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REVIEW OF INDIVIDUALIZED TOOLS

Patient Centered Assessment in Psychotherapy: A Review of Individualized Tools

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Abstract

There has been an increasing interest in patient centered assessment of psychological treatments. This paper reviews the existing patient-generated measures (PGM) that have been used by clinicians and psychotherapy researchers to collect evaluation data from the patient perspective. A systematic review of literature was performed to identify PGM in empirical studies between 1990 and 2014. Twenty tools were identified, of which three were designed to assess the outcome and 17 to assess the process of therapy. The characteristics of each are described and discussed, including psychometric data and evidence of clinical utility. This review helps professionals and researchers to implement the recommendation of health policies which advocate the importance of patient-centered care.

Keywords: Patient-generated measures (PGM), patient-reported measures, patient experiences, personalized assessment, outcome and process assessment, idiographic, patient-centered assessment.

Patient Centered Assessment in Psychotherapy: A Review of Individualized Tools

The relevance of patient-centered measurement is being increasingly acknowledged and there is a call for personalized approaches that tailor assessment to the specific needs and views of patients (e. g., Crawford, Rutter, Manley, Weaver, Bhui, Fulop, & Tyrer, 2002; NICE, 2012; Norcross, 2011; Roberts, 2010; Sales & Alves, 2012; Taylor, 2013). This paper aims to guide practitioners and researchers, by reviewing the individualized assessment tools for current use in therapy, their psychometric properties, and their clinical utility.

Measurement approaches in health can be classified on a continuum of patient involvement, ranging from professional-based assessment with minimal patient input (for instance, when evaluating the clinical condition only through observation), to patient-based assessment where patients are directly asked their view (for instance, filling in a questionnaire about their health). This last strategy makes use of patient-reported measures, i.e., questionnaires with a series of questions that are administered through pen-and-paper forms, interviews, or electronic devices (Fitzpatrick, Davy, Buxton & Jones, 1998). The use of patient-reported measures has become a priority in health care because this approach to assessment shifts the balance of power away from health professionals toward the patient, according to patient-centered quality standards. Several bodies, such as the American Psychological Association and the United Kingdom's National Institute for Health and Care Excellence recommend that managed care systems adopt patient-centered measurement that listens to patients, enables patients to communicate their personal values, priorities, and expectations for health, and involves the patients views in shared decision making processes.

Traditionally, patient-reported measures follow a nomothetic measurement approach. Items reflect dimensions that are common to all people, in varying degrees, and

the role of the assessment is to locate the patient on those universal dimensions by comparing his or her score with population norms. However, questions have arisen as to whether nomothetic patient-reported tools are truly patient centered and to what extent they truly represent what is relevant to patients (Carr & Higgins, 2001). Nomothetic patient-reported tools limit patients' opportunity to express their personal views because they consist of lists of pre-defined items with pre-determined response options. These measures may include items that are irrelevant for an individual patient, while relevant items that matter to people might be absent (Carr & Higgins, 2001). Moreover, patients criticize the normative nature of pre-set questionnaires because the same item may have different individual meanings (Blount, Evans, Birch, Warren, & Norton, 2002). By asking every patient the same questions, nomothetic tools fail to capture the individual nature of health status and treatment experiences, and overlooks the personal meaning of items.

An alternative approach is the idiographic measurement, which relies on the unique features and views of the person. It makes use of individualized patient-based tools, also called Patient-Generated Measures (PGMs). These are "instruments in which the respondent is allowed to select issues, domains or aspects that are of personal concern that are not predetermined by the investigator's list of questionnaire items" (Fitzpatrick, Davy, Buxton & Jones, 1998, p. 12). PGMs have a standardized structure that defines the format of the instrument but it is the patient who defines the contents to be evaluated. That way a PGM used to measure a specific outcome may have a pre-set format of three items that the patient rates for intensity on a 6-point Likert scale; however the items are free-text propositions indicated by the patient and correspond to his or her three main problems.

When PGM are used for outcome assessment, they are called patient-generated outcome measures (PGOM), and consist of open-ended scales "where the items to be measured are defined by the patient" (Ashworth et al., 2004, p. 28). Outcome is assessed

by change in self-completed scores on these patient-generated items. PGOM are also known as individualized PROMs (individualized patient-reported outcome measures). But PGM can also be used to assess therapy processes. In contrast with closed-ended questionnaires, in which the contents are defined by the researcher (e.g. Working Alliance Inventory; Horvath & Greenberg, 1989), patient-generated process measures (PGPM) use open-ended questions to elicit the patient experience while in treatment. The patient experience of treatment includes “sensations, perceptions, thoughts and feelings during and with reference to therapy sessions” (Elliott & James, 1989, p. 444). PGPMs hence assess the treatment variables that are relevant from the point of view of patients. This paper aims to make available an updated overview of the existing PGM and how they are used to personalize outcome and process assessment.

Methods

A systematic search was conducted by the two authors. The search was performed between November 2011 and December 2014. Three strategies were employed: electronic searches in major international databases using terms such as *patients*, *perspectives*, *psychotherapy* and its synonyms and also *qualitative research*; hand-searches in the specialist journal *Psychotherapy Research* (from 1990 to 2014) and reference lists of relevant papers; and direct e-mail consultation with experts through the mailing list of the Society for Psychotherapy Research.

The identified papers were screened for duplicates, and both reviewers independently selected the papers to be included in the review, according to eligibility criteria. The inclusion criteria were: 1) Empirical studies in psychotherapy that used PGM; 2) Studies reporting the development of PGM; and 3) English, Portuguese, French or Spanish papers (peer-review, grey literature, conference proceedings) published between 1990 – 2014. Exclusion criteria included: 1) Print / downloadable form of the full-text

version unavailable; and 2) Theoretical papers without empirical data. Disagreements were discussed until consensus was reached (see Flowchart in Figure 2 available online).

