School of Social Sciences
Department of Social and Organizational Psychology

Patient involvement in psychological therapies for substance misuse: towards a personalised outcome measurement

Paula Cristina Gomes Alves

Compilation of articles specially presented for the fulfillment of the degree of
Doctor in Psychology

Supervisor:
Doutora Célia Maria Dias Sales, Investigadora
Universidade do Porto

Co-Supervisor:
Doutor Mark Ashworth, Senior Clinical Lecturer
King's College London

December, 2016

ISCTE IUL
Instituto Universitário de Lisboa

School of Social Sciences
Department of Social and Organizational Psychology

Patient involvement in psychological therapies for substance misuse: towards a personalised outcome measurement

Paula Cristina Gomes Alves

Compilation of articles specially presented for the fulfillment of the degree of
Doctor in Psychology

Jury:
Doutora Isabel Alexandra de Figueiredo Falcão Correia, Professora Associada com Agregação do Departamento de Psicologia Social e das Organizações do ISCTE – Instituto Universitário (Chair)

Doutora Eugénia Maria Ribeiro Pereira, Professora Associada do Departamento de Psicologia Aplicada da Escola de Psicologia da Universidade do Minho

Doutor Marco Alberto Vicente Barreto Torrado, Professor Auxiliar da Faculdade de Medicina da Universidade de Lisboa

Dra Dagmar Hedrich, Especialista na área da tese, Diretora do Departamento Health Consequences and Responses do European Monitoring Centre for Drugs and Drug Addiction

Doutora Carla Marina Madureira de Matos Moleiro, Professora Auxiliar do Departamento de Psicologia Social e das Organizações do ISCTE - Instituto Universitário

Doutora Célia Maria Dias Sales, Investigadora no Centro de Psicologia da Faculdade de Psicologia e de Ciências da Educação da Universidade do Porto (Supervisor)

December, 2016

This project was funded by the Portuguese Foundation for Science and Technology [Fundação Portuguesa para a Ciência e a Tecnologia] – FCT, in the form of an individual PhD grant (FCT SFRH/BD/87308/2012).

FCT
Fundação para a Ciência e a Tecnologia
MINISTÉRIO DA CIÊNCIA, TECNOLOGIA E ENSINO SUPERIOR

Ackowledgements

I would like to express my gratitude to my supervisors for their guidance, support and friendship throughout this process. I would also like to thank all the managers, clinical and administrative staff of the substance misuse treatment services where data was collected, and the senior researchers that helped us interpreting that data. I am really thankful for all the time and effort of the Psychology students (University of Évora, University of Lisbon) for collaborating with us as voluntary research assistants. My most warm and sincere words of gratitude go to the individuals that agreed to participate in this project and were happy to share their most intimate emotions and thoughts with us. I am sure that, at least to some of them, this was not an easy task. Lastly, to my dearest family members (either related by blood or heart) and friends, thank you very much for walking with me on this personal and professional journey and for believing in me, endless and unconditionally, even when I most doubted myself. Most people say that completing a PhD is a lonely experience; but I am fortunate to say that this was not my case. Therefore, to all of you that contributed for this thesis (including me): congratulations, we made it!

Abstract

Patient involvement with healthcare provision is limited, particularly in treatment outcomes measurement. This is even more critical in substance misuse treatment, where patients tend to be stigmatised and their perspectives devalued. There are calls for a paradigm shift towards a greater patient involvement and personalisation of outcome measurement in substance misuse treatment. Responding to such call, this project implemented an idiographic outcome measurement approach in substance misuse treatment, through the use of individualised patient-reported outcome measures (I-PROMS). Unlike the traditional nomothetic method, which relies on standardised measures with pre-set items, I-PROMS are tailor-made tools with items created by patients, in their own words. I-PROMS do not only increase patient involvement with outcome measurement, by asking patients to actively contribute for the generation of items, but also permit a personalisation of measurement by focusing on topics of relevance for each individual case. The findings of our five articles showed that patients welcomed the freedom provided by I-PROMS to express their personal concerns, mainly in the presence of their therapists. I-PROMS allowed the identification of qualitative information that standardised measures targeting general psychological distress and drug-related problems missed to capture. On psychometrics, I-PROMS produced good reliable scores but were not strongly correlated with standardised outcome measures. Overall, our project suggests that, in substance misuse treatment, I-PROMS are a potential strategy to successfully increase patient involvement with outcome measurement and to personalise the evaluation of treatment outcomes. The combined use of I-PROMS with standardised measures is recommended for optimal results.

Keywords: substance misuse treatment, patient involvement, patient perspectives, outcome measurement, idiographic approach, personalised health assessment, I-PROMS.

Resumo

O envolvimento dos pacientes com a prestação de cuidados de saúde é limitado, em particular na avaliação dos resultados do tratamento. Esta situação torna-se mais crítica na área do tratamento para a dependência de substâncias, onde os pacientes tendem a ser estigmatizados e as suas perspectivas desvalorizadas. A comunidade científica tem apelado para uma mudança paradigmática no sentido de um maior envolvimento dos pacientes e uma maior personalização da avaliação do tratamento para a dependência de substâncias. Respondendo directamente a tal apelo, este projecto implementou uma estratégia idiográfica de avaliação do tratamento, através do uso de medidas individualizadas de avaliação dos seus resultados (I-PROMS, do inglês *individualised patient-reported outcome measures*). Contrariamente ao método tradicional nomotético, que se baseia em medidas estandardizadas com itens pré-definidos, as I-PROMS são instrumentos feitos à medida do paciente com itens criados por si, nas suas próprias palavras. As I-PROMS não só aumentam o envolvimento dos pacientes com a avaliação do tratamento, ao permitirem que os pacientes contribuam activamente para a criação dos itens, como também personalizam a avaliação ao atender aos aspectos que são relevantes para cada caso individual. Os resultados obtidos nos cinco artigos demonstram que os pacientes apreciam a liberdade dada pelas I-PROMS para expressar os seus problemas pessoais, principalmente na presença dos seus terapeutas. As I-PROMS possibilitaram a identificação de informação qualitativa que as medidas estandardizadas focadas no sofrimento psicológico ou na dependência de substâncias não conseguiram captar. A nível psicométrico, as I-PROMS produziram avaliações (*scores*) fiáveis para quantificar o sofrimento dos pacientes, mas não se correlacionaram fortemente com as medidas estandardizadas. Em suma, o nosso projecto sugere que, no tratamento para a dependência de substâncias, as I-PROMS são uma estratégia potencialmente bem-sucedida para aumentar o envolvimento dos pacientes com a avaliação do tratamento e para personalizar a avaliação dos seus resultados. O uso combinado de I-PROMS com medidas estandardizadas é recomendado para uma maior optimização dos resultados.

Palavras-chave: tratamento para a dependência de substâncias, envolvimento dos pacientes, perspectivas dos pacientes, avaliação dos resultados, estratégia idiográfica, avaliação personalizada da saúde, medidas I-PROMS.

Table of contents

BACKGROUND OF THE PROJECT

General introduction

"It is a truth universally acknowledged, that a single man in possession of a good fortune, must be in a want of a wife", wrote Jane Austen in her worldwide acclaimed novel *Pride and Prejudice*, released in 1873. Even though literary masterpieces such as this are not to be compared with psychological manuscripts, this quote illustrates how important it is for us to understand the universal laws of human behavior, so that individuals' actions can be predicted as accurately as possible.

For decades, searching for what is common across individuals, using objective and quantifiable variables, has been the preferred approach to psychological science. The concept of "psychological experiment" was born with the works of Wundt at the end of the ninetieth century. Back then, Wundt dedicated himself to the study of social phenomena, but soon this so-called positivist approach spread to other fields of psychology, including the evaluation of psychological treatment outcomes. Resembling what occurs in other health-related fields, the evaluation of psychological treatment outcomes has traditionally followed a nomothetic approach. This nomothetic approach focusses on "dimensions that are common to all people, in varying degrees, (…) to locate the patient on those universal dimensions by comparing his or her score with population norms" (Sales & Alves, 2016, p. 266). When treatment evaluation has a nomothetic scope, the measurement is based on standardised questionnaires, containing pre-set items that are applicable to a large group of individuals. According to Möller (2009), the majority of psychology and psychiatry research and practice has relied on standardised measures to assess changes in patients' psychological status, which may occur with or without clinical interventions. These measures serve this purpose because they not only allow an objective quantification of psychological phenomena, but also facilitate data analysis with statistical methods and communication of findings to wider audiences (Möller, 2009). Because of this, standardised measures, which tend to be driven by experts and professionals, have become the gold standard to evaluate the outcomes of psychological treatments (Paul, Sanson-Fischer, & Carey, 2013).

However, when it comes to evaluating the outcome of psychological treatments, the nomothetic approach has received a major criticism from the literature: overlooking subjective and distinctive characteristics of individuals (Elliott et al., 2016; Möller, 2009; Sales & Alves, 2012; 2016). In other words, standardised measures have minimal input from patients, who are poorly involved in the selection of topics that are relevant for their own reality.

To improve this situation, the use of alternative methods capturing the individual features of patients started to emerge, leading to the so-called idiographic measurement approach, which was first introduced in the 1930's by authors such as Allport and Shapiro (cit. Elliott et al., 2016). By definition, the idiographic approach targets the particular features of patients, taking into account the uniqueness of each individual and what differentiates him/her from the population (Elliott et al., 2016; Sales & Alves, 2012; 2016). As such, the idiographic measurement approach relies on individualised tools, which are tailor-made instruments where patients have the opportunity to freely define the aspects, or items, that have personal relevance, without the pre-definition of investigators or clinicians (Fitzpatrick et al., 1998).

