

Implementing routine outcome measurement in psychiatric rehabilitation services in Israel

DAVID ROE^{1,2}, MARC GELKOPF^{1,2}, MIRIAM ISOLDE GORNEMANN²,
VERED BALOUSH-KLEINMAN³ & EFRAT SHADMI⁴

¹Department of Community Mental Health, Faculty of Social Welfare and Health Sciences, University of Haifa, Israel,

²Centre for Community Mental Health, Research, Practice and Policy, Faculty of Social Welfare and Health Sciences, University of Haifa, Israel, ³Mental Health Services Department, Ministry of Health, Jerusalem, Israel,

⁴Cheryl Spencer Department of Nursing, University of Haifa, Israel

Abstract

In this article we present the design, development and implementation of the Psychiatric Rehabilitation Routine Outcome Measurement (PR-ROM) project, the first systematic effort to implement mental health routine outcome measures in Israel. The goal of the PR-ROM is to provide updated information about the process and impact of psychiatric rehabilitation services in Israel and to establish a sustainable infrastructure and foundation for routine outcome monitoring of rehabilitation services to improve care, inform policy, generate incentives for service improvement, increase informed decision-making and provide data for research purposes.

The rehabilitation services evaluated and the characteristics of the population being served are described and the methods and nature of the collected data as well as some preliminary findings are presented. We discuss the major barriers encountered, our efforts to deal with them and lessons learned during the process. We conclude with a description of the current state of the initiative and plans for the future.

Background

In line with policies enacted in most developed countries, Israel has made efforts to shift from long-term psychiatric hospitalization to community-based mental health and psychiatric rehabilitation services (Roe et al., 2009). Traditionally, services for people with serious mental illness (SMI) in Israel were, on the whole, limited to psychotropic medication and some psychotherapy provided by psychiatric hospitals and community mental health centres. Some additional services such as vocational rehabilitation, hostels and social clubs were available, but were limited both in the number of people they reached and the extent to which they met their participants' needs (Levav & Grinshpoon, 2004).

A major breakthrough was the passing of the Rehabilitation of Psychiatrically Disabled Persons in the Community Act (2000). The law is among the most progressive social laws enacted in Israel, aiming to improve the quality of life and community integration of people with SMI (Aviram et al., 2012; Drake et al., 2011). This law was formulated taking into

account contributions from diverse stakeholders including mental health professionals, family organizations, patients, human rights advocates and policy-makers. The law entitles people over 18 who pass the threshold of 40% disability due to psychiatric illness, based on the criteria of the National Insurance Institute, to apply for a 'basket' of psychiatric rehabilitation services.

This basket of services addresses many of the key areas in which service users often experience difficulties, including vocation, education, recreation, social life, dental care, and accommodation/housing needs (see a more detailed description hereunder). The services also help participants plan and carry out individualized rehabilitation plans and goals (Aviram et al., 2012; Roe et al., 2007, 2010b).

The passing of the law led to the establishment of the National Council for Rehabilitation of Mentally Disabled in the Community in 2002, which serves to guarantee the implementation of the new law and to support the Ministry of Health (MOH) in promoting further policy developments (Aviram et al., 2012;

Roe et al., 2010a). In accordance with the law, regional rehabilitation committees have been established. These committees approve service eligibility, foster rehabilitation plans and conduct annual follow ups during which progress is reviewed and suitability of services are evaluated and adapted when needed.

Since the enactment of the law, the number of inpatient psychiatric beds per population in Israel has declined by more than 50%, from 7,000 to 3,400 (Hornik-Lurie et al., 2012; Lerner et al., 2012). In parallel, the number of rehabilitation services has been growing dramatically, users of rehabilitation services have increased almost four-fold (nearly 21,000 today) and the designated budget for these services increased eight-fold (Aviram et al., 2012). These processes, and in particular the reduction in number of inpatient psychiatric beds per population, have been estimated to generate a major decrease in costs even after including the growing budget for rehabilitation services (Aviram, 2013).