Results

The search strategy generated 72 empirical papers, from which 20 PGM were identified. Of these, three were PGOM and 17 PGPM. We will start by presenting the PGOMs, including psychometric data and evidences of clinical utility, when available. We also include an example of a study that illustrates the use of each measure.

Patient-Generated Outcome Measures

Simplified Personal Questionnaire (PQ). The PQ (Elliott, Mack & Shapiro, 1999; Shapiro, 1961) is an outcome measure meant to assess changes in the problems that patients report when they seek treatment. The PQ items are generated in a pre-treatment semi-structured interview, where the patient reports a list of problems that motivated him or her to seek therapy. This results in a list of items in the patient own words (i.e., “My son does not talk to me anymore”) that are ranked and rated for the degree of distress (7-point scale, from 1 - *not at all* to 7 - *maximum possible*), and for duration (from 1 - *less than a month* to 7 - *more than 10 years*). The PQ can be administered in a pre-post therapy design, or on a session-to-session basis. Patients are free to add or remove items on every application. PQ is available in Portuguese and Spanish and also in an outcome management software system (IPPS - Individualised Patient-Progress System; Sales & Alves, 2012; Sales & Alves, 2013; Sales, Alves, Evans & Elliott, 2014). An example of a study using the PQ is a clinical case described by Carvalho and colleagues, where session-to-session changes on PQ were connected to the content of the session, in order to understand if therapy caused clinical changes (Carvalho, Faustino, Nascimento & Sales, 2008).

Reliability and validity. A recent meta-analysis of five clinical samples collected in the U.K., U.S. and Portugal presents the psychometric properties of PQ (Elliott, Wagner, Sales, Rodgers, Alves & Café, 2015). In this study, the internal reliability between all patients in the five samples was 0.80 (standard error 0.03). In four of these samples, test-retest reliability was calculated correlating the ratings provided at intake (pre-treatment) and before session one, with an overall value of 0.57 (95% confidence interval: 0.43 to 0.68). With respect to convergent validity, the PQ has been correlated with several instruments, with the CORE-OM (Evans et al., 2000) being the most commonly used. In a sample of 971 assessments, the authors found an overall weighted Pearson's correlation of 0.56 (0.49, 0.63) between the PQ and the other outcome measures used in the five samples.¹ Concerning sensitivity to change, it was found that, on a pre-post basis (for patients who received more than three therapy sessions), the standardized differences of the mean (Cohen's *d*) reached an overall value of 1.25 ($n = 348$; CI: 0.26 to 2.24); on a session-to-session basis, these values ranged from 0.06 to 0.13. (see Elliott, Wagner, Sales, Rodgers, Alves & Café, 2015).

Clinical utility. In a therapist survey, PQ was considered to be useful for several clinical tasks, such as:

Session to session outcome monitoring, to know the specific complaints of the patient/family, using session to session outcome in clinical decision making, pre-treatment case analysis, relevant/useful additional information on cases, help establish relational systemic diagnosis (pre-treatment phase), saving time/number of sessions, help produce reports and treatment goals/progress, now individual

¹ In this meta-analysis, the measures correlated with the PQ were: GAF Therapist Rating, CORE-OM, SCL-90, GSI, NEO Neuroticism, PHQ-9, BDI, Social Phobia Inventory, Rosenberg Self-Esteem, Harter Self-Concept, Self-Relationship Scale Self-Affiliation and Self-Attack, Social Adjustment Scale, Inventory of Interpersonal Problem, Strathclyde Inventory.

family members resources, perspective on family history warning emerging problem. (Sales, Gonçalves, Fragoeiro, Noronha & Elliott, 2007, p. 154).

However, in this same survey, the PQ was also reported to be time-consuming. In a study conducted by Lucas, Soares, Oliveira, Sales and Alves (2012), therapists reported that PQ “helps patients to think about their difficulties and which ones they can deal with better”.

Comment. The PQ is an outcome measure of mental health, with satisfactory psychometric properties, high acceptability and some evidence of clinical usefulness. However, it presents feasibility constraints, mainly because of the time and resources required in the initial interview for item generation. Also, it is unclear how PQ data are analyzed when patients drop or add an item during therapy. Even though this instrument allows the possibility of adding or deleting items, only those that were elicited in the first assessment and remain until discharge can be used to evaluate pre-post change. On the other hand, if an item is dropped, the reason for this is unknown (e.g., was the problem solved?), which hinders interpretation.

Psychological Outcome Profiles (PSYCHLOPS). The PSYCHLOPS (Ashworth et al., 2004) is a self-report questionnaire that evaluates changes in personal problems across treatment. It asks the patient to write down what are the two problems that trouble him or her the most, and a third question asks what was hard to do because of those problems. Each item is rated by patients twice: first with respect to how much the problem has affected him or her in the last week (6-point Likert scale, from 0 – *Not at all affected* to 5 – *Severely affected*) and second with respect to the duration of the problem (5-point Likert scale, from 0 – *Less than a month* to 4 – *More than 5 years*). The PSYCHLOPS contains an additional pre-set question about overall well-being: “How have you felt in yourself this last week?” (rated from 0 - *Very good* to 5 - *Very bad*). There are three versions of the PSYCHLOPS (pre-treatment point, during treatment, and at the end of

treatment). The latter two versions vary by asking if new problems have become important, besides evaluating the items generated at pre-treatment. The end of treatment version includes an extra retrospective question for patients to evaluate how they feel in comparison with pre-treatment. The PSYCHLOPS is available in Dutch, Icelandic, Polish and Portuguese and has recently been incorporated in the outcome management software system CORE-Net (Barkham, Mellor-Clark, & Stiles, 2015). Free copies can be downloaded from www.psychlops.org.uk. As an example of a study, Robinson, Ashworth, Shepherd and Evans (2008) used the PSYCHLOPS to ask patients receiving therapy in primary care to list their most important problems when presenting to treatment.