The present work aimed to contribute with knowledge about the idiographic approach to outcome measurement, through the use of individualised measures, and in comparison with the traditional nomothetic strategy. We focussed on patients in substance misuse treatment settings as our target population, which is one of the clinical settings where patients' individualities tend to be less considered (Orford, 2008). In the next pages we present the theoretical, empirical and ethical principles that guided the research reported henceforth.

Treatment outcome measurement and the role of patient-reported outcome measures (PROMS)

The impact, or value, of psychological interventions is generally estimated according to the outcomes that they generate (Schulte, 1995). Hence, evaluating the outcomes of treatment is a way of comprehending the utility and the effect of such treatment, namely, how patients are feeling, functioning, or even surviving (Walton et al., 2015).

Nearly 20 years ago, Schulte (1995) proposed a three-step classification system to consider in the outcome measurement process. The first refers to “operationalization”, i.e., choosing the method(s) to capture information and the most relevant data sources to capture information from. There are methods that can be used for this purpose, including self-report questionnaires, observations, interviews or even biological markers. All these methods have been extensively used in many clinical contexts and, to date, there is an incommensurable number of measures available for researchers and practitioners to use, depending on their objectives. More challenging is to decide who constitutes the best source of information to collect data from: patients, staff members (e.g. therapist), significant others or neutral observers (e.g. researchers). The second step in outcome measurement is, to Schulte (1995), the “definition of success criteria”, i.e. determining which aspects should be measured and with which norms or references they should be compared against. This comparison (e.g. pre-post treatment evaluation) will inform us about the outcome of treatment. The third step to consider in outcome measurement is the “design of data collection”, i.e. the procedure by which the study is conducted, including aspects such as the points in time where the evaluation is to be carried out. From a theoretical perspective, our research focussed on the two first steps of Schulte’s (1995) classification.

Let us concentrate on how outcome measurement should be operationalised, namely, which data sources provide us with relevant, useful and reliable knowledge about psychological treatments. Health professionals have expertise that gives them authority and autonomy to make decisions about treatment, based on their own clinical judgement (Bower & Gilbody, 2010). Similarly, the expertise of researchers in a given field also tends to play a key role in determining the research agendas of clinical services and university centres. Assuming that this is correct, i.e. that professionals and researchers are those who best know how to detect psychological changes, methods such as observational scales or staff-targeted check lists of behaviours/symptoms would be enough for professionals to measure those changes. This assumption is not entirely true. It is unquestionable that professionals and researchers possess a vast level of experience about delivering treatment. But patients themselves are in a privileged position to inform us about their concerns and how they are feeling; and we will never have access to this information – unless we ask them (Devlin & Appleby, 2010).

Until very recently, patients' reports about their own clinical status and well-being were seldom collected as a routine procedure in health services (Snyder et al., 2011). In 2010, an innovative outcome measurement approach was introduced by the United Kingdom's National Health Service that would lead to a paradigm shift: the patient-reported outcome measures (PROMS) initiative (Devlin & Appleby, 2010). This initiative gave patients a key role in outcome measurement, by providing them with an opportunity to contribute for the evaluation of their condition. PROMS can be defined as questionnaires, or tools, that are meant to be completed by patients and aim to gather their own perception about how they are feeling and the impact of treatment on their health (Greenhalgh et al., 2014). By following this measurement strategy, we are therefore assuming that patients are, indeed, a valuable source of information about their condition (Bren, 2006).

PROMS follow a nomothetic approach and, according to Devlin and Appleby (2010), share a common feature: they are based on a pre-set, standardised series of structured questions for patients to report on their current health. Two main types of PROMS have been identified in the literature (Sales, 2016): generic PROMS, targeting general health and unspecific health-related topics, such as quality of life or level of functioning, and that are potentially relevant to patients with various clinical conditions (e.g. EuroQol; http://www.euroqol.org/); and specific PROMS, targeting a particular type of disorder, and which are only relevant to a certain patient group (e.g. Beck Depression Inventory; Beck, Steer, & Garbin, 1988).

One of the greatest criticisms that PROMS have received throughout the years is the subjectivity of their data, for being generated directly by patients. But as Devlin and Appleby (2010) put it, this is exactly the purpose of PROMS: to understand the patients' views. One advantage of PROMS is their potential to improve the communication between patients and clinicians, ultimately leading to better care delivery and outcomes (Valderas et al., 2008). For instance, even though Flückiger and collaborators (2012) did not use PROMS in their study, they showed that asking patients to provide their views about treatment was likely to increase the quality of the therapeutic relationship, which is widely acknowledged as one of the variables that most contributes to treatment success. Other benefits of PROMS include the screening of problems, monitoring patients' progress throughout treatment or at follow-up appointments and, most importantly, to facilitate the delivery of a more patient-centred care (Snyder et al., 2011). But there is a challenge that traditional, standardised PROMS are not able to surpass: capturing the unique features of each individual patient (Sales & Alves, 2016).

The emergence of the individualised patient-reported outcome measures (I-PROMS)

PROMS emerged as a direct response to the necessity of involving patients in the evaluation of their healthcare. This was a positive move, by inviting patients to rate their level of distress. There are, though, a growing number of authors stating that this nomothetic approach to measurement, through the use of standardised PROMS, is not enough if we aim for a truly patient-centred outcome measurement (Valderas, 2008; Basch, Abernethy, & Reeve, 2011).

For outcome measurement to focus on the particularities of each patient, it must follow an idiographic approach. In such circumstances, patients are asked not only to quantify their distress, but also to define the contents of the instrument itself. When instruments are based in contents directly generated by patients, they are designed as individualised outcome measures. Therefore, unlike their standardised counterparts, individualised outcome measures do not rely on pre-set lists of questions, selected by others, but are instead comprised of items generated by patients, about whichever domains that are important and meaningful to them (Basch, Abernethy, & Reeve, 2011; Fitzpatrick, 1988).

Individualised outcome measures arose in 1937 when authors such as Allport reported that "as long as psychology deals with universals and not with particulars, it won't deal with much" (cit. Elliott et al., 2016). Since then, individualised outcome measures have emerged in many different fields, receiving different, yet similar designations, such as "patient-generated outcome measures" (PGOMS; Ashworth et al., 2004), "client-generated outcome measures" (CGOMS; Elliott et al., 2016) and also "individualised patient-reported outcome measures" (I-PROMS; Sales, 2016). These designations have been used as synonyms in the literature, based on the authors' preferences, the field of study and also the time of publication. The interchangeable use of these terms is also present in this compilation of articles, to meet publication requirements. However, hereafter, we shall be using the term I-PROMS since, to our belief, it is currently the most accurate designation for these type of instruments.

I-PROMS have not yet become "normal science", as Kuhn (1962) would have put it. This is mainly due to the fact that I-PROMS are focussed on what is specific about a single person, hindering the aggregation of data about common features among patients in a certain population, service, or even at a national/international level. However, there are several signs showing that we are now potentially entering an "extraordinary science" period (Kuhn, 1962), which is calling out for a new paradigm in outcome measurement. Using McNamara's (2007) words, now our "challenge is to [understand how to] make the important measurable, not the measurable important". I-PROMS are not necessarily innovative by providing patients with an opportunity to talk about their problems. In fact, listening to patients' complaints is part of any therapeutic intervention, particularly in the first treatment sessions when therapists are learning about what brought patients to treatment. However, this individualised information tends to be mostly used for clinical-related tasks, such as treatment planning or decision-making, and is usually lost for the purposes of outcome measurement. This is where the greatest advantage of I-PROMS lies: generating individualised information about patients, in the format of items, that can be scored by patients and be used to evaluate clinical changes that patients undergo whilst in treatment, as standardised measures do (Elliott et al., 2016; Sales & Alves, 2016). This is a step forward in outcome measurement, by providing an opportunity for patient's concerns to be heard and, simultaneously, transformed into numbers that can be shared with clinical staff, service managers and funding agencies, for data management purposes.

Moving towards a personalised outcome measurement approach

To this point, we have demonstrated that standardised and individualised outcome measures are both advantageous and necessary for a successful and meaningful outcome measurement process. Hence, instead of opposing strategies to evaluate treatment, it has been advocated that they can and should be used to complement each other (Möller, 2009).

In 2000, an international and multidisciplinary group of researchers and therapists formed a practice-based research network to investigate how to increase patient involvement with outcome measurement in mental health treatments. After a decade of fruitful collaboration, this group was designated as International Research Network on Personalised

Health Assessment (IPHA Group; Sales, Alves, Evans & Elliott, 2014). To date, the IPHA Group integrates dozens of professionals coming from countries such as Portugal and the United Kingdom, who have been collaborating to develop, implement and reflect about I-PROMS and how they can be integrated with standardised measures.

The co-joint work of the IPHA Group has resulted in the proposal of a new strategy for outcome measurement: the personalised measurement approach. More than a method, this approach is an evaluation philosophy, rooted in the assumption that it is possible to reach a successful compromise between nomothetic and idiographic measures. The first attempt to translate this approach into practice emerged in 2010, with the development of the Individualised Patient-Progress System (IPPS; Sales & Alves, 2012; Sales, Alves, Evans, & Elliott, 2014). This system is a web-based patient progress tracking software that includes one standardised PROM about general psychological distress, the Clinical Outcomes Routine Evaluation – Outcome Measure (CORE-OM; Evans, Connell, Barkham, Mellor-Clark, & Audin, 2002) and one I-PROM focusing on patients' target complaints, the Personal Questionnaire (PQ; Elliott et al., 2016). IPPS derived from the well-stablished CORE-Net system (Mellor-Clark, 2007), which included CORE-OM only, and illustrates the movement towards the integration of standardised and individualised PROMS in the same evaluation protocol (Barkham, Mellor-Clark, & Stiles, 2015).