While there is some evidence to support the effectiveness of rehabilitation services in improving satisfaction and quality of life, reducing severity of psychiatric symptoms and re-hospitalization rates (Grinshpoon et al., 2007; Roe et al., 2010b; Struch et al., 2011), the impact of the rehabilitation services in Israel has not been subject to systematic investigation. As indicated by Israel's State Comptroller and the National Council, the rehabilitation administration lacks information that would allow policy-makers to make data-informed decisions (Israel State Comptroller, 2006). Given the growing number of users of these services and the relative growth in funds invested, this evaluation has become a priority item on the mental health agenda in Israel. Thus, there has been growing consensus for the need for ongoing, systematic data collection to enable the evaluation of the quality and impact of services provided (Roe et al., 2009).

In line with this need, in July 2011 the Israeli MOH and the Laszlo N. Tauber Family Foundation, a not-for-profit organization striving to support the mental health field in general and the psychiatric rehabilitation field in particular, signed a contract with the University of Haifa to launch the Psychiatric Rehabilitation Routine Outcome Measurement (PR-ROM) project. The goal of the PR-ROM, in line with Paul Ellwood's 'outcome management' strategy (Ellwood, 1988) is to provide updated information about the process and impact of psychiatric rehabilitation services in Israel and to establish a sustainable infrastructure and foundation for routine outcome monitoring of rehabilitation services aimed to (1) improve clinical care, (2) inform policy, (3) improve the process of allocating services, (4) generate incentives for service improvement, (5) increase

informed decision-making, and (6) provide data for research purposes (see Table 1).

In this article we present the design, development and implementation of the PR-ROM project to date. We describe the rehabilitation services being evaluated and the characteristics of the population being served; the methods and nature of the data collected as well as some preliminary findings are described; the major barriers encountered, the strategies to overcome them and lessons learned during the process are discussed. We conclude with a description of the current state of the initiative and plans for the future.

Characteristics of the population

In line with the previously mentioned goals of the PR-ROM project and the need to evaluate the impact of the Rehabilitation Law, the project targets *all* people using psychiatric rehabilitation services under the auspices of the MOH. As described earlier, receiving rehabilitation services is contingent upon having being diagnosed with a mental illness which has caused at least a 40% psychiatric disability determined by a committee and recognized by the National Insurance regulations. Previous research has estimated that the majority (86%) of those who have met these criteria had a diagnosis of schizophrenia-related disorder (Struch et al., 2009). In addition to users of rehabilitation services, the approximately 5,000 family members receiving services through the rehabilitation basket will also be offered the opportunity to complete an assessment before and after receiving support services.

Preliminary demographic data of patients who have participated in the project so far ($n = 4200$), indicate that the majority are men (59%), single, divorced or widowed (86%). Distribution by age is as follows: 22% are younger than 35 years old, almost half (48%) are between 36 and 55 years old, and 30% are older than 56. Almost two thirds (63%) had finished high school education. The most common diagnosis is schizophrenia (77%), and more than half of service users have more than one diagnosis. Diagnosis was based upon data obtained from the MOH and refers to the last diagnosis obtained from a psychiatrist when last treated either at a psychiatric hospital or a mental health clinic.

Table 1. Planned uses of ROM.

Improve clinical care
Inform policy
Improve the process of allocating services
Generate incentives for service improvement
Increase informed decision-making
Provide data for research purposes

Characteristics of the services assessed

The Psychiatric Rehabilitation Service ‘basket’ provides a range of services in the following areas: housing, recreation, family and vocational services, academic support and case management. Currently, the supported residence services reflect a continuum of support levels, from relatively low levels of support, such as supported housing with one to three participants in a rented apartment with staff visiting them on a regular basis 1–5 h a week, to high levels of support such as 24-h staffed hostels with about 20–30 tenants. Currently, about 60% of those in residential care are in supported housing and 40% are in hostels (Hornik-Lurie et al., 2012).

Vocational services also comprise a range from low to highly supported services. Approximately 46% consume supportive employment and work in competitive jobs while receiving support in finding and keeping the job or in various work initiatives in the community, 40% work in sheltered workshops, and 14% work in vocational clubs (Ministry of Health, 2008). Other services include supportive socialization, leisure and a range of supportive education.