Reliability and validity. Ashworth, Evans and Clement (2009) report a PSYCHLOPS pre-treatment internal reliability (Cronbach's α) of 0.75 (0.65-0.82). . With respect to convergent validity, the PSYCHLOPS has been compared with CORE-OM, demonstrating a moderate pre-treatment correlation ($r = 0.65$), which increased to a coefficient of 0.74 at the end of therapy (Ashworth et al., 2005). The PSYCHLOPS also correlated moderately with the HADS (Zigmond & Snaith, 1983, pre-treatment $r = 0.47$), increasing to a post-treatment value of 0.63 (Ashworth, Evans & Clement, 2009). Moreover, the PSYCHLOPS showed a larger effect size both in comparison with CORE-OM (1.53 vs. 1.06; Ashworth et al., 2005) and HADS (1.61 vs. 1.15; Ashworth, Evans & Clement, 2009). A qualitative study (Ashworth, Robinson, Evans, Shepherd, Conolly & Rowlands, 2007) categorized the contents of the free text PSYCHLOPS items into 61 sub-themes. These subthemes were contrasted with the CORE-OM items. It was found that 27 (44%) sub-themes were not covered by CORE-OM. Moreover, 121 patients (60%) reported at least one problem that was not covered in CORE-OM.

Clinical utility. Ashworth and colleagues (2009) found that the PSYCHLOPS had adequate levels of acceptability among clinicians and feasibility in practice, showing

evidence of clinical utility. More recently, a focus group has been conducted to explore what patients with drug and alcohol misuse problems think about the PSYCHLOPS in comparison with standardized PROMs (Alves, Sales & Ashworth, 2013). Preliminary findings show that patients in this population appreciate the freedom to express their problems, whether drug-related or not (Alves, Sales & Santos, 2014). Another on-going study that also includes the PSYCHLOPS and the PQ in the same evaluation protocol is being conducted in a psychiatric context. In a focus group, patients reported difficulties filling in the PSYCHLOPS, particularly elderly people, patients with low literacy skills or patients with high levels of anxiety. Among these patients, the PQ was preferred over the PSYCHLOPS because it was an interview-based procedure.

Comment. The PSYCHLOPS has similarities to the PQ, as it asks patients to generate items (problems) in their own words, to rate them for intensity and duration, and allows them to include new items over the course of the treatment. The fact that the PSYCHLOPS is a self-report and shorter tool supports its use in routine clinical settings. It has high acceptability among clinicians. However, data on patients' acceptability differs across samples, due to difficulties of self-disclosure or autonomy in reading/writing. Research shows that the PSYCHLOPS gives patients the opportunity to suggest personal outcome items that would have been overlooked using standardized measures. As in the PQ, pre-post change is computed only for items indicated in the first PSYCHLOPS administration, not allowing consideration of new items added during therapy. Unlike the PQ, these new items are not rated in the subsequent applications of the PSYCHLOPS. Instead, a generic score is obtained in the post-therapy version of the PSYCHLOPS referring to the collective impact of any new items described during the course of therapy. This generic score has not been independently evaluated or studied in any trials.

Goal Attainment Scaling (GAS). The GAS (Kiresuk & Sherman, 1968) is an interview-based procedure in which patients identify their main problems and establish a set of priority goals, in collaboration with the therapist. After defining the goal, the idea is to set the “expected outcomes” for each of the goal, which correspond to the “most probable result if the patient receives the expected treatment”, ranging from -2 – *Much less than expected outcome* to 2 – *Much greater than expected outcome*. As exemplified by Kiresuk and Sherman (1968), for the goal “Dependency on mother”, the least favourable outcome could be “Lives at home, does nothing without mother’s approval” (-2 points), and the most favourable outcome “Establishes own way of life, chooses when to consult mother” (+2 points) (for a practical guide on how to use GAS see www.kcl.ac.uk/lsm/research/divisions/cicelysaunders/attachments/Tools-GAS-Practical-Guide.pdf). An example of the GAS used as a PGOM in mental health is Booth (1997), who used GAS as “a personalized method for measuring outcome”, stating the scale was “suitable because outcome studies of counselling in general practice have traditionally been based on diagnostic measures of mental illness and such measures are not necessarily the most appropriate for this context” (p.177).

Reliability and validity. The GAS has been mostly used as a professional-based tool to help the clinical team to define and evaluate goals. In this format, the patient is not actively enrolled in the generation of the items and, consequently, data reporting the use of the GAS as PGOM in mental health, are scarce. However, the psychometric properties of the GAS have been studied in numerous other care settings, revealing excellent properties. Regarding inter-rater reliability, for instance, the GAS has obtained values of 0.87 (geriatric care; Stolee, Rockwood, Fox & Streiner, 1992) or 0.92 (brain injury rehabilitation; Joyce, Rockwood & Mate-Kole, 1994). Regarding validity, the scores of the GAS have correlated highly with clinician judgments ($r = 0.81$ in brain injury

rehabilitation; Joyce, Rockwood & Mate-Kole, 1994) and with other standardized PROMs ($r = 0.86$ with the Barthel Index and $r = .82$ with the Global Clinical Outcome Rating in geriatric care; Stolee, Rockwood, Fox & Streiner, 1992).