With the development of IPPS, the personalised measurement approach was introduced in several therapeutic contexts and clinical populations, with positive results (Sales, Alves, Evans, & Elliott, 2014). This included university counselling services (Lucas, Soares, Oliveira, Sales, & Alves, 2012), general hospitals (Vieira, Torres, & Moita, 2013) and also private psychotherapy practices (Cruz, 2014).

According to its preliminary users, the personalised measurement approach has several helpful and hindering aspects. On the positive side, therapists reported that this methodology ‘highlights situations that represent patients’ distress or harm’, ‘supports clinical decision making’, ‘helps patients to re-think about themselves and their problems’ and provide a ‘quick picture of patients’ psychological distress’ (Sales, Alves, Evans, & Elliott, 2014). As downsides, therapists stated that using this measurement approach is “a lengthy process, particularly at the pre-treatment evaluation’ (Sales, Alves, Evans, & Elliott, 2014).

Within such panorama, there is a need to continue exploring I-PROMS and what we can gain by combining them with standardised measures, from a qualitative and quantitative point of view. The present project was a step in this direction.

The status of outcome measurement in substance misuse treatment

Unless there is a pre-treatment evaluation with diagnostic purposes, it is impossible to predict what motivated patients to psychological treatment when they arrive for their first clinical session. This is not what occurs in specialist services, though, which are focussed in a particular target population. In these services, professionals are expecting to address a primary behaviour, and co-occurring, or secondary problems may be disregarded or perceived as a “dilemma” (Drake, Mueser, & Brunette, 2007). Such is the reality of specialist treatment services for substance misuse disorders.

It has been stated that problem screening and outcome measurement is essential and should be a routine practice in substance misuse treatment services (British Psychological Society, 2008; Deady, 2009). To Deady (2009), this measurement is particularly important for case formulation purposes, i.e. “gathering information about factors that may be relevant to treatment planning, and formulating a hypothesis as to how these factors fit together to form the current presentation of the client’s symptoms” (p. 9), as well as identifying “symptoms that may require further investigation and treatment” (p. 9). According to the British Psychological Society (2008), the purposes of substance misuse treatment measurement are clear and include the following: to confirm substance misuse; to evaluate the severity of dependence; to identify complications of substance misuse and related risk-behaviours; to identify medical, social and mental health problems; to evaluate expectations of treatment and motivation to change; to determine the most appropriate treatment pathway and expertise required; to evaluate the need for substitute medication; and to refer/liaise with other services and forms of care.

Despite general recommendations, information about how the measurement procedure should be conducted and which tools should be used is diffuse. However, when patients are referred to or request treatment at substance misuse treatment services, they tend to be provided with brief evaluation forms that focus on topics related to history of substance misuse and typically associated behaviours, such as criminality. An example is the Treatment Outcomes Profile (TOP; Marsden et al., 2008), which is widely used in the United Kingdom (http://www.nta.nhs.uk/healthcare-TOP.aspx) and targets the following sections: ‘substance use’, ‘injecting risk behaviour’, ‘crime’ and ‘health and social functioning’. In Portugal, even though no instrument in itself is recommended by health authorities, patients tend to be invited for an induction session with a key worker and an initial evaluation with a psychologist or psychiatrist, which includes topics such as previous history of substance use and treatment (Serviço de Intervenção nos Comportamentos Aditivos e Dependências, see http://www.sicad.pt/PT/Intervencao/TratamentoMais/SitePages/ModelosRespostas.aspx).

From a research point of view, international large-scale outcome studies have targeted similar criteria. The most popular were the National Treatment Outcome Research Study (NTORS; http://www.ntors.org.uk/), conducted in the United Kingdom, evaluating aspects such as ‘substance use’, ‘risk behaviours’, ‘health’ and ‘personal/social functioning’; the Australian Treatment Outcome Study (ATOS; Ross, Teesson, Darke, Lynskey, Ritter, & Cooke, 2004), that included ‘treatment experiences’, ‘heroin and other drug use’, ‘mental health’ and ‘criminal activity’; and the Drug Abuse Treatment Outcome Studies (DATOS;

http://www.datos.org/), conducted in the United States of America, which evaluated ‘employment status’, ‘criminal status’, ‘mental health’, ‘medical and health-related data’, level of drug/alcohol use’, ‘primary drug and patterns of dependence’ and ‘HIV risk behaviours’. Even though these studies identified positive outcomes, the reality showed a different picture, presenting a high number of treatment drop-outs, relapse and a low percentage of treatment success (Gordon, 2003). Such findings call out for a reflection about how outcomes are being measured in substance misuse treatment. Are we missing something?

Patient involvement with substance misuse treatment measurement

As in other mental health settings, patients in substance misuse treatment are powerful sources of information when it comes to identifying relevant outcomes or success criteria. In line with this, in 2006, the United Kingdom’s National Treatment Agency advocated that ‘service users should be involved in all key aspects of decision making in relation to their care’ (p. 1). However, patients in substance misuse treatment tend to be poorly engaged with most clinical-related tasks, including evaluation of treatment (Orford, 2008; Trujols et al., 2011).

One of the main reasons behind the poor engagement of substance misusers with treatment-related tasks is the stigmatisation of the addictive behaviour. The literature shows that substance misusers are likely to be criminalised and discriminated for their behaviour, and perceived as ‘tainted’, ‘discounted’ and ‘undeserving’ persons whose views tend to be discredited and/or not even requested (Fischer et al., 2007; Ti, Tzemis, & Buxton, 2012; Trujols et al., 2011). Also, as Fischer and Neale (2008) highlighted, several health professionals ‘disregard’ the concerns of patients in this population, which reduces their involvement with treatment and weaken their self-worth and self-confidence as individuals. This view is also supported by Cheng and Smith (2009), who claim that the controversies over the moral, criminological and bio-medical aspects of addiction hinders the development of initiatives to improve the engagement of patients with clinical services. According to Fischer and collaborators (2007), other barriers impeding the involvement of substance users in their treatment include power imbalances between professionals and patients; patients' vulnerability or lack of interest to participate in treatment-related tasks; and patients' beliefs that therapists are experts and know how to make the best decisions for them.

For authors such as Fischer and colleagues (2007), the movement towards a greater involvement of users was slower in substance misuse treatment in comparison with other health fields (e.g. cancer treatment). However, the increasing body of literature that emerged in the past decades suggests a stronger interest in including the patients' voices in areas such as treatment evaluation and development of clinical guidelines (Fischer et al., 2007; Trujols et al., 2011). As Trujols and collaborators (2011) pointed out, this paradigm is likely to have derived from the general tendency to modify the hierarchised relationship between doctors and patients, which underlined a biased assumption of substance misusers as non-competent individuals.

It is now widely acknowledged that for services to be improved and more relevant for substance misusers, they must take the needs of patients into account (Ti, Tzemis, & Buxton, 2012). Otherwise, there is a risk that services will not be sensitive to this population's problems and preferences (Fischer et al., 2007). Asking for patients' involvement is also a means of increasing their empowerment, confidence and self-esteem as individuals, which are likely to be impaired in substance misusers; as well as potentially increasing the level of acceptability and utilization of services by patients (Fischer et al., 2007; Ti, Tzemis, & Buxton, 2012). A study conducted in Scotland (cit. Fischer, 2007) illustrated the potential benefits of involving patients more actively with their clinical interventions. In this study, patients who had been involved in treatment-related decisions reported being more satisfied with their care, had longer treatment stays and presented more positive outcomes than their counterparts who were less engaged with treatment. Moreover, as Crawford et al. (2002) put it, it is a democratic right and ethical obligation to involve substance misusers in the treatment they are receiving; otherwise, they will continue to be dehumanised and condemned for their behaviour. This is of particular importance in countries such as Portugal, whose decriminalisation policy adopted 15 years ago (Law nr. 30/2000) states that individuals who misuse drugs are referred to treatment, instead of being convicted with a crime sentence or even incarcerated.

Despite the appeal for a greater involvement of patients with substance misuse treatment (Orford, 2008), there is little guidance on how to translate this recommendation to practice. This work aimed to fill this gap by proposing, testing and gathering patients' experiences with a methodology to include patient perspectives in the measurement of treatment outcomes.

Project rationale

In our literature review, we highlighted the critical situation of outcome measurement in substance misuse treatment services, where 1) it is uncertain whether the “right” criteria are being used to measure treatment; and 2) patients’ perspectives tend to be neglected. I-PROMS have been introduced in several mental health fields with promising results. Therefore, this research project was an extension of IPHA group previous work, by introducing I-PROMS in substance misuse treatment and exploring their potential towards a greater patient involvement and personalisation of outcome measurement in this specific field.

For our project, we devised a naturalistic cross-sectional study, where a personalised evaluation protocol was administered to patients entering substance misuse treatment services in Portugal, which resulted in two empirical articles; a focus group qualitative study to investigate patients’ experiences with that evaluation protocol, leading to one empirical article; and a scoping review to explore how relevant the existing outcome measures for substance misuse treatment are for this patient group, which resulted in our last empirical article.

The evaluation protocol combined I-PROMS with standardised outcome measures. Using standardised tools was necessary not only for comparison purposes, but also to investigate the benefits and drawbacks of using both type of measures co-jointly, as the literature advocates (Sales & Alves, 2016; 2012; Sales, Alves, Evans, & Elliott, 2014). Addiction researchers (Neale & Strang, 2015) have also promoted the complementary use of personalised, qualitative information with standardised data about patients.

Two I-PROMS were included in the evaluation protocol, namely, the Personal Questionnaire (PQ; Elliott, 2016) and the Psychological Outcome Profiles (PSYCHLOPS; Ashworth et al., 2005). Even though both PQ and PSYCHLOPS have an idiographic scope, these differ in the method for item generation (interview vs. self-report) and quantity of individualised items requested (unlimited vs. three). To our knowledge, no previous study had ever compared the similarities and differences between these two I-PROMS.