In addition to the services described above, the last decade has been characterized by an increased delivery of cutting edge practices and interventions including illness management and recovery (Garber-Epstein et al., 2013; Hasson-Ohayon et al., 2007; Roe et al., 2012), family psycho-education (Levy-Frank et al., 2011), narrative enhancement cognitive therapy (Roe et al., 2010c, 2014), social cognitive interaction treatment (Hasson-Ohayon et al., 2014), Keshet, a locally developed programme to enhance coping skills of family members (Hadas-Lidor et al., 2011), development and assessment of readiness (Farkas et al., 2000), and self-advocacy (Kuzminsky, 2004).

Brief description of the project

We describe first the organizational structure of the project, then the development and description of the assessment tools, a pilot that was set up, the way the data is used, and primary findings.

The administrative and organizational structure of the project

The MOH rehabilitation system is organized into nine regional departments. Each department has its own administrative organization that functions under the authority of the MOH. It was decided to approach the implementation of the project by following this organizational scheme to take advantage of the relevant administrative support. This approach gave us the possibility to gradually add regions and apply the project

in a coherent way, as well as to hire staff in a stepwise fashion. In addition, it provided us with the opportunity to apply what was gradually learned to the new regions where the project was implemented.

The first steps of the implementation of the project started in the northern region of Israel, including the setting up of an organizational structure (and the hiring of workers). We then set up an implementation team at the University of Haifa which coordinated with different arms of the project players and the MOH representatives. The data collection process began via combined efforts of the University of Haifa outcome team and the MOH representatives to recruit all rehabilitation service users to the project. This design was implemented later in additional regions.

Data sources

Data is currently being obtained from four different sources, namely participant self-report, participant-related assessments by staff members, demographic and service use information obtained from the MOH, and from family members. In the next paragraphs we describe the development and choice of assessment tools.

Accessibility of assessment tools

Service users are offered a range of options to complete the self-report assessment, including completing it on their own, with the support of an external adviser (someone from the implementation team) or an ‘in house’ service provider (staff at the agency), depending on the level of support needed. The self-report questionnaire is completed either on a computer or using paper and pencil. The questionnaire was made accessible in six languages (Hebrew, Arabic, English, French, Spanish and Amharic) and a short version was offered for those who experienced difficulties in completing the standard one. As described above, practitioners are also asked to complete a questionnaire on their perception of the participant’s situation with instruments that mirror the ones designed for the participant. Family members using caretaker support services are also asked to complete self-report questionnaires before and after participating in time-limited (14 sessions) group interventions within family support centres.

Questionnaires

Both self-report and staff questionnaires were developed through a comprehensive process to ensure cultural relevance, face and content validity as well as reliability. The process included the following steps: (1) the initial selection of a number of outcome

measures from the current literature and their translation and back translation from English into Hebrew and other languages, (2) the examination of the questionnaire by a committee of 14 experienced mental health professionals (the project's professional committee) and the project's steering committee, (3) discussing the questionnaire with major stakeholders, including participants and their family members through focus groups, (4) making a final decision on questionnaire domains and items by the committee mentioned above following the focus groups' input, and (5) information from unanswered questions and psychometric information (e.g. redundant items, Cronbach's alpha) from a pilot study which will be described below. The questionnaires were also evaluated for test-retest reliability during the pilot study and were further updated following the data collection experience and participants' feedback. Filling in the entire questionnaire took on average 28 min (SD = 12). The updated combined questionnaire included participant and provider's versions of the following measures.

- Quality of Life (9 items, $\alpha = 0.779$), based on the Manchester Short Assessment of Quality of Life (Priebe et al., 1999).
- Effects of symptoms on daily functioning (3 items, $\alpha = 0.829$), based on the Sheehan Disability Scale (Sheehan, 1983; Sheehan & Sheehan, 2008) to assess the effect of mental health symptoms on daily functioning.
- Patient global impression (1 item, $r = 0.67$), modified from the self-assessed version of the Clinical Global Impression scale (Guy, 1976; Haro et al., 2003).
- Goal setting and attainment, based on the Goal Attainment Scale (Kiresuk & Sherman, 1968; Kiresuk et al., 1994).
- Daily functioning (9 items, $\alpha = 0.782$), based on the Behavior and Symptom Identification Scale (Eisen et al., 1999, 2004) and the Role Functioning Scale (Goodman et al., 1993).
- Recovery and empowerment (6 items, $\alpha = 0.794$), based on the Maryland Assessment of Recovery in People with Serious Mental Illness scale (Drapalski et al., 2012).
- Changes in life domains (5 items, $\alpha = 0.790$), to identify extent and direction of major changes over the past 6 months in five life domains: quality of life, functioning, the recovery process, physical health, and mental health.
- Physical health (6 items), to assess physical health, functional impairment, use of medical services, health behaviours, and active health behaviour promotion by rehabilitation workers.
- Satisfaction with services: 15 different tools were built for service users to assess the quality of the