Clinical utility. There is extensive evidence supporting the clinical utility of the GAS. For instance it is valuable for establishing individual treatment goals by multidisciplinary intervention teams, such as in nursing-homes (Gordon, Powell & Rockwood, 1999) or rehabilitation settings (Malec, 1999). The GAS may include objectives in different areas of care, which can be elicited by the patient or his/her peers. The GAS thus allows monitoring of patient progress in different domains and evaluation of the success of care according to the individual prognosis. Even though these features support the overall clinical utility of the GAS, there is scant information on its use as a PGOM in mental health. In a study with children with learning disabilities, Young and Chesson (1997) reported that the therapeutic goals elicited by patients on the GAS have “the potential to inform decision making regarding treatment options” and is a “particularly appropriate evaluative tool” (p. 111).

Comment. The GAS requires several steps: Identifying problems, defining possible solutions/goals to attain, and rating goals. It involves a complex cognitive process that may be too difficult for certain patients in mental health care. The application of the GAS combining professional, family, and patient established goals might be considered. Unlike the PQ and PSYCHLOPS, the GAS provides a formula to compare patients’ scorings. This is based on the weight assigned to each goal, the numerical value achieved by each goal and the expected correlation between the goal scales (for an example of how this formula can be applied, see Stolee, Rockwood, Fox & Streiner, 1992). As psychometric properties of the GAS have been studied mostly in health care with items generated by professionals rather than patients, it is necessary to further extend research to mental health settings.

Patient-Generated Process Measures

In addition to outcome measures, we also found PGPM that explore the process of therapy. Some of them were ad-hoc instruments developed by authors for a specific study, with no intention for use outside that context; these tools will not be described. Instead, we present the PGPM that can be used in multiple contexts, with a wide range of patients or situations. Studies on the properties of PGPM (psychometrics and clinical utility) are scarce. Data about these properties will be presented whenever available.

PGPM for a single session. Seven tools are used to elicit the patient's views and experiences concerning one therapeutic session. These include interviews and self-report questionnaires.

Interpersonal Process Recall (IPR). The IPR (Elliott, 1986; Kagan, 1975) is a qualitative interview to identify the most significant moments in therapy sessions, based on video or audio recordings. Recordings are watched by the patient and therapist together and the patient identifies/describes his or her in-session experiences, such as feelings, thoughts and impact of the session events and of therapist actions. As an example, Henretty, Levitt and Mathews (2007) used the IPR method to interview 10 patients about their experience of sadness, in order to derive a model of sadness.

Brief Structured Recall (BSR). The BSR (Elliott, 1993a; Elliott & Shapiro, 1988) is the short version of IPR and comprises a form of tape-assisted recall where patients focus on significant events previously identified, for instance, in the HAT (Elliott, 1993b; Llewelyn, 1988), a self-report measure that asks patients to report the most helpful and hindering aspects of each session (the HAT is described in more detail later in this paper). In the presence of the recordings, patients might not review the entire session but focus on the identified event. The BSR may also incorporate quantitative procedures, by asking patients and therapists to score several aspects of the events (e.g., impact, helpfulness). As

an example, in 2011, McVea, Gow and Lowe used the BSR as part of a comprehensive process analysis to explore how patients resolve their “painful emotional experience during psychodrama group therapy” (p. 416).

Cross-contextual qualitative diaries (CCQD). The CCQD (McKrill, 2008) consist of narratives that patients are encouraged to record about their experiences in each session, as well as in other daily contexts. Before creating their therapy diary, patients are asked to reflect about the “significance of the psychotherapy sessions and how they changed their everyday lives”. This method assumes that psychotherapy is a cross-contextual practice that should take extra-therapy aspects into consideration. Therapists are also invited to keep a diary, which can be later exchanged and discussed with patients. It is available in Danish language. For instance, Mackrill (2008) used these diaries to encourage patients to record the strategies for change that they were already using when they first entered therapy.

Significant Events Form. The SEF (Moreno, 1995) is an open-ended self-report questionnaire designed specifically for group therapy. Patients are asked to identify the three most significant events (e.g., thoughts, feelings, memories, fantasies, behaviors or interactions) that occurred during each group meeting and why these events were significant. Moreno, Fuhriman and Hileman (1995) used the SEF with a group of patients receiving psychodynamic therapy for eating disorders. The aim was to record what patients found significant and why. A qualitative analysis of the contents result in implications for group theory and practice.

Important Events Questionnaire (IEQ). The IEQ (Cummings, Martin, Hallberg & Slemmon, 1992) asks patients what were the most important events in a session, why and how they were relevant and, additionally, collects information about perceived therapeutic changes. It includes the following questions: “a) what was the most important thing that

happened in this session; b) why was it important and how it was helpful or not helpful; c) what thoughts and feelings do you recall experiencing / having during this time in the session; d) what did you find yourself thinking about or doing during the time in between sessions that related in any way to the last session; and e) are you experiencing any change in yourself? If so, what?”. In 1992, Cummings and his collaborators used the IEQ to explore the relationship between recalling important events in a session with the effectiveness of that therapeutic session.

Post Session Questionnaire (PSQ). The PSQ (Helmeke & Sprenkle, 2000) asks patients enrolled in couple and family therapy, to identify pivotal moments, breakthroughs or turning points that occurred during session. Moreover, patients are asked to identify what changed during the therapeutic session and what aspects accounted for that change. Besides the patient version, there is also a version of the PSQ for therapists. Helmeke and Sprenkle (2000) have used the PSQ in a qualitative study to explore the change process in couples therapy. The goal was to build a grounded theory about pivotal moments and understand how the events reported by the different spouses did or did not overlap.

