and the gaining of more control over the course of their disease [6,10].

Care for patients with schizophrenia has in recent years improved considerably with the implementation of care programs and the Multidisciplinary Guideline Schizophrenia [5]. This, however, has not yet resulted in an integrated care system in all Dutch regions, and in a sound and systematic application of all guideline recommendations.

In recent years, several initiatives have dealt with emphasising the role of the patient and implementing patient tailored care according to current guidelines and care programs [10-13].

In today's mental health care, patients increasingly take a central role in the management of their disease. Patients want a greater involvement in their treatment and ask to be informed about their health. Feedback about treatment effects to both patients and (in)formal caregivers can have a positive influence on treatment results [14,15].

There are, till now, no Dutch studies looking at an integrated Disease Management (DM) approach with active participation of patients with schizophrenia and their formal and informal caregivers. In the most recent update of the multidisciplinary guideline schizophrenia [5] emphasis is put on an integrated DM approach which would improve quality of care, rehabilitation and recovery, and stimulate self-management of patients with severe mental illness.

In order to facilitate optimal quality and continuity of care and self-management of patients with schizophrenia, a comprehensive internet-based platform has been developed for patients with schizophrenia or related psychotic disorders and their (in)formal caregivers: Personal Control in Rehabilitation (PCR) [16]. With the use of PCR, patients' self-management is facilitated, informal caregivers have access to information about treatment, and formal caregivers have easy access to the multidisciplinary guideline schizophrenia and to regional treatment plans. Such direct access to evidence based information is expected to lead to more optimal treatment and considerable savings in costs [17,18].

PCR provides caregivers and patients with a kind of dashboard, giving caregivers (tailored) information about the physical and psychosocial situation of patients and their compliance with treatment; and facilitating optimal self-management for patients.

Expected benefits of PCR are that:

Patients are given more control over their situation, illness and treatment, take part in an adequate network of care, have easier, safer and more frequent contacts with caregivers, with better information about treatment and more continuity of care [19,20].

Formal caregivers receive up to date information about the situation of patients, their compliance with treatment, and information from regional care programs and the Multidisciplinary Guideline Schizophrenia [5]. More proactive care has been shown to result in a better focus on prevention, rehabilitation and recovery [5,7].

These changes are expected to increase quality of care for patients with schizophrenia [21] and to decrease the period needed for treatment and associated costs (as a result of less face to face contacts, more efficient communication and less no shows).

PCR has been developed and implemented at two large mental health organisations in the Netherlands from 2008 till 2011. PCR has been used by patients and their (in)formal caregivers from November 2009 till 2011. In the present study, the first experiences with the use PCR will be described.

Research questions of this study are:

- How does the use of PCR influence self-management of patients and the perceived quality of care?
- Has PCR been implemented as meant and what are the experiences of patients and their formal and informal caregivers?

## 2. METHODS

### 2.1. Intervention: Personal Control in Rehabilitation

PCR consists of an open portal and three protected, personalized portals for patients with schizophrenia, their informal caregivers and their formal caregivers. The three personalized portals are protected by a user name and password and are open for use at any time. Only authorized (in)formal caregivers and relatives are allowed to make use of PCR. Authorization to informal caregivers and relatives has to be granted by the patient.

The content and the design of PCR are developed in close cooperation with patients and their formal and informal caregivers.

Using PCR, patients and caregivers can collect reliable information, cooperate, communicate and follow the course of treatment. In PCR several innovations are joined: interventions regarding self-management for patients (making appointments, safe communication and the possibility to look into their personal signal and treatment plan), evidence based care programs for caregivers (from the multidisciplinary guideline).

PCR is not meant to substitute regular patients and caregivers contacts. It is, however, expected that the

number of face to face contacts will decrease over time and the number of short digital and telephone contacts will increase, resulting in an overall reduction of time spent by caregivers. Furthermore, the number of crisis interventions and (re)admissions are expected to decrease by the use of PCR.

PCR is developed to support caregivers and patients in monitoring the course of disease and its treatment, and the course of rehabilitation and recovery improving quality and continuity of care for people with schizophrenia.

The focus in PCR is on monitoring physical and mental symptoms, social functioning, quality of life and self-management of patients. Regarding the care delivered, there is a focus on providing good, safe and efficient care leading to less and shorter readmissions, better psycho-education, more meaningful cooperation of caregivers, and monitoring of symptoms and functioning.

Patients and their informal caregivers can get and add information from/to the system themselves (like information about the course of their disease, their treatment plan, relapse prevention plans, perform self-tests, complete questionnaires and a logbook). The system also provides information on different treatment options, psycho-education and health risks, and patients can have digital contact with other patients and their caregivers (through email and chat function).