specific service they consume. Each of the tools contained 8–11 items relevant to the goals and principles of a specific rehabilitation service (e.g. 'I am satisfied with my work schedule' for supportive employment, or 'I am satisfied with the living conditions' for a housing service), which were rated on a 4-point scale (1 = not at all, 4 = very much). This questionnaire was built by the implementation team, in close cooperation with the MOH, a professional committee, stakeholders and members of each of the different services.

- Assessment of families: in order to conduct a routine outcome measurement of family members we used two widely published tools assessing family burden the Burden Assessment Scale (Reinhard et al., 1994) for families of the seriously mentally ill (the scale captures both objective and subjective consequences of providing ongoing care to the seriously mentally ill), and the Experience of Caregiving Inventory (Szmukler et al., 1996), a self-report measure of the caregiving experience of a carer of a person with a serious mental illness. Redundant questions were removed and the questionnaire was shortened in cooperation with different stakeholders (families, family service providers, MOH, and the implementation team). The final questionnaire consisted of nearly 100 items.

Pilot study

Once the routine outcome measures and questionnaires were chosen and adapted, a preliminary pilot study to evaluate the feasibility of conducting assessments with these instruments and to test their psychometric properties was carried out. The pilot included the assessment of 360 patients, receiving psychiatric rehabilitation services from 16 representative prototypes of the various PSR services. A signed informed consent was required from patients to participate in the pilot. The pilot study enabled us to assess feasibility, test participants' capabilities to respond to the questionnaires, and assess whether outcomes would differ depending on the person who supported the participant in filling out the self-report questionnaires (local staff versus an external implementation team member). We also evaluated the type of help that participants required to fill in the questionnaires (e.g. reading, using the computer, understanding sentences). The pilot enabled us to fine-tune some of the questions and even remove or change some of our assessment tools, to evaluate the psychometric properties of those questions that remained, and to identify the efficiency of the process. Preliminary results of this pilot strongly suggest

that internal or external support did not significantly bias participant responses (Gelkopf et al., 2014, unpublished) and that most asked for some degree of support in completing the questionnaire.

Procedure

Data is collected once a year at pre-defined times. As most receive some kind of housing service, first hostel inhabitants were surveyed, and then service users receiving other types of services were assessed. All service users were invited to participate, and those who agreed, after signing an informed consent, were asked to complete all questions. Service users who had particular difficulties were offered a shortened version. Participant-related assessments by staff members were completed at the same time. For each participant the staff member most familiar with the participant was asked to complete the survey. Family members using services were invited to complete an assessment before and after each of the three interventions they were offered (four individual sessions and two sequential independent sessions of family psycho-education groups).

Use of data

The data is aimed to be used in a number of different ways and for a number of different purposes. The first goal is to provide participants with immediate feedback using simple visual graphs which reflect their own evaluation of how they are doing across the broad range of areas which were assessed. The goal is to provide each participant with the opportunity to have a tangible summary from which he/she can learn, plan and monitor progress over time. Similar feedback exists for practitioners' evaluation regarding the service users they work with. The idea behind this is that the participant, if he or she so desires, can initiate a discussion with the practitioner regarding his or her rehabilitation process, and thereby enrich the rehabilitation dialogue. The rationale for this type of feedback was based on findings of the effect of individual feedback at the user-provider level on improving clinician-patient communication (Carlier et al., 2012; Unsworth, Cowie & Green, 2012), improving patient outcomes (at least in the short term) (Carlier et al., 2012; Donnelly et al., 2011), and on improving outcomes for poorly responding patients (Bickman et al., 2011; Donnelly et al., 2011; Lambert & Shimokawa, 2011; Whipple & Lambert, 2011). At this point in the implementation of the project we simply provide 'snapshot outputs' in the form of graphs (like a report card) to participants who completed their self-assessment. These 'snapshots' provide participants with a sense of how they are doing in the different domains, and enables them

to discuss with their providers what they might want to do to improve in areas of their choice.