Helpful Aspects of Therapy Form (HAT). The HAT (Elliott, 1993b; Llewelyn, 1988) is a self-report questionnaire about the significant events, including the most helpful and hindering events of each therapy session (Elliott & Shapiro, 1988). It includes questions such as “Of the events which occurred in this session, which one do you feel was the most helpful or important for you personally? What made this event helpful/important and what you got out of it? Did anything happen during the session which might have been hindering? Please describe this event briefly”. Patients are also asked to rate the helpfulness of the events identified (9-point scale, from 1 – *Extremely hindering* to 9 – *Extremely helpful*), to provide comparison between sessions. In a therapist survey, the HAT was found to be adequate in terms of applicability and feasibility in routine practice

(Sales, Gonçalves, Fragoeiro, Noronha & Elliott, 2007). The HAT is available in Spanish and Portuguese in pen-and-paper format and also in IPPS. As an example, a clinician in the Psychological Association Practice Research Network described the benefits of using the HAT: “She was most interested in learning from her patients, after each session, what they found helpful, as this might help her to be a better therapist” (Castonguay et al., 2010, p. 339). Also in a survey, therapists stated the HAT was useful for session-to-session qualitative outcome monitoring and immediate feedback about the session (Sales et al, 2007). As downsides, therapists mentioned that, for some patients, “the completion of the HAT can be very anxious, for they might fear what therapists are going to think about what they wrote” and “when a session is emotionally intense, patients usually are too exhausted to think and write something down in the end of session” (Lucas, Soares, Oliveira, Sales & Alves, 2012).

PGPM for multi-session periods. We found 10 tools (interviews and self-report questionnaires) to elicit the patient’ views and experiences about periods of the treatment, including the whole treatment in retrospective.

Narrative interviews. Narrative interviews are a set of interview protocols that help patients telling the story of their own treatment. An example of such protocols is the *Therapy Story* (McAdams, 1986, 2006), where patients give a sequential description of treatment from pre-treatment to its ending, in order to identify the key moments. Narratives should include the following scenes: the problem (a scene in which the presenting problem was clear or vivid), the decision (a scene in which patient decided to undertake therapy), most important session (a session in which the patient considers as pivotal), another important session (a session, different from the first one, which was also significant) and ending (a scene that describes the period before, at or after the ending of treatment, in which the impact of the therapy was clear or vivid). A sixth scene might also ask about

other important information which was not captured by the narrative. In 2011, Marcus and his colleagues used this method to study experiences of patients receiving counselling for generalized anxiety reduction.

Critical Incidents Technique. This technique (Flanagan, 1954; Greenberg, James & Conry, 1988) involves a structured interview to “describe specific incidents in therapy that stood out for them (patients) as helpful or hindering” and also the process of change underlying in such incidents (“how each incident was helpful or not helpful”, “what changed for the person through the incident”, and “how this change occurred”). As an example, Greenberg, James and Conry (1988) relied on this technique to interview patients who received emotionally focused couples therapy over a period of 8 sessions.

Client Change Interview (CCI). The CCI (Elliott, Slatick, & Urman, 2001) aims to identify changes due to therapy. It includes questions such as “What changes, if any, have you noticed in yourself since therapy started; Has anything changed for the worse for you since therapy started; Is there anything that you wanted to change that hasn’t since therapy started.” Each of these changes is rated in terms of its level of expectancy, likelihood of occurrence without therapy and importance. After this, patients are queried about attributions (i.e. what has caused such changes), helpful aspects (i.e. what was helpful about therapy), problematic aspects (i.e. what was unhelpful, painful or missing in therapy) and suggestions. This protocol also gathers information about treatment history in general (e.g. number of treatment sessions), how patients felt during treatment and patients’ self-description. There is also the option of asking patients to reflect on their pre-treatment self-ratings and self-descriptions. The CCI is currently available for individuals and family therapy, both in Spanish and Portuguese. In a clinical trial to study the effectiveness of psychodrama therapy for eating disorders (Vieira, 2014) the CCI and the HAT were used to explore mediating factors from the patients’ point of view.

Feedback letter. The feedback letter is a method that invites patients to write a letter to their therapists in order to give feedback regarding their perception of the therapeutic relationship and their level of agreement about the therapeutic goals and tasks. In a study by Flückiger and colleagues (2012) this method was used to explore if and how asking for patients' feedback about therapy impacted the therapeutic alliance. Feedback letters have also been used by authors such as Ryle (1995), who have incorporated them in Cognitive Analytic Therapy as a co-joint task of therapists and patients, where both re-write aspects about the patient's story.

Corrective Experiences Questionnaire (CEQ). The CEQ (Friedlander, Hetherington, Constantino, Messer, Kortz & Shaffer, 2011) is a self-report tool that includes two open-ended questions about perceived changes: "1) Have there been any times since you started the present therapy that you have become aware of an important or meaningful change (or changes) in your thinking, feelings, behavior or relationships? This change may have occurred in the past four weeks or any time during the present therapy. Please describe such change (or changes) as fully and vividly as possible" and "2) If yes, what do you believe took place during or between your therapy sessions that led to such change (or changes)?" It assumes that corrective experiences are moments in which the patient experiences events (or relationships) in a different way. Friedlander and collaborators (2011) used the CEQ to compare corrective experiences across different types of therapy.

Role Analysis (RA). The RA (adapted from Clayton, 1992) is a self-report qualitative tool to explore areas of concern, resources and changes in young people receiving psychodrama sessions. It asks patients to write down the following behaviors: "Things I do best / am doing better", "Things I do that seems to help me / helps me sometimes / doesn't help me at all" and "Things I have done that I don't do very often /

don't work". Kirk and Dutton (1992) used RA in a psychodrama group with children with Asperger's Syndrome in order to study the treatment impact in social interactions.