## 2.2. Participants

Sixty patients and their formal and informal caregivers were asked to participate in this project by using PCR, completing a questionnaire and (a sample) to participate in focus group discussions. For patients, inclusion criteria were: age between 18 and 66 years, having had a first psychosis or receiving care for schizophrenia for a longer time, being able to participate in the study and to complete a questionnaire. Of each participating patient, one informal caregiver and at least one formal caregiver was asked to participate in the study. A sample of patients, (social psychiatric) nurses, psychologists, social workers, psychiatrists and managers, covering both mental health organisations was asked to participate in the focus group discussions

## 2.3. Procedure

Patients and their (in)formal caregivers were trained to use PCR and they received help from a psychiatric nurse in using PCR during the project. At each mental health organisation a project coordinator managed the study and answered any questions from patients and (in)formal caregivers about the use of PCR. These coordinators could consult a helpdesk from the software company and the researchers for any questions about the platform and the study.

Patients and their (in)formal caregivers were asked to complete a questionnaire at the start of using PCR and again after nine months. At baseline, patients and informal caregivers completed a written version of the questionnaire, while formal caregivers completed a digital version. At the follow-up measurement patients and their (in)formal caregivers completed a digital version of the questionnaire on PCR. Participants received a letter or e-mail about the questionnaire to be completed on PCR. Reminders were sent at two and four weeks after the first request. At 15 months from baseline, focus group discussions were organized with patients and their (in)formal caregivers.

Patients and their informal caregivers participated together in focus group discussions per organisation at all measurements. All formal caregivers except psychiatrists participated together per organisation. A third focus group consisted of managers and psychiatrists.

## 2.4. Questionnaire and Focus Groups

Questionnaires for patients and (in)formal caregivers contain questions about socio-demographic characteristics and some open questions about the use, usability and usefulness of PCR. Besides these questions, some frequently used and validated questionnaires are used to measure some important variables.

The questionnaire for patients contains questions about empowerment [22], quality of life [23], social participation [22] and quality of care (a questionnaire based on the Euroqol 5d) [24,25]. For the formal caregivers it contains questions about work load and work satisfaction [26]. The questionnaire for informal caregivers contains questions about caregiver strain [27] and quality of life [28].

Twenty-four patients, 35 formal caregivers, 10 informal caregivers, and three managers with were asked to take part in the focus group discussions. The focus groups were led by two researchers and checklists were used to guide and standardize the focus group discussions. There were three kinds of focus groups: of patients and informal caregivers together, of formal caregivers (psychiatric nurses, social workers and psychologists), and focus groups of managers and psychiatrists. Questions at baseline concerned communication among/between patients and (in)formal caregivers, expectations of PCR and first experiences with PCR. Questions at follow-up concerned experiences, advantages of and problems with the use of PCR and wishes and ideas how to optimize PCR and its use.

All focus group discussions were recorded by audiotape.

Data of the focus group discussions were transcribed and main themes deduced by both researchers separately. Discrepancies in themes were discussed until consensus

was reached.

### 3. RESULTS

Since response to the questionnaires, especially at follow-up, was not adequate for statistical analyses of its results (at baseline and at nine months, respectively: 25 and 18 patients, 35 and 7 formal caregivers and 10 and 0 informal caregivers completed the questionnaire). Therefore, the focus of this paper is on the process evaluation as measured with the open questions of the questionnaire and the focus group discussions. In this section, main results of the focus group discussions and open questions of the questionnaire are described. Participants to the focus group discussions consisted of 19 patients (14 men and 5 women), 12 informal caregivers, 15 nurses, 8 social psychiatric nurses 3 psychologists, 4 social workers, 3 psychiatrists and 3 managers.

At baseline discussions, both patients and their (in)formal caregivers considered the term “schizophrenia” as too stigmatizing to use in PCR, therefore the concept: “psychological vulnerability” is used in the platform.

#### 3.1. Use of PCR

During the first two months of the study, PCR had about 1980 visits each month, with an average of 64 times a day (range: 2 - 143 times a day); during the last two months the number of visits of PCR had stabilized around 1230 times each month with an average of 41 times a day (range: 1 - 37 times a day) at the two participating organisations together. For example: in June 2010, caregivers used PCR 214 times to communicate with patients about changes of the treatment plan and patients used PCR 246 times to ask questions, 83 times to make appointments with their formal caregivers and 439 times to contact them.