As standardised measures, we opted for including tools that addressed the commonest psychological, physical and social problems of this population. Psychological health, including depression, anxiety, personality disorders and post-traumatic stress are reported to be amid the most important areas to tackle in substance misuse treatment (Wanigaratne, Davis, Pryce, & Brotchie, 2005). Psychological distress has been considered in previous large-scale outcome studies (e.g. DATOS, NTORS and DTORS), in particular depression and suicidal ideation. Because of this, we selected the Clinical Outcome Routine Evaluation – Outcome Measure (CORE-OM; Evans, Connell, Barkham, Mellor-Clark, & Audin, 2002), a self-report measure about general psychological distress; and the Patient Health Questionnaire – 9 (PHQ-9; Kroenke, Spitzer & Williams, 2001), another self-report measure targeting mood disorders, in particular, depression. To evaluate substance misuse and related behaviours, the researcher-administered Treatment Outcomes Profile (TOP; Marsden et al., 2008) was added to our evaluation protocol, which is one of the most popularly used measures targeting drug-related problems.

To sum up, this research project was designed to improve outcome measurement in substance misuse treatment, through the personalisation of the evaluation process with I-PROMS; and to increase patient involvement with outcome measurement, by actively asking for their collaboration in the selection of topics to be evaluated. We endeavoured that this work could contribute to the development of a new methodological approach to measure substance misuse treatment outcomes. Can we shift the current paradigm?

Aims and overview

Our main goal was to explore the potential of I-PROMS as a strategy to personalise the outcome measurement process in substance misuse treatment services, following a mixed-methods (qualitative and quantitative) approach. More specifically, we aimed to explore the nature of qualitative information and the scorings generated by I-PROMS, as well as their practicability and adequacy as outcome measures. Additionally, we also explored the perspectives of patients about I-PROMS.

The outputs of our work were divided into five scientific articles. The first article had a theoretical scope and aimed to provide a literature-based foundation for our measurement philosophy and to present it to the scientific community, since there were no accounts of individualised measures in substance misuse treatment. For this article, we followed a critical literature review approach to reinforce the importance of patient involvement, and to overview the methods currently used to increase this involvement in healthcare. I-PROMS were suggested as a method to involve patients more actively in treatment. In particular, we discussed how asking patients in substance misuse treatment to complete individualised measures is likely to reduce the stigmatisation of these individuals, humanise the outcome measurement process and value the perspectives of those who have first-hand experience with substance misuse. This article was concluded by enhancing the challenges in using I-PROMS in this field, as well as future research needed to make this approach a more feasible, reliable and robust method.

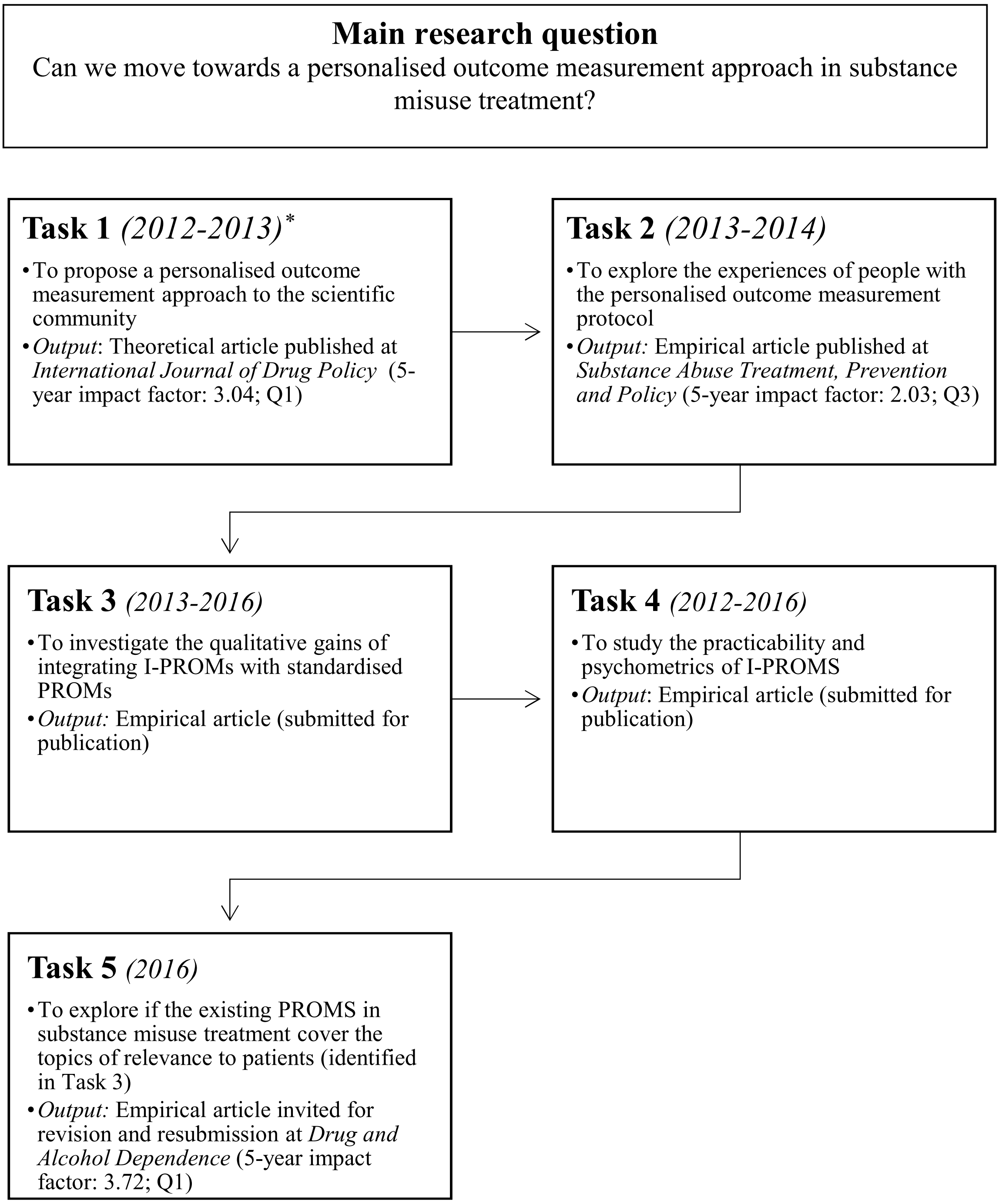
The second article presented a qualitative study, using a focus group approach, in which we interviewed a sub-sample of patients (N = 10) who completed the evaluation protocol. Its main goal was to explore patients' experiences and thoughts about the I-PROMS and standardised measures that were part of the protocol and to comprehend how relevant and appropriate those measures were for this population, from their point of view. We expected to learn from patients what is necessary to increasingly make outcome measurement a more meaningful and comfortable experience. From an ethical point of view, and particularly in a project about patient involvement, it was imperative to consult patients about our measurement approach. Otherwise, it would have been contradictory to our research philosophy to suggest a methodology to improve patient involvement without involving them in this process as well.

After learning that I-PROMS were positively perceived by patients, we proceeded to the third article. This study explored if I-PROMS generated additional information about patients that standardised measures overlooked. For this, we categorised 489 I-PROMS items, generated by 93 patients. Items were categorised according to their underlying sub-theme, based on a classification system proposed by Ashworth and collaborators (2007). A thematic comparison was made between these sub-themes and the contents of pre-set items provided in the three standardised measures. Our aim was to understand if, from a qualitative perspective, I-PROMS were a valuable complement to standardised measures.

The fourth article had a quantitative scope and its aims were twofold: first, to investigate the practicability of I-PROMS in substance misuse treatment services, based on quantitative parameters (e.g. administration times, response rates); and second to explore the scorings of I-PROMS from a psychometric point of view. In other words, we wanted to investigate to what extent I-PROMS could be used to quantify patients' distress in a reliable and valid manner, in addition to providing relevant qualitative information about patients. The findings of this study were meant to build on preliminary reports about the psychometrics of I-PROMS and its potential as outcome measures.

To this point, our studies were limited to the comparison of I-PROMS with three standardised measures. For that reason, the fifth and final article had a more general scope, by exploring how outcome measures currently recommended in Europe for substance misuse treatment reflect the concerns of patients. This study followed a scoping review methodology and derived from the findings of the third article using the I-PROMS sub-themes that emerged from our naturalistic sample. The aims were to identify the domains covered by outcome measures and to contrast them with I-PROMS sub-themes. We intended to take a step further from the findings obtained in our project, potentially demonstrating that even when a broader range of PROMS is considered, I-PROMS are still needed to capture patients' individual concerns.

This work is concluded with a general discussion of the main findings that emerged from the five articles, having in mind the objectives of the research project. We also sought to discuss the meaning of our research outputs in light of what is already reported in the literature and directions for future research. Lastly, we aimed to highlight preliminary recommendations on how to use I-PROMS in substance misuse treatment settings, which derived from our findings. Figure 1 provides a visual diagram that summarises our research tasks, their sequenced implementation and the timeframes in which each task was performed.



Main research question

Can we move towards a personalised outcome measurement approach in substance misuse treatment?