Evaluation of Therapy Form (ETF). The ETF (Gershefski, Arnkoff, Glass & Elkin, 1996) is a self-report questionnaire that starts by asking: "Were there any aspects of your treatment that were particularly helpful to you? If so, please describe these. Be as specific as possible". Then it asks patients to rate a pre-set item concerning satisfaction with the treatment received, on a 7-point Likert rating scale. Gershefski and collaborators (1996) used the ETF at the end of a treatment for depression in order to understand patient's perceived impact of the intervention.

Client Assessment of Change (CAC). The CAC (Halstead, 2012) is also a self-report questionnaire that explores the extent that patients experience therapy as helpful. It contains 3 open-ended questions for the identification of helpful or hindering events that were relevant to outcome (idiographic section). In addition, a nomothetic section includes 10 statements about perceived changes to be rated on a 9-point Likert scale, for instance "Dealing with my problems has got..." (from 1- *Very much worse* to 9 - *Very much better*). According to its author, the CAC "can be used as part of a therapy review process" (Halstead, 2012, p. 3), to "alert therapists to aspects of therapy that are not going well" (Halstead, 2012, p. 3). Clinicians find the resulting "qualitative data very useful and a possible stimulus for discussion about the continuation of therapy" (Halstead, 2012, p. 3). An example of a study using CAS is exemplified by Hampton (2008), where it was used routinely in a psychotherapy service at the end of therapy.

Client Post Therapy Questionnaire (CPTQ). The CPTQ (Strupp, Wallach, & Wogan, 1964) combines idiographic open-ended questions, such as "In general, how would you describe your attitude towards your therapist", with a nomothetic section, consisting of a list of 38 items that describe in-session experiences and perceptions about

the therapist. Patients rate each item on a 9-points Likert scale. Jones, Wynne and Watson (1986) used CPTQ to compare the experiences of patients that received crisis intervention with patients in long-term psychotherapy.

Client Evaluation of Treatment Questionnaire (CETQ). The CETQ (Swift & Callahan, 2009) starts with a nomothetic section consisting of six pre-set items on three domains (therapeutic relationship, the patient's current coping ability and effectiveness of treatment) that patients rate on a 9-point Likert scale. In the second part, patients are invited to indicate their two most important problems and what has been most helpful in therapy. The nomothetic module of this questionnaire was found to have an adequate level of reliability (Cronbach's $\alpha=0.84$; Swift & Callahan, 2009). Swift and Callahan (2009) used the CETQ to explore the preferences of patients regarding treatment, and to determine if including these preferences had an impact on treatment outcome.

Discussion

The aim of this review was to identify patient-generated tools that maximize patient involvement in the assessment of outcome and process of psychotherapy. Altogether, we found 20 PGM that have been used with a wide range of psychotherapeutic models, both in Europe and the U.S. We start by providing general recommendations for the selection of the tools. We then discuss PGM advantages comparing to nomothetic measures, as well as their limits and issues that require future research.

Selecting PGM

Figure 1 shows a diagram that can support the selection of PGM. Concerning outcome assessment, a crucial aspect to consider is to what extent the patient is able to generate and write the items. The PQ and GAS are interview-based, which might be more appropriate than the PSYCHLOPS when cognitive functioning is compromised, in cases of extreme anxiety, or poor literacy. However, the choice must consider the practical

requirements of conducting interviews, especially if data collection takes place in clinical settings on a routine basis. Building the PQ requires one session, and the establishment of change goals on the GAS might take several encounters. In contrast, the PSYCHLOPS takes a few minutes and can easily be filled out in the waiting room. Given that these tools provide clinical information that is useful for diagnosing and treatment planning, an alternative format of administration in practice-based studies might be that the therapist him/herself includes the items generation process as part of the initial sessions. Also, the PSYCHLOPS can be administered orally in the therapy session, though further research is needed to ascertain the validity of adapted formats of administrations of PGOMs. We recommend that therapist in-session administered PGOMs are used in association with well-established nomothetic PROMs, in order to check validity for outcome measurement purposes.

Concerning process measures, although there are a large number of tools, most of them explore the same central theme: the key aspects of therapy that promote change. The apparent diversity of PGPM is due to the different formats of administration (interview vs. self-report), or time units examined (i.e. patient views about a session vs. multi-session periods). The availability of diverse formats is an advantage because this facilitates the task of selecting the tool that is appropriate to specific settings. PGPMs that focus on a single session are indicated for prospective session-to-session data collection designs, whereas tools that focus on multisession time periods can be used in retrospective studies, since they inquire about past experiences. This provides a resource for naturalistic research conducted by clinicians, meaning that studies can be planned a posteriori after the treatment has begun or even after treatment completion (e.g., Marcus et al., 2011).