Only for one organisation, it was possible to get information about the kind of users of PCR. The number of visits of patients and formal caregivers is comparable: about 71 times a month during the first seven months. During this period, informal caregivers made use of PCR for only seven times per month.

At the start of the project there were some safety problems leading to a break of two months. After the restart of the program, the enthusiasm and motivation of participants to use PCR was tempered.

#### 3.2. Experiences of Patients with PCR

Before the implementation of PCR, patients expected advantages of its use regarding a more optimal communication with their (in)formal caregivers and with other patients. They also expected faster answers of caregivers to their questions.

Some patients were afraid about privacy issues and that PCR would lead to less face to face contacts.

At nine months after the introduction, patients perceived advantages of using PCR in: putting forward questions to caregivers whenever they want, being able to formulate their problems more accurately, receiving better help by caregivers, better possibilities for social functioning, more accurate and reliable information about their disease, and being able to look into their treatment, relapse prevention and medication plan.

Patients reported that PCR worked well but several technical aspects had to be improved: size of letters was too small and some parts of PCR didn't function well. Furthermore, some patients had concerns about security and privacy of PCR. Another disadvantage according to some patients was that PCR was focussed too much on illness and treatment which doesn't stimulate its use. They pronounced the importance of more personal content of PCR.

Overall, PCR was evaluated positively by patients as a modern way to communicate, the overview of their treatment goals and medication was reported to facilitate them to communicate and decide about their treatment goals. The structured information provided on PCR about disease and its treatment was appreciated by patients as a way to reduce the burden of disease.

#### 3.3. Experiences of Informal Caregivers

At the start of the study, informal caregivers had positive expectations about the use of PCR but they were afraid of a resulting decrease of the number of face to face contacts. They expected better communication and information about disease, its treatment and rehabilitation, more contact with patients and formal caregivers and better planning of support.

At nine months after the introduction of PCR, informal caregivers considered the improved and faster communication and information about schizophrenia as the main advantage of PCR.

Because of privacy, patients had to authorize their informal caregivers and relatives to use PCR and to look into their data. At follow-up it appeared that most patients didn't do that. Reasons mentioned were that patients didn't want their informal caregivers to know everything about their treatment and that informal caregivers often were not motivated to be involved in treatment.

#### 3.4. Experiences of Formal Caregivers

Before the implementation of PCR, formal caregivers were reserved about its use, because of the complex problems of many patients. Their main concern was that the use of computers and internet could strengthen paranoia. Another concern was that computerised support

might replace face to face contact. According to the caregivers, regular face to face contact with chronic patients is important. Therefore caregivers mentioned that PCR has to be an aid next to the existing care, instead of a replacement for face to face contacts. Especially in crises, personal contact with patients is considered necessary, to check how patients are doing.

At nine months caregivers mentioned that they considered the use of PCR as time consuming. Working with PCR was considered as an additional activity since it was not integrated in the Electronic Patient Record. As a consequence some activities had to be performed twice resulting in extra work load. Another disadvantage mentioned by formal caregivers was that messages placed on PCR may be missed by caregivers.

Formal caregivers suggested to introduce some behavioural codes for using mail by caregivers and patients, like minimal time periods within which to respond to messages of patients. It is expected that the use of PCR will lead to a more equivalent contact with patients, with more transparency and more personal control for patients.

Caregivers appreciated the modern way of communication with patients and each other. According to them, the use of PCR has led to a change in thinking and attitude. From the introduction of PCR, caregivers used computerised communication, like e-mail more often. It is also appreciated that patients have more personal control about treatment decisions, because of easy access to their treatment goals and medication. PCR may also have a function in signalling worse functioning of patients enabling caregivers to react more quickly.

The information provided in PCR is considered as good to understand and reliable, and the use of PCR is considered to enlarge the patients' horizon.

Management of both mental health organisations perceived a financial advantage by the use of PCR, because formal caregivers can combine home visits and appointments and can have contact by internet. At the pilot study, internet wasn't available for every individual patient and its quality wasn't always as good as possible.

#### 4. DISCUSSION

Results of this pilot study suggest that the introduction of PCR in mental health organisations is feasible and supplies patients and informal caregivers with an aid supporting self-management. This corresponds with results of other studies [19,20].

As a result of the poor response to the questionnaires at follow-up, statistical analyses of its results over time were not possible. Therefore, the focus of this paper is on the process evaluation as measured with some open questions of the questionnaire and the focus group discussions.