Task 1 *(2012-2013)**

- To propose a personalised outcome measurement approach to the scientific community
- *Output*: Theoretical article published at *International Journal of Drug Policy* (5-year impact factor: 3.04; Q1)

Task 2 *(2013-2014)*

- To explore the experiences of people with the personalised outcome measurement protocol
- *Output:* Empirical article published at *Substance Abuse Treatment, Prevention and Policy* (5-year impact factor: 2.03; Q3)

Task 3 *(2013-2016)*

- To investigate the qualitative gains of integrating I-PROMs with standardised PROMs
- *Output:* Empirical article (submitted for publication)

Task 4 *(2012-2016)*

- To study the practicability and psychometrics of I-PROMS
- *Output*: Empirical article (submitted for publication)

Task 5 *(2016)*

- To explore if the existing PROMS in substance misuse treatment cover the topics of relevance to patients (identified in Task 3)
- *Output:* Empirical article invited for revision and resubmission at *Drug and Alcohol Dependence* (5-year impact factor: 3.72; Q1)

Notes: * refers to the time interval where the article / research study was conducted. For empirical articles, the first date refers to the beginning of data collection, and the last corresponds to the submission of the article to scientific journals.

Figure 1. Outline of the main research question, tasks and outputs of this project.

References

Ashworth, M, Shepherd, M, Christey, J., Matthews, V., Wright, K., Parmentier, H., Robinson, S., & Godfrey, E. (2004). A client-generated psychometric instrument: the development of "PSYCHLOPS". *Counselling and Psychotherapy Research*, *4*, 27-31. doi: 10.1080/14733140412331383913

Ashworth, M., Robinson, S., Godfrey, E., Shepherd, M., Evans, C., Seed, P., Parmentier, H., & Tylee, A. (2005). Measuring mental health outcomes in primary care: the psychometric properties of a new patient-generated outcome measure, 'PSYCHLOPS' ('psychological outcome profiles'). *Primary Care Mental Health*, *3,* 261-270.

Ashworth, M., Robinson, S., Evans, C., Shepherd, M., Conolly, A., & Rowlands, G. (2007). What does an idiographic measure (PSYCHLOPS) tell us about the spectrum of psychological issues and scores on a nomothetic measure (CORE-OM). *Primary Care and Community Psychiatry, 12,* 7-16. doi: 10.1080/17468840701560805

Barkham, M., Mellor-Clark, J., & Stiles, W. (2015). A CORE approach to progress monitoring and feedback: enhancing evidence and improving practice. *Psychotherapy*, *52*, 402-411. doi: 10.1037/pst0000030

Basch, M., Abernethy, A., Reeve, B. (2011). Assuring the patient centeredness of patient-reported outcomes: content validity in medical product development and comparative effectiveness research. *Value in Health*, *14*, 965-966. doi: 10.1016/j.jval.2011.10.002

Beck, A. T., Steer, R.A., & Garbin, M.G. (1988) Psychometric properties of the Beck Depression Inventory: Twenty-five years of evaluation. *Clinical Psychology Review, 8*, 77-100. doi: 10.1016/0272-7358(88)90050-5

Bower, P., & Gilbody, S. (2010). *The current view of evidence and evidence-based practice.* In Barkham, M., Hardy, G., & Mellor-Clark, J. (Eds). Developing and delivering practice-based evidence: a guide for the psychological therapies. West Sussex: John Willey & Sons.

Bren, L. (2006). The importance of patient-reported outcomes…It's all about the patients'. *Food and Drug Administration.* Retrieved from http://permanent.access.gpo.gov/lps1609/www.fda.gov/fdac/features/2006/606_patients

Crawford, M., Rutter, D., Manley, C., Weaver, T., Bhui, K., Fulop, N., & Tyrer P. (2002). Systematic review of involving patient in the planning and development of health care. *British Medical Journal*, *325*, 1263-1265. doi: 10.1136/bmj.325.7375.1263

Devlin, N., & Appleby, J. (2010). *Getting the most out of PROMS: putting health outcomes at the heart of the NHS decision-making.* London: The King's Fund.

Elliott, R., Wagner, J., Sales, C., Rodgers, B., Alves, P. & Café, M. (2016). Psychometrics of the Personal Questionnaire: a client-generated outcome measure. *Psychological Assessment*, *28*, 263-278. doi: 10.1037/pas0000174

Evans, C., Connell, J., Barkham, M., Mellor-Clark, J., & Audin, K. (2002). Towards a standardised brief outcome measure: psychometric properties and utility of the CORE-OM. *British Journal of Psychiatry*, *180*, 51-60. doi: 10.1192/bjp.180.1.51

Fitzpatrick, R., Davey, C., Buxton, M. J., & Jones, D. R. (1998). Evaluating patient-based outcome measures for use in clinical trials. *Health Technology Assessment*, *2*, 1-86. doi: 10.3310/hta2140

Flückiger, C., Del Re, A., Wampold, B., Znoj, H., Caspar, F., & Jörg, U. (2012). Valuing clients' perspective and the effects on the therapeutic alliance: a randomized controlled study of an adjunctive instruction. *Journal of Counselling Psychology*, *59*, 18-26. doi: 10.1037/a0023648

Greenhalgh, J., Pawson, R., Wright, J., Black, N., Valderas, J., Meads, D., Gibbons, E., Wood, L., Wood, C., Mills, C., & Dalkin, S. (2014). Functionality and feedback: a protocol for a realist synthesis of the collation, interpretation and utilisation of PROMs data to improve patient care. *BMJ Open, 4,* 1-7. doi:10.1136/bmjopen-2014-005601

Kroenke, K., Spitzer, R. L., & Williams, J. B. (2001). The PHQ-9: validity of a brief depression severity measure. *Journal of General Internal Medicine*, *16*, 606-613. doi: 10.1046/j.1525-1497.2001.016009606.x

Möller, H. (2009). Standardised rating scales in Psychiatry: Methodological basis, their possibilities and limitations and descriptions of important rating scales. *The World Journal of Biological Psychiatry*, *10*, 6-26. doi: 10.1080/15622970802264606

Marsden, J., Farrell, M., Bradbury, C., Dale-Perera, A., Eastwood, B., Roxburgh, M., & Taylor, S. (2008). Development of the Treatment Outcomes Profile. *Addiction*, *103*, 1450-1460. doi: 10.1111/j.1360-0443.2008.02284.x

Neale, J., & Strang, J. (2005). Blending qualitative and quantitative research methods to optimize patient reported outcome measures (PROMs). *Addiction*, *10*, 1215-1216. doi: 10.1111/add.12896

Orford, J. (2008). Asking the right questions in the right way: the need for a shift in research on psychological. *Addiction, 103*, 875-885. doi: 10.1111/j.1360-0443.2007.02092.x

Paul, C., Sanson-Fischer, R., & Carey, D. (2013). Measuring psychosocial outcomes: is the consumer or the professional the best judge? *European Journal of Cancer Care*, *22*, 281-288. doi: 10.1111/ecc.12048

Sales, C. (in press). Seeing the person in the patient: making the case for individualized PROMs in mental health care. *Current Psychiatry Reviews*.

Sales, C., & Alves, P. (2012). Individualised patient-progress systems: Why we need to move towards a personalized evaluation of psychological treatments. *Canadian Psychology*, *53*, 115-121. doi:10.1037/a00280537

Sales, C., Alves, P., Evans, C., & Elliott, R. (2014). The Individualised Patient Progress System (IPPS): A decade of international collaborative networking. *Counselling and Psychotherapy Research*, *14*, 181-191. doi:10.1080/14733145.2014.929417

Sales, C., & Alves, P. (2016). Patient centred assessment in Psychotherapy: A review of individualised tools. *Clinical Psychology: Science and Practice*, *23*, 265-283. doi:10.1111/cpsp.12162

Schulte, D. (1995). How treatment success could be assessed. *Psychotherapy Research, 5,* 281-296. doi: 10.1080/10503309512331331406

Snyder, C., Aaronson, N., Choucair, A., Elliott, T., Greenhalgh, J., Halyard, M., Hess, R., Miller, D., Reeve, B., & Santana, M. (2012). Implementing patient-reported outcomes assessment in clinical practice: a review of the options and considerations. *Quality of Life Research, 21,* 1305-1314. doi: 10.1007/s11136-011-0054-x

Valderas, J. M., Kotzeva, A., Espallargues, M., et al. (2008). The impact of measuring patient-reported outcomes in clinical practice: A systematic review of the literature. *Quality of Life Research*, *17*, 179-193. doi: 10.1007/s11136-007-9295-0

Valderas, J. (2012). Future use of Patient Reported Outcome Measures (PROMs): Use for individual patients. Retrieved from https://www.kingsfund.org.uk/sites/files/kf/jose-valderas-future-use-patient-reported-outcome-measures-individual-patients-kingsfund-nov12.pdf

Walton, M., Powers, J., Hobart, J., Patrick, D., Marquis, P., Vamvakas, S., Isaac, M., Molsen, E., Cano, S., & Burke, L. (2015). Clinical outcome assessments: conceptual foundation. Report of the ISPOR clinical outcomes assessment – emerging good practices for outcomes research task force. *Value in Health*, *18,* 741-752. doi: 10.1016/j.jval.2015.08.006

Wanigaratne, S., Davis, P., Pryce, K., Brotchie, J. (2005). The effectiveness of psychological therapies on drug misusing clients. Retrieved from http://www.dldocs.stir.ac.uk/documents/rb11_final.pdf

COMPILATION OF ARTICLES

Personalising the evaluation of substance misuse treatment: a new approach to outcome measurement[¤]

Paula C. G. Alves[a,b*], Célia M. D. Sales[c], & Mark Ashworth[b]

Patient involvement in healthcare, in general, and in substance misuse in particular, has become a topic of paramount importance (Rutter et al., 2004). Patient involvement can be conceptualised as listening to the patients' perspective and encouraging patients to take an active role in the care they are receiving. This approach is advocated by international authorities in health and social care such as the United Kingdom's National Institute for Health and Care Excellence (NICE), which recommends "person-centred care" that takes into account the patient's "needs, preferences and strengths" (Crawford, 2011). According to Orford (2008), the perspectives of patients in substance misuse treatment tend to be overlooked and their involvement with treatment is limited. However, the evidence on how patient involvement can be improved within the context of substance misuse programmes are scarce. Can we do something to shift this reality?