Strengths and Potentialities

A major strength of PGMs is proximity to the clinical reality. Although an outcome measure is inevitably reductionist, it is important that it captures the complex nature of psychotherapy. Standardized PROMS have been the preferred method for measuring outcome, because of the evidence of their psychometric properties and because they easily allow comparison of the individual patient with a normative sample, as well as the aggregation of data and comparison of programs, therapists, and services (Overington & Ionita, 2012). However, standardized PROMs have been criticized for their limits to capturing change in psychotherapy and this is one reason for the reluctance of professionals to use this approach in clinical routine (e.g., Gilbody, House & Sheldon, 2002; Hatfield & Ogles, 2004). Moreover, patients note several problems in well-established standardized PROMs, such as vague items and language, cultural assumptions and slang, inappropriate length, state-bias and response-set (Crawford et al, 2011). On the other hand, PGMs follow processes that resemble the clinical assessment carried out by practitioners: They encourage patients to expose their views, similarly to patient-therapist communication; the patient is directly involved in the establishment of the evaluation criteria of his or her own treatment, and assessment is tailored to the relevant and meaningful aspects of each individual. Such resemblance of PGM to the clinical reality is an advantage that overcomes some of the limitations of nomothetic tools in measuring change in psychotherapy. The ability of outcome measures to capture clinical reality is a critical aspect in managed care, where routine outcomes of all patients are used as service quality indicators. Outcome assessment has ceased to be a matter limited to the therapist-patient interaction, or to research, and serves to evaluate the services and to inform decisions at the health system level, in order to balance costs and quality of care (Valderas et al, 2008). Following a logic of transparency, outcomes are aggregated and feedback is provided managers, politicians,

and to the general public. Often, the financing of services depends on this assessment (Mellor-Clark, Twigg, Farrell & Kinder, 2012). Under these circumstances, the method used to assess outcomes regains importance. What is a therapy with success? Success of a therapy represents optimisation of mental health, well-being, and quality of life within the limits of the prognosis and the aims of the patient (Blount, Evans, Birch, Warren & Norton, 2002). PGOM allow patients to include their voices in the formal outcome assessment. By their proximity to the case-tailored nature of psychotherapy, PGOM are an option in managed care.

PGM can also play a relevant role in evidence-based research. Empirically supported treatments (interventions that have produced therapeutic change in controlled trials) have limited value as prescriptive guides for treatment selection or for the designing of health care and reimbursement systems (e.g., Kazdin, 2008). In real care situations, the choice of an intervention and its effect depend on context variables, and need to be informed by evidence derived from practice (Smith & Pell, 2003). Evidence-based practice² needs rigorous research carried out in routine clinical settings from the point of view of patients. This review showed that PGPMs are valuable tools to identify what aspects make interventions more useful for people under specific care contexts. Likewise, the inclusion of PGM in controlled studies facilitates the understanding of the mechanisms by which interventions produce change (via PGPMs), and allow the determination of treatment effects on those aspects that are relevant for the patient.

Finally, PGMs are a valuable resource in the therapeutic relationship. PGOM provide therapists with patient inputs for treatment planning, and PGPM give therapists clinically relevant feedback on the patient experiences, which are useful for on-going case

² Evidence-based practice is the “clinical practice that is informed by evidence about interventions, clinical expertise, and patient needs, values, and preferences and their integration in decision making about individual care” (Kazdin, 2008, p. 147).

management. PGM acceptability among therapists and patients eases its incorporation in practice.

Limits and Issues to be Addressed in Future Research

Despite their advantages, there are several concerns about PGMs that should be addressed by research. A first issue is the quality of the items. Since patients are free to indicate items, PGOMs may include non-psychological or non-symptomatic variables, such as “money worries”, or “work-related problems” (e.g. Ashworth et al, 2007). These items are of interest to practice as they inform about issues that affect the patient’s quality of life. However, doubts exist as to whether they should be used for measuring therapeutic change. Should all patient-generated items be included in outcome assessment and if not, how to compute different scorings of PGOM? Elliott (2012) proposed a quality item rating system for PQ. An item is classified as *well-formed* if it is a specific problem, a personal difficulty that is reasonably a focus for psychotherapy; it is considered a *low quality* item if it describes *vague personal difficulties* (e.g., relationships); if it is *formulated as a goal*, instead of a problem (e.g., get along better with people); or if it addresses *general societal problems* (e.g., general economic situation). The system allows that *other item quality issues* are identified and described. Although it is unclear what constitutes a quality item for PGOM and how it can be evaluated across individuals, we recommend that all studies using PGOMs include the analysis of the quality of items.

Uncertainty exists concerning the process of building PGOMs. In a systematic review on the influence of the mode of questionnaire administration in data quality (Bowling, 2005) it was found that it is easier to establish rapport during the course of interviews, resulting in higher motivation for study participation and less missing data, relative to self-report measures. Conversely, in an interview there is a greater likelihood of socially desirable answers, while self-report questionnaires might encourage participants to

disclose sensitive information. To what extent do different modes of item generation (interview vs self-report) lead to different patient-generated items? Further research is needed on the reliability of PGOM according to administration modes, for instance, by comparing the PQ (interview-based) and the PSYCHLOPS (self-report). Likewise, it is not clear if PGM are adequate to different clinical populations, or sensitive to mood fluctuations that favor or hinder self-disclosure.

Concerning the methods of analysis of PGM, several challenges remain. As contents are determined by patients, psychometric analyses that involve score comparison with nomothetic tools cannot be made at the level of the dimensions but only at the total score level. It is not clear if and how the contents of PGM should be used to ascertain PGM psychometric properties. Also in PGOM, the analysis of change is computed by the pre-post score difference, not considering items either added or dropped as therapy progresses. This method makes partial use of the information offered by PGOMs by ignoring the qualitative dimension.

Furthermore, case comparison is problematic, particularly for target complaint PGOMs, such as the PQ and the PSYCHLOPS. Each PGOM is unique because they vary not only in terms of their content but also in terms of number of items (for example, the patient decides the number of problems to be included in the PQ). These characteristics make it difficult to compare across patients, because it requires the comparison of the items' content, the comparison of the ratings, and also the comparison of the number of items indicated by the different patients. To overcome this difficulty, a method has been proposed for comparing patients based on their PQ (Metric-Frequency Similarity, MF; Sales & Wakker, 2009) (free MF Calculator available in <http://mfcalculator.celiasales.org/>; Sales, Wakker, Alves & Faísca, 2015). However, more data analytic techniques are needed.