Patients appreciated that, with the use of PCR, they were able to look for reliable information about disease, communicate with their caregivers, make appointments and look into their treatment, relapse prevention and medication plan. They consider these aspects to give them more control about their situation. Patients considered it as a relief to write down their worries and questions which facilitated them to formulate their questions more clearly. Results correspond with those of Bäuml *et al.* who showed that psychoeducational interventions for patients with schizophrenia and their families decrease disease related distress and the number of readmissions, and increased empowerment and perceived support [20].

Technical aspects, including security and privacy are very important at any time of the implementation of a new platform, especially in patients with schizophrenia. Much attention is needed to make sure that applications function well and security is warranted.

PCR is meant as an aid in communication between patients and their (in)formal caregivers. Agreements about its use were of utmost importance for optimal involvement in its use. In the present pilot study such agreements were not always clear enough (time periods for answering questions from patients) or not useful (communication with informal caregivers happened via patients). The use of PCR asks for discipline from patients and their caregivers and its use is not informal. Both patients and caregivers have to be actively involved to use PCR and to be alert on new messages in PCR. And have to react within a certain time period agreed upon by both parties. When this is not clear or agreements are not followed, the use of PCR may decrease.

At the start of the study, all participating parties were afraid that the use of PCR would lead to less face to face contacts between caregivers and patients. First results indicated that this was not the case at nine months, both the number of face to face contacts and shorter contacts by email or telephone had increased at that time. The use of PCR may result in a change of roles for formal caregivers especially: from caregiver to coach. A coach in supporting patients keeps control of their situation. This may need some adaptation of caregivers and may result in future resistance to use PCR.

Further research is needed to study the effectiveness of PCR in a longitudinal controlled trial.

A limitation of the present study is the small number of participating patients and (in)formal caregivers, and its focus on qualitative data. As a result, there were no quantitative data to test for the effectiveness of PCR.

Expectations of both patients and (in)formal caregivers were great, but not all of them turned out to be positive or could be measured in the present study (*i.e.* its effect on quality of care, quality of life, better social functioning, more efficient functioning, less time needed

for treatment). Further longitudinal research, using a controlled study design is needed to investigate such aspects.

## 5. MAIN CONCLUSIONS

Patients and caregivers perceived PCR as a useful platform to improve self-management and communication, to take more responsibility and to be better informed about their care-rehabilitation and reintegration supplies.

According to patients and caregivers, PCR led to an increased knowledge of and attention for the importance of self-management and rehabilitation in patients with schizophrenia.

The better accessibility of caregivers is perceived as an advantage of PCR. Patients can raise questions directly to their caregivers, maintain contacts with peer patients and describe their experiences and agreements.

At the start of the study, formal caregivers expected that the use of PCR would lead to more efficient work and would result in shorter and more focussed contacts via PCR. Further longitudinal research is needed to make this clear

According to formal caregivers, care can be given more care-driven by monitoring their patients from a distance. They can take action when needed, giving their patients more personal control. They foresee a change of roles of themselves and their patients, a change from caregiver to coach and patients having a more active role in their treatment

An important advantage of PCR, according to formal caregivers, is the possibility of signalling worse functioning of their patients earlier and react to this more quickly.

For the participating mental health organisations, the use of PCR is perceived to result in more efficient communication, in saving time, and in more knowledge regarding the care process.

## 6. RECOMMENDATIONS FOR FURTHER IMPLEMENTATION OF PCR

Patients considered it important that PCR focuses on rehabilitation and less on disease and its treatment, there should be more attention for improving personal skills. Patients also mentioned the value of making PCR more interactive with more possibilities to control who is allowed to look into their personal data.

To assure that PCR functions well, it should be integrated in the daily routine of caregivers, by linking it directly to the Electronic Patient Record and by using it in regular meetings of professionals.

It is important that caregivers work actively with PCR

and react consequently and timely to messages of patients and informal caregivers. It can be suggested to make agreements about the time period in which caregivers have to react to messages and questions of patients.

Formal and informal caregivers should be actively involved to use PCR. It's use is not informal.

Attention for styling and the interactive character of PCR is essential and determines the way patients use this platform.

The use of PCR might be extended to other groups of patients and their (in)formal caregivers, like patients with autism, depression and addiction disorders.

## 7. FUTURE DEVELOPMENTS

At the end of the pilot study (April 2011) an improved version of PCR was available, ready to be used and tested for its effectiveness in other mental health organisations.

Major advantages of the new version of PCR are its synchronization with the Electronic Patient Record, its improved flexibility, usability and usefulness, and the possibility to add other functionalities if desired. Moreover, different additional functionalities are added to PCR, like screen to screen communication, a tool for sending SMS reminders, a comprehensive electronic dictionary of medical concepts, shared decision making and several self-management modules for patients.

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