In healthcare, patients can become actively involved by collaborating with treatment outcome evaluation. In psychological treatments the commonest approach to this involves the use of standardised outcome measures (SOM), whose pre-set items, developed by research

---

[¤] Article published at the International Journal of Drug Policy, under the reference Alves, P., Sales, C., & Ashworth, M. (2015). Personalising the evaluation of substance misuse treatment: a new approach to outcome measurement. *International Journal of Drug Policy, 26*, 333-335. doi: 10.1016/j.drugpo.2014.11.014

[a] Instituto Universitário de Lisboa (ISCTE-IUL), CIS-IUL, Lisboa, Portugal

[b] Division of Health and Social Care Research; Faculty of Life Sciences & Medicine, King's College London

[c] Centro de Psicologia da Universidade do Porto, Faculdade de Psicologia e de Ciências da Educação, Universidade do Porto.

[*] Corresponding author. E-mail address: paulagomesalves@hotmail.com

experts or professionals are rated by patients. The majority of SOM, both in psychological treatments (e.g., CORE-OM; Evans, Connell, Barkham, Mellor-Clark, & Audin, 2002) and in substance misuse (e.g., TOP; Marsden et al., 2008), have had their psychometric properties extensively explored and their results are widely acknowledged as valid and reliable to evaluate treatment. However, due to their universal scope and applicability to both healthy populations and those with mental health conditions, SOM are unlikely to cover all the subjective concerns of patients, their priorities and their personal experiences in treatment.

There is a different approach to evaluate treatment, which is based on patient-generated, or individualised, outcome measures (PGOM). PGOM include items that are created by patients, resulting in personalised tailor-made scales that can be rated for severity, just like SOM (Sales & Alves, 2012). There are several protocols to generate these personalised scales: for instance, the Personal Questionnaire (PQ; Elliott, Mack, & Shapiro, 1999) is a semi-structured interview where patients are asked to say which are "the main problems that led them to treatment" and then to rank order them by importance; or PSYCHLOPS (Ashworth et al., 2004), a self-report instrument where patients write down the two main problems they are currently experiencing and one thing that has become difficult to do because of those problems. When PGOM are used, the level of patient involvement with treatment evaluation increases substantially, which is important not only because patients and clinicians tend to appraise treatment differently, but also because most measurements are developed without direct input from patients (Crawford et al., 2011). Also, PGOM data is not fixed in time and allows patients to revise, delete obsolete problems or add new ones that might have arisen during therapy.

PGOM are becoming increasingly popular in psychological treatments, given their advantages for outcome evaluation and clinical practice. As outcome measures, PGOM include patient case-specific information, as well as scores that quantify the distress caused by such problems, allowing a personalised evaluation of outcome (Sales & Alves, 2012); one of the properties of PGOM is greater sensitivity to clinical change when compared with SOM; the trade-off is that PGOM have slightly lower levels of test-retest reliability and internal reliability (Lacasse et al, 1999). Nevertheless, the reliability levels of PGOM are satisfactory and this should not detract their role as highly sensitive measures of change (Ashworth et al., 2008; Elliott et al., 2014). Also, PGOM allow outcome measurement to take patient's perspectives into account, making them feel more valued as individuals (Alves, Sales, & Santos, 2014). As clinical tools, PGOM have been considered to be useful to complement diagnoses, case formulation and clinical-decision making (Sales et al., 2007; Sales, Alves, Evans, & Elliott, 2014); and recently, patients reported satisfaction with the freedom that PGOM give them to focus on the topics which they prioritise during the evaluation process (Alves, Sales, & Santos, 2014).

But there are downsides to using PGOM. For instance, they have been considered time-consuming and are difficult to use with patients with certain impaired cognitive functions (e.g. memory). Moreover, PGOM hinder the comparison between patients (Sales et al., 2007; Soares et al., 2012), making it difficult to interpret their scores against population norms since each 'individualised' measure is, in effect, offering a score for unique, individually defined items. Hence, PGOM are not the "holy grail" of outcome assessment and cannot provide, alone, all the information that is needed to evaluate patients' clinical situation.

It has been recently suggested that PGOM should be added to standardised data for optimal results, in a strategy called personalised outcome measurement approach (Sales & Alves, 2012). In practice, this approach implies the combination of PGOM and SOM in the same evaluation protocol. Here is one example: to use, at the pre-treatment evaluation session, PQ or PSYCHLOPS, followed by CORE-OM. With SOM, therapists can quickly assess the patient's level of distress based on clinical cut-offs; whilst PGOM identify the specific concerns of patients, giving more insight about how they perceive their own clinical situation. According to the characteristics of the service, personalised outcome protocols can be administered pre and post treatment; or on a session-to-session basis, to monitor the progress of patients throughout treatment. In such cases, as aforementioned, patients are able to update the contents contained in their PGOM, as many times as desired.

The personalised outcome measurement approach has already been implemented in various mental health settings, from university-based counselling centres to day psychiatry units and also group therapy interventions, with positive results. These studies have been conducted as part of a practice-based research network, dedicated to personalised assessment, the IPHA Group (Sales, Alves, Evans, & Elliott, 2014).

As earlier stated, failing to include the patient's perspective has been identified as one of ten areas which require a paradigm shift in psychological addiction treatment (Orford, 2008). If the personalised outcome measurement approach seems to work, on the one hand, and is, on the other, a potential strategy to increase patients' involvement in treatment, could we extend it to this specific context? What would we gain from doing so?

In substance misuse, improvements in mental health are among the most important treatment goals (Wanigaratne, Davis, Pryce, & Brotchie, 2005). However, psychological health tends to be evaluated with SOM such as the SF Health Survey (see Drug Treatment Outcomes Research Study, Jones et al., 2009 for an example), where the level of patient involvement is minimal, as previously explained. Also, as shown in previous reviews (e.g. Livingston et al., 2011), substance misuse disorders tend to be more stigmatized in comparison with other health problems. This may not only act as a barrier for seeking healthcare, but also to poor and inadequate provision of care, potentially leading to early treatment drop-out and poor adherence (Livingston et al., 2011).

From a clinical perspective, we believe that substance misuse treatment services could benefit from adopting the personalised measurement approach. First, the use of PGOM potentially allows clinicians to better understand how patients perceive their own situation. This is particularly relevant at the pre-treatment stage, because it helps clinicians preparing treatment plans that take the priorities of patients into account, instead of adopting "by-the-book", or protocol driven interventions. Also, in a population where drop-out rates are relatively high, to formally ask for patients' help to evaluate their own situation might increase their motivation to continue with the treatment programme.

Second, adding PGOM to outcome measurement encourages patients to select and prioritise their own problems, regardless of whether these are drug-related or not. In this context, the tools used for screening and outcome measurement purposes focus primarily on drug use and drug-related risk behaviours (e.g. TOP; Marsden et al., 2008). However, patients may have other concerns that are perceived as equal or of greater importance than their drug use (e.g. recent death of a relative). As a female patient put it in focus group recently conducted in Portugal, "This questionnaire [PSYCHLOPS, a PGOM] helps people to think about all their difficulties in life. It is not just the alcohol" (Alves, Sales, & Santos, 2014). Thus, even though PGOM do not substitute for diagnostic interviews or disorder-specific scales (e.g. Beck Depression Inventory; Beck, Steer, & Garbin, 1988) they may serve as flag alerts for clinical practice and further assessments.

We also hope that using PGOM will contribute to diminishing, to some extent, the stigmatization of patients with substance misuse problems. It is not uncommon for these patients to be perceived as manipulative and untruthful, which may be related to reasons why their own perspectives tend to be overlooked. However, as illustrated in the previous paragraph, asking patients' opinions about their own problem priorities enables health care workers to offer more holistic care (cf. above: "it's not just the alcohol").

The personalised outcome assessment approach is also a potential tool to influence policies regarding treatment provision in this field. On the one hand, this measurement approach provides an action plan, ultimately in the format of guidelines, for therapists to understand how to put the principle of “patient-centred” care into practice, as a means of improving quality of care in general. This is of importance at the time being, when health care budgets are increasingly constrained and funding decisions are dependent upon evidence of effectiveness judged both by professionals and patients.

Second, personalised outcome measurement is a strategy that reconciles the existing approach to outcome assessment, with personalised questionnaires that serve not only as complementary outcome measures, but also as clinical tools that are useful to practice, and humanize the assessment procedure that is often regarded as impersonal ‘tick-box’ measures.

As PGOM reflect the patient’s perspectives, we believe that they might provide insights about the problems which are most relevant to this population, so that we know, through the patient’s eyes, which areas should be more emphasized in drug misuse treatment programs. For instance, if the majority of patients report that unemployment is what concerns them the most, it might be necessary to revise the policies regarding social rehabilitation of patients in drug misuse treatment (e.g. increasing the number of partnerships between treatment centres and employment agencies).

Also, adding PGOM to traditional outcome measures will lead to more comprehensive policies of treatment evaluation and delivery, for it includes the point of view of all the parties involved in healthcare, namely, the voice of patients who are likely to be unheard in substance misuse settings.

Finally, as aforementioned, the use of tools to include the perspective of patients will, ultimately, contribute to a greater humanization of the substance misuse treatment system. All in all, from an ethical point of view, it is imperative to enhance patient autonomy in patient care. By valuing what patients have to say, and involving them as actively as possible in the delivery of health care, we consider that this approach will maximize the potential benefit of treatment programmes.