In face of the issues discussed, we recommend that PGMs are used in association with well-established nomothetic scales (Sales & Alves, 2012). A personalized assessment in health that combines in the same protocol individualized and standardized measures has been proposed as a solution for balancing the gains and pitfalls of idiographic and nomothetic measurement. It is especially relevant in practice-based studies conducted in routine settings. The aforementioned outcomes management software IPPS follows this personalized approach by combining the PQ and the HAT with the CORE System (Barkham, Mellor-Clark & Stiles, 2015).

Conclusion

Overall, this review shows that therapists and researchers have currently at their disposal a complete array of individualized tools with acceptable psychometric properties, which allow personalized outcomes assessment and provide a closer picture of the real experience of each patient undergoing psychological treatment. These tools are a promising resource to fit managed health requirements of routine assessment and quality monitoring of care. They have potential to assist therapeutic tasks and to be included in outcome management systems. They are equally relevant for patient involvement in evidence-based research. By using patient-generated measures, the voice of patients and their priorities become part of formal assessment processes and are heard at the time of deciding about treatment options, service management and health policy, which is in line with patient-centred care. These are enough motives to carry on research that clarifies and find solutions for their limits.

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Supporting Information

Additional supporting information can be found in the online version of this article:

Figure 2. Flowchart illustrating the search strategy and selection of papers

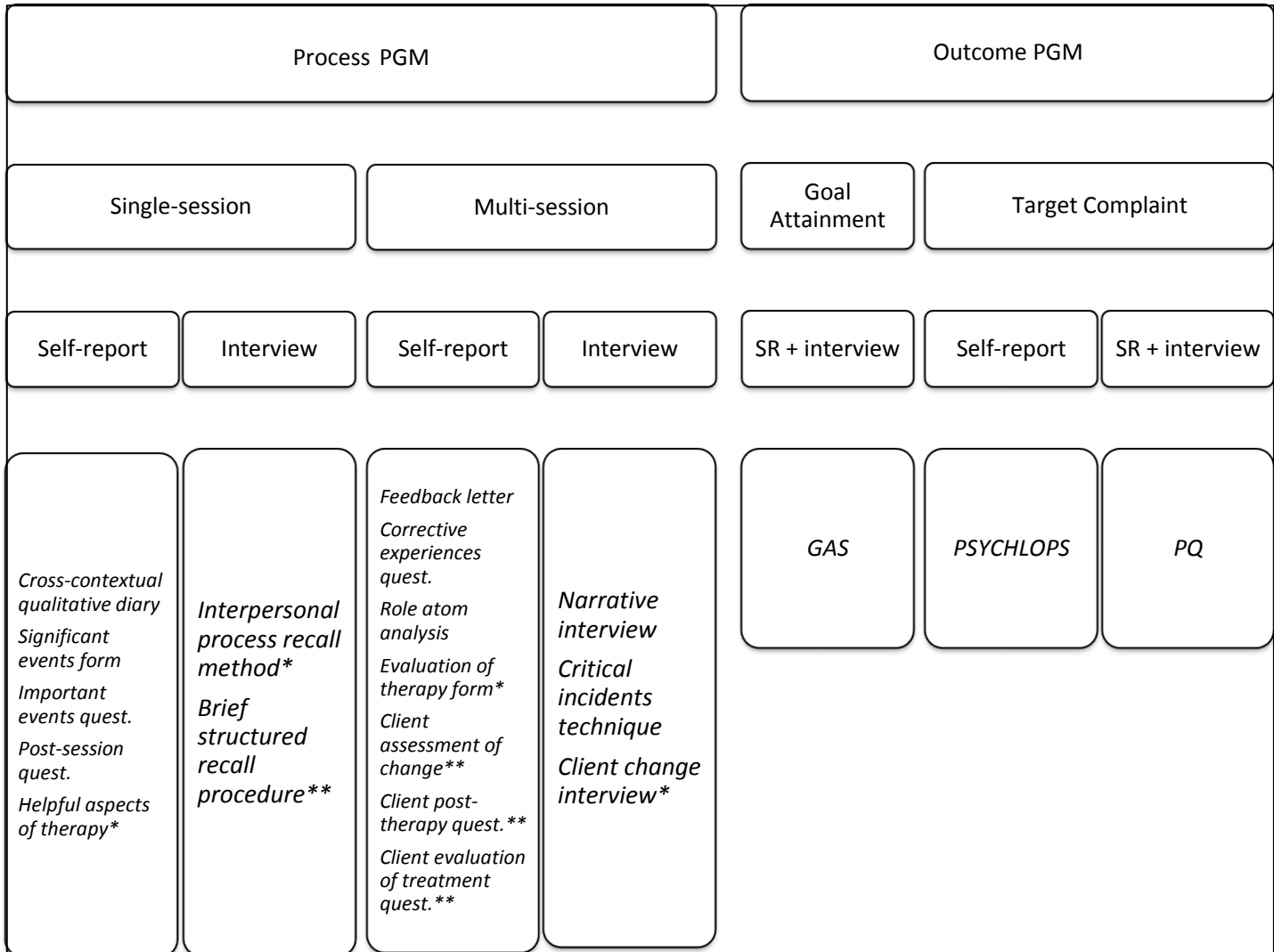


FIGURE 1: General guidelines for choosing PGM

Note: * Tools that include ratings of patient-generated data; ** tools that include pre-set nomothetic items. PGM Patient Generated Measures; SR Self-Report.