Second, a written report is provided to each rehabilitation service agency, which includes a user-friendly short summary of the total scores of all assessed domains of the service users as well as the practitioners' reports of those service users and a comparison between them. The report is prepared by the implementation team at the University of Haifa but delivered by MOH staff to services and agencies. Thereupon the agencies are required to send the MOH a written report describing the specific actions they plan to take in order to improve their results based on what they learned from the report.

Third, a written report is given to each of the nine administrative regions where psychiatric rehabilitation services are offered as well as to the rehabilitation department of the MOH.

Finally, an annual written report summarizing all findings is given to the rehabilitation department of the MOH, to help shape policy. The information included in the report, (e.g. what kind of comparisons) is decided upon by a professional committee which meets regularly to oversee and discuss the project.

About 50% signed the informed consent and 65% of those consenting to participate actually completed the questionnaire. The reports include aggregated data, potentially on all users of the service.

The report includes three parts. The first includes data of all participants who completed the questionnaire. The second includes only data for participants for whom a staff member also completed the questionnaire (staff completed questionnaires for about 60% of participants). The third part includes comparisons to aggregated data from participants from comparable services (by type of service). For each part, the report indicates the percentage of valid responses.

Preliminary findings

By mid August 2014, data had been collected from 4200 service users and from 3000 service providers; although in the initial stages of the project data was collected using external assessments, 15% of the participants' data has been collected through internal staff. This trend is planned to continue as a decision has been made to have internal rather than external personnel support the completion of the questionnaire. Not only is this more feasible in the long run, but it is also hoped that this will help local agencies as well as the MOH to be more actively involved and gain a sense of 'ownership' over the project.

While the data analysis is still in process, a number of interesting findings are beginning to emerge. The majority of service users and their practitioners report that they have been able to set rehabilitation

goals and made progress towards them over the last year and evaluated their overall trajectory as improving in almost all domains. The use of a larger number of services within the 'rehabilitation basket' was associated with better outcomes, that is, consuming more services was associated with improvement. In the coming years when participants complete additional routine outcome measurement, it will be possible to broaden the analysis of change over time.

Outcomes varied depending on the region, which requires further exploration as to whether these discrepancies were related to demographic/clinical characteristics or the nature and quality of services offered in different regions. Finally, there were notable gaps between participant self-report and their practitioner's evaluation of the participant's outcomes, with participants consistently rating their outcomes higher than their practitioners. This finding emphasizes the importance of assessing both perspectives, particularly in light of the inherently subjective nature of most of the domains.

Although these are very preliminary findings based on a relatively small amount of cross-sectional data, they offer a glimpse of the many important questions on which the project will be able to shed light as the data collection and analysis process proceeds.

Lessons learned

The most important factor in the successful execution of the project so far has been the commitment and enthusiasm of all project partners (The MOH, the University of Haifa and the Tauber Foundation). However, the interaction of three different organizational cultures has not always been easy and has had an impact on the process. Forming the professional committee to plan and discuss the numerous aspects of the project and provide fast solutions for problems was essential from the very start.

The original planned project called for the collection of data on service users and family members through face-to-face interviews by an external team, making the need to obtain informed consent mandatory. The percentage of those who signed the informed consent ranged from 36% to 57% and was on average 50%, thereby significantly limiting participation. All efforts to surmount this challenge yielded only modest improvements. Recently, as a result of the above-mentioned low response levels, the MOH made data collection mandatory for service users and practitioners as part of the routine assessment by service agencies. From now on the data will be collected by staff working in these agencies, thereby bypassing the need to obtain informed consent, while maintaining confidentiality through a secured computerized system. We hope this major change will increase participation rates.