There are, however, several steps that need to be taken before this approach is fully acknowledged as feasible and reliable in substance misuse treatment. These include: 1) piloting the personalised assessment approach in several international treatment agencies, to increase its robustness; 2) discussing, with international drug monitoring agencies, the appropriateness of developing and disseminating international guidelines for personalised assessment, to reduce the gap between treatment delivery and outcome assessment across countries; and 3) creating practice-based networks for drug treatment services to collaborate and share their experiences with personalised assessment, extending the cooperation between therapists, researchers and patients towards the improvement of healthcare (e.g. International Exchange Platform for Personalising Substance Misuse Treatment; Alves, Sales, & Ashworth, 2013).

To sum up, in this paper we have presented the personalised outcome measurement approach as a potential strategy to increase patient involvement with substance misuse treatment, an area in need of an urgent paradigm shift. Overall, this strategy potentially allows us to better accommodate the diversity and the idiosyncrasies of each patient that enters each consultation room. There is, however, the danger of becoming so individualized that it becomes difficult to have an overview about the population’s heterogeneity, rendering it harder to plan services at a population level. Hopefully, the compromise that we propose between personalised and standardised measures is the ideal strategy to bridge these two worlds, but only further testing of where the balance lies will enable us to maximize the benefit from both approaches.

References

Alves, P., Sales, C., & Santos, M. T. (2014, June). Involving patients in healthcare provision [PowerPoint slides]. Paper presented at the International Meeting of the Society for Psychotherapy Research, Copenhagen, Denmark.

Alves, P., Sales, C., & Ashworth, M. (2013). Enhancing the patient involvement in outcomes: a study protocol of personalised outcome measurement in the treatment of substance misuse. *BMC Psychiatry*, *13*, 337-343. doi: 10.1186/1471-244X-13-337

Ashworth, M., Shepherd, M., Christey, J., Matthews, V., Wright, K., & Parmentier (2004). A client-generated psychometric instrument: the development of “PSYCHLOPS”. *Counselling and Psychotherapy Research*, *4*, 27-31. doi: 10.1080/14733140412331383913

Ashworth, M., Evans, C., & Clement, S. (2008). Measuring psychological outcomes after cognitive behaviour therapy in primary care: a comparison between a new patient-generated measure “PSYCHLOPS” (Psychological Outcome Profiles) and “HADS” (Hospital Anxiety and Depression Scale). *Journal of Mental Health*, *18*, 169-177.

Beck, A. T., Steer, R.A., & Garbin, M.G. (1988) Psychometric properties of the Beck Depression Inventory: Twenty-five years of evaluation. *Clinical Psychology Review, 8*, 77-100. doi: 10.1016/0272-7358(88)90050-5

Crawford, M. (chair) (2011). Service user experience in adult mental health: improving the experience of care for people using adult NHS mental health services. Manchester: National Health Service.

Crawford, M. J., Robotham, D., Thana, L., Patterson, S., Weaver, T., & Barber, R. (2011). Selecting outcome measures in mental health: the views of service users. *Journal of Mental Health*, *20*, 336-346. doi: 10.3109/09638237.2011.577114

Elliott, R., Wagner, J., Sales, C., Rodgers, B., Alves, P. & Café, M. (2016). Psychometrics of the Personal Questionnaire: a client-generated outcome measure. *Psychological Assessment*, *28*, 263-278. doi: 10.1037/pas0000174

Elliott, R., Mack, C., & Shapiro, D. A. (1999). Simplified Personal Questionnaire Procedure. Toledo: University of Toledo.

Evans, C., Connell, J., Barkham, M., Mellor-Clark, J., & Audin, K. (2002). Towards a standardised brief outcome measure: psychometric properties and utility of the CORE-OM. *The British Journal of Psychiatry*, *180*, 51-60. doi: 10.1192/bjp.180.1.51

Jones, A., Donmall, M., Millar, T., Moody, A., Weston, S., & Anderson, T. (2009). The Drug Treatment Outcomes Research Study (DTORS): Final outcomes report. United Kingdom.

Marsden, J., Farrell, M., Bradbury, C., Dale-Perera, A., Eastwood, B., Roxburgh, M., & Taylor, S. (2008). Development of the Treatment Outcomes Profile. *Addiction, 443*, 1450-60. doi: 10.1111/j.1360-0443.2008.02284.x

Orford, J. (2008). Asking the right questions in the right way: the need for a shift in research on psychological treatments for addiction. *Addiction, 103*, 875-885. doi: 10.1111/j.1360-0443.2007.02092.x

Rutter, D., Manley, C. Weaver, T., Crawford, M. J., Fulop, N. (2004). Patients or partners? Case studies of user involvement in the planning and delivery of adult mental health services in London. *Social Science & Medicine*, *58*, 1973-1984. doi: 10.1016/S0277-9536(03)00401-5

Sales, C., Alves, P., Evans, C., & Elliott, R. (2014). The Individualized Patient Progress System: A decade of collaborative networking. *Counselling and Psychotherapy Research*, *14*, 181-191. doi: 10.1080/14733145.2014.929417

Sales, C., & Alves, P. (2012). Individualized Patient-Progress Systems: why we need to move towards a personalized evaluation of psychological treatments. *Canadian Psychology*, *53*, 115-121. doi: 10.1027/a0028053

Sales, C., Goncalves, S., Fragoeiro, A., Noronha, S., & Elliott, R. (2007). Psychotherapists openness to routine naturalistic idiographic research. *Mental Health and Learning Disabilities Research and Practice*, 145-161.

Soares, L., Cruz, A. S., Moita, G., Sales, C., & Alves, P. (2012, October). Feedback loops between researchers, therapists and patients using IPPS [PowerPoint slides]. Paper presented at the 3rd joint meeting of the Society for Psychotherapy Research European and UK chapters, Porto, Portugal.

Wanigaratne, S., Davis, P., Pryce, K., Brotchie, J. (2005). The effectiveness of psychological therapies on drug misusing clients. London.

“It is not just about the alcohol”: service users’ views about individualised and standardised clinical assessment in a therapeutic community for alcohol dependence[¤]

Paula C. G. Alves[a,b*], Célia M. D. Sales[c], & Mark Ashworth[b]

Abstract

The involvement of service users in health care provision in general, and specifically in substance use disorder treatment, is of growing importance. This paper explores the views of patients in a therapeutic community for alcohol dependence about clinical assessment, including general aspects about the evaluation process, and the specific characteristics of four measures: two individualised and two standardised. A focus group was conducted and data were analysed using a framework synthesis approach. Service users welcomed the experience of clinical assessment, particularly when conducted by therapists. The duration of the evaluation process was seen as satisfactory and most of its contents were regarded as relevant for their population. Regarding the evaluation measures, patients diverged in their preferences for delivery formats (self-report vs. interview). Service users enjoyed the freedom given by individualised measures to discuss topics of their own choosing. However, they felt that part of the standardised questions were difficult to answer, inadequate (e.g. quantification of health

---

[¤] Article published at Substance Abuse Treatment, Prevention and Policy, under the reference Alves, P., Sales, C., & Ashworth, M. (2016). “It is not just about the alcohol”: service users’ views about individualised and standardised clinical assessment in a therapeutic community for alcohol dependence. *Substance Abuse Treatment, Prevention and Policy, 11*, 1-7. doi: 10.1186/s13011-016-0070-5

[a] Instituto Universitário de Lisboa (ISCTE-IUL), CIS-IUL, Lisboa, Portugal

[b] Division of Health and Social Care Research; Faculty of Life Sciences & Medicine, King’s College London

[c] Centro de Psicologia da Universidade do Porto, Faculdade de Psicologia e de Ciências da Educação, Universidade do Porto.

[*] Corresponding author. E-mail address: paulagomesalves@hotmail.com

status in 0-20 points) and sensitive (e.g. suicide-related issues), particularly for pre-treatment assessments. Patients perceived clinical assessment as helpful for their therapeutic journey, including the opportunity to reflect about their problems, either related or unrelated to alcohol use. Our study suggests that patients prefer to have evaluation protocols administered by therapists, and that measures should ideally be flexible in their formats to accommodate for patient preferences and needs during the evaluation.

Keywords: user involvement, clinical assessment, personalised assessment, evaluation measures, patient views, individualised measures, qualitative research.

Introduction

Most mental health literature is based on a professional perspective, generated by researchers or practitioners (Rose & Thornicroft, 2006). However, service users have expertise by experience, which is why their involvement is increasingly acknowledged as a crucial part of the health care agenda (INVOLVE Strategy, 2012; Rose, 2014; Tait & Lester, 2005; Wu, Snyder, Clancy, & Steinwachs, 2010).

One area where service user involvement is paramount is the selection of measures to evaluate the patient's clinical condition (Blount, Evans, Birch, Warren, & Norton, 2002; Crawford et al., 2011; Ennis & Wykes, 2013). Evaluation measures are helpful for clinical work at different points in time during treatment. At treatment intake, they allow the assessment of patients' distress, and if administered at pre-post treatment, they provide data for outcome assessment purposes. Several authors have suggested that, to maximize their clinical utility, these measures should be relevant, acceptable and valuable for both professionals and service users (Blount, Evans, Birch, Warren, & Norton, 2002; Slade, Thornicroft, & Glover, 1999). The reality, though, is that many popularly used measures do not reflect the service users' perspective (Gilbody, House, & Shelton, 2013; Perry & Gilbody, 2009; Rose, Evans, Sweeney,

& Wykes, 2011). Consequently, we have little information on whether the existing evaluation tools are meaningful, personally relevant, and expressed in terms which make sense to users (Blount, Evans, Birch, Warren, & Norton, 2002; Ennis & Wykes, 2013; Rose, 2011).