As with other ROM projects implemented elsewhere around the world, this project was met by strong resistance by agency staff and professionals (Brower, 2003; Pirkis & Callaly, 2010; Trauer, 2010). In order to counteract this resistance a significant effort was made to reach out and explain the potential benefits of the project using a bottom-up strategy. These included the development of user-friendly materials, accessible on the Internet and personal meetings within services and organizations. As a result, a significant shift in the interest and cooperation of many organizations was noted. In addition, top-down administrative efforts have been applied by the MOH, entailing the creation of new regulations and administration (e.g. the appointment of regional champions and specific 'project champions' in services) to strengthen the project.

Actions to increase chances for sustainability

As part of our attempt to facilitate data gathering we assessed the feasibility of using web-based questionnaires. These proved very efficient during the pilot phase, improving response rates, reaching patients who lived far from centralized service provisions and reducing the need for personal contact between external support staff and the patient. Unfortunately, and due to new national information security regulations, the ongoing use of web-based questionnaires for data collection could not be approved by the MOH. This hampered the vision of reaching as many patients as possible and procuring as much independence as possible in completing the questionnaires. In order to circumvent this problem, and after much discussion, the MOH has requested that the official Internet government platform should become the gateway to collect the questionnaires. We are thus currently adapting the self-report questionnaires to the demands of the government platform. This process will be time-consuming and costly, but will increase the likelihood of sustainability by providing a solid long-term computer-based government system used by all agencies.

Current status and next steps

The PR-ROM is probably one of the most ambitious projects co-opted by the Mental Health division of the MOH in recent years. It holds the potential to significantly change the face of not only psychiatric rehabilitation services but mental health services in general by providing tools to monitor system quality and accountability. These in turn hold the potential to upgrade services and improve the quality of life of many people with SMI and their families in Israel.

After 3 years we were able to establish a committed leadership team to promote, develop and to implement this project. We also succeeded in engaging people in the field to cooperate with data collection in spite of the (initial) resistance encountered at the start. In addition, several important tasks were accomplished, including the development of training programmes and materials, the design of questionnaires with good psychometric properties, conducting a pilot programme proving the feasibility of data collection, and ensuring sustainability on an administrative level as well as in the field.

At this point it is clear that the original idea to develop and implement such a complex project within the original 5-year time frame was not realistic. Unexpected barriers together with the bureaucratic intricacies the MOH has to deal with, as well as a rapidly changing cultural and organizational environment all caused major delays (see Table 2 for a list of barriers). The project has been extended by 2 years to allow for the new database to be developed and adapted, using the computerized governmental database platform and to allow for the training of all services to collect the required data from their participants. Service users and clinicians will complete the questionnaires once a year. In addition, the MOH will build the necessary administrative infrastructure which will include positions designated to data collection within the services. During the final phases of the project the Haifa project team will transfer all tasks to the MOH staff.

What we hope to accomplish in the following years, in addition to the smooth implementation of ROM across rehabilitation services in the country, is to provide information to policy-makers, directors of services, practitioners, participants and family members, and researchers regarding service provision, use and effectiveness. Important areas we wish to investigate include characteristics of individuals utilizing psychiatric rehabilitation services, patterns of service utilization, processes involved in receiving rehabilitation services, quality of service provision, service and user factors associated with participant outcomes, cost of care, and impact of service use on objective and subjective outcomes.

Table 2. Barriers encountered in setting up and running ROM.

Interaction of different organizational cultures of the institutions involved in the project (i.e. Ministry of Health, Rehabilitation Services, University of Haifa)
Need for informed consent
Level of participation of users and staff
Resistance by agency staff and professionals
Information security regulations regarding the use of web-based surveys

Despite notable and perhaps expected challenges we have been confronted with, we are encouraged by the project gradually becoming more accepted and appreciated. We are committed to continuing to identify all the possible tangible benefits of the project to all stakeholders. We envision patients, family members and practitioners enthusiastic to be part of this effort, due to their positive experience with ROM's potential to inform participants' rehabilitation process, future goal setting and means (including but not limited to service use), to promote progress. We hope the personal feedback will provide opportunities for meaningful dialogue between patient and practitioner and improve collaboration and rapport. We hope that the data provided to agencies, the nine administrative regions and the rehabilitation department of the MOH will help guide data-informed decision-making and policy, and generate improvement. Finally, the rich, large, and multidimensional data collection can help advance science by trying to identify factors that contribute to change over time.

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