User involvement in health care is even more challenging among socially excluded and stigmatised groups, since their views tend to be discredited, undermined and regarded as unworthy (Bryant, Saxton, Madden, Bath, & Robinson, 2008; Hayter, 2011; Livingston, Milne, Fang, & Amari, 2012; Ti, Tzemis, & Buxton, 2012). This often applies to patients in substance use disorder treatment services, who seldom participate actively in shared decision-making activities (Alves, Sales, & Ashworth, 2015; Bryant, Saxton, Madden, Bath, & Robinson, 2008; Orford, 2008). Just as with patients in general, patients in substance use disorder treatment services have first-hand knowledge about their clinical condition and are in a privileged position to inform providers about which outcomes of interest best reflect their reality (Bryant, Saxton, Madden, Bath, & Robinson, 2008; Neale et al., 2015). According to the European Monitoring Centre for Drugs and Drug Addiction, there are currently over 50 tools to measure treatment outcomes in this population. The vast majority of these are standardised, and do not take the patients' perspective into account. A recent study gathered 76 variables commonly used by professionals to evaluate recovery from substance use disorder, and service users were asked their views about those criteria (Neale et al., 2015). Patients reported that some variables were unrealistic and hard to achieve (e.g. to be completely anxiety-free). This study also highlighted the frustration expressed by patients that most existing variables did not capture individual idiosyncrasies and personal preferences, stating that service providers "had no idea of their experiences" (p. 31).

There has been a recent call for the use of individualised data in the evaluation of substance use disorder treatment (Alves, Sales, & Ashworth, 2015; Neale & Strang, 2015; Trujols, Iraurgi, Batlle, Durán-Sindreu, & Pérez de Los Cobos, 2015). Such data can be collected with individualised measures, which are tailor-made lists of items (problems or goals), generated in patients' own words (Sales & Alves, 2016). Similarly to pre-set standardised measures, these individualised items are rated for intensity in quantitative scales (e.g. Likert scales). This allows an evaluation of patients' level of distress, based on their unique problems.

Our study sought to address three main concerns in this field. First, there are a growing number of studies exploring what users of mental health services think about clinical assessment, including views about the measures and the process by which they are administered (Gordon, Ellis, Siegert, & Walkey, 2013). With the exception of the study by Neale and colleagues (2015), little is known about what patients in substance use disorder treatment think about clinical assessment. Second, a pioneer study published by Duong et al. (2016) has compared patients' perspectives about standardised and individualised measures in school mental health. To the best of our knowledge, there are no reports on the use of individualised measures in the field of substance use disorder treatment, nor do we know how this population perceives such measures. Third, the literature has suggested that the majority of measures and patient-focussed materials in substance use disorder treatment tend to require literacy skills above the average level of literacy among this population (Greenfield, Sugarman, Nargiso, & Weiss, 2005; McHugh et al., 2014). However, those who are most likely to have low reading / writing skills (e.g. low socio-economic status, limited education, marginalised populations, and rural settings) are seldom asked to contribute with their views on clinical assessment.

We were interested in understanding what patients in substance use disorder treatment services, with low literacy skills, think about clinical assessment, in general, and in particular about standardised and individualised measures. More specifically, our aims for this study were two-fold: to explore patients' overall perspectives about their experience with the evaluation process; and to investigate patients' views about what is helpful and hindering about each of the four measures in the evaluation protocol. Ultimately, our goal was to understand what makes patients engage, feel (de)motivated or (un)comfortable whilst using evaluation measures as part of their treatment.

Method

A single focus group with 10 service users was conducted in a therapeutic inpatient community for females with alcohol dependence, based in a rural area of northern Portugal. This service targets women with severe alcohol dependence problems, who are referred to this facility by local drug and alcohol outpatient units, child protection and social security services and general practitioners. The treatment programme in this facility lasts approximately for 8 months.

On sample characteristics, service users had a mean age of 45 years (*SD* = 7). Six had completed primary school (i.e. 4 years of education, from the age of 6 to 10, also known as the 1st cycle of basic education in Portugal), whilst the remaining 4 were illiterate. The majority were unemployed (6 participants) and nearly all (8 participants) had a previous history of substance use treatment episodes. The group took place in the community and was moderated by the first author (PA), assisted by the community's therapist. Ethical approval was granted by the community's clinical director. As explained earlier, we opted for a sample with these characteristics (i.e. severe addiction problems, disadvantaged socio-economic status, low literacy skills) since this is likely to represent patients with greater difficulties understanding evaluation measures.

The evaluation protocol used in the therapeutic community consisted of four measures. Two were standardised measures, namely, Treatment Outcomes Profile (TOP; Marsden et al., 2008) and Clinical Outcome Routine Evaluation – Outcome Measure (CORE-OM; Evans, Connell, Barkham, Mellor-Clark, & Audin, 2002); and two were individualised, Psychological Outcome Profiles (PSYCHLOPS; Ashworth et al., 2004) and Personal Questionnaire (PQ; Elliott et al., 2016) (see Table 1 for more information). These measures were chosen for being widely used in an international context.

The focus group was conducted in December 2013 and lasted for 2.5-3 hours. Eight participants completed the measures at treatment intake only (between October-November 2013). The remaining two completed the measures twice i.e. at treatment intake (June 2013) and 7 months after (December 2013).

The group discussion was guided by a semi-structured interview focusing on patients' views about: 1) the evaluation process, i.e. overall satisfaction, duration in time, administration and adequacy of contents of the evaluation protocol; and 2) the helpful and hindering characteristics of each measure in the evaluation protocol i.e. questionnaire length, delivery format and topics covered by the items.

The session was audio-recorded and transcribed verbatim. The transcripts were analysed following a framework synthesis approach (Carroll, Booth, Leaviss, & Rick, 2013), based on categories, created *a priori*, that reflected the information which we aimed to extract (i.e. general aspects about the evaluation process and helpful and hindering aspects of each measure). Data extraction and synthesis was made by one of us (PA) and later discussed with two senior academics (CS and a senior lecturer in Philosophy with expertise in health ethics).

Table 1

Summary of measures used in the research protocol

Type of measure	Measure	Generation of items/problems	Domains covered	Nr. items	Size (A4 pages)	Type of items	Delivery format	Example of item
Standardised	TOP	Researchers/Professionals	Drug and alcohol use, injecting risk behaviours, offending and criminal involvement, health and social functioning	21	1	Yes/no, slidings scales	Interview	Q3 response: “Committed assault or violence”
	CORE-OM	Researchers/Professionals	Subjective well-being, symptoms, functioning, risk	34	2	Likert scale	Self-report	Q2 response: “I have felt tense, nervous or anxious”
Individualised	PSYCHLOPS	Patients	Any of patient’s own choosing	4	1	Likert scale	Self-report	Q1 response: “People in my neighborhood disrespect me”
	PQ	Patients	Any of patient’s own choosing	Unlimited	2	Likert scale	Interview	PQ response: “I miss my family”

Notes . “Q”, followed by a number (“Q1”) refers to the number of the item in the questionnaire.

Results

General views about the evaluation process

The evaluation process was reported by most service users as a positive experience, because it helped them to reflect about their clinical situation. The overall duration of the evaluation protocol was considered as adequate ("The bigger it is, the more we discover things that we did not know about ourselves", P7). Patients found it helpful to have their own therapist administering the measures, since "these things are very intimate… if it wasn't our therapist, we wouldn't have cared" (P4).

Among those that completed the questionnaires twice, patients felt that certain topics had been difficult to address at treatment intake ("The questions are not wrong, but we're not used to being honest with ourselves, I was still sort of numb", P9). However, when answering later in treatment, another patient reported that the questionnaires made her aware of how much she had changed since starting the therapeutic community programme ("It made me think about how different I am. When I arrived I was at the bottom and now I am a new woman", P7). Patients also considered that all evaluations performed after treatment intake should have been focussed on other aspects besides their personal problems, particularly their progress in treatment and the changes that they perceive ("We were given the chance to talk about the problems that we still had, but we could also talk about how we were recovering (…) and I have come such a long way", P7).

Helpful and hindering aspects of the evaluation measures

Nearly all measures in the protocol were deemed as adequate in their length, except for CORE-OM, which was considered as "too big" (P4). There was some variability regarding the preferred delivery format, with some patients finding the self-report structure to be more appealing, as "it was easier to tick boxes… we don't have to think so hard about our problems"

(P9) and that “we can be more honest by using a pen” (P3); and others reporting that “if we are forced to talk, it is better because we end up saying something” (P7). Regarding the topics covered by the items, particularly among the standardised measures, there were certain questions that patients found impropriate and hard to answer. Table 2 summarizes the helpful and hindering aspects of each measure as identified by patients.

Table 2

Summary of measures used in the research protocol

	Helpful		Hindering	
	Key aspects	Patients’ voices	Key aspects	Patients’ voices
TOP	Raises awareness about the quantity of drugs / alcohol used Promotes emotional / breakthrough experiences	“It is a way of getting yourself together, we have no idea about how much alcohol we used to drink and the money we spent”, P3	0-20 scale questions to rate psychological/ physical health and quality of life difficult to understand and meaningless	“When I was asked about this I answered by chance. It meant nothing to me. Later we are able to answer in another way”, P5
CORE-OM	User-friendly Contents relevant to this population Enhances self-awareness	“This instrument is related to what we are”, P7	Large number of items Contains questions about sensitive topics (e.g. suicide) Items not generated by patients	“The questions were made by other people and the words didn’t come from inside of us”, P7
PSYCHLOPS	Easy to understand Helps reflecting about personal difficulties Provides freedom of expression to talk about any topic, related or not to substance use Makes patients feel like “normal” people	“It not just about the alcohol, we feel bad about many other things in life. My sister doesn’t drink alcohol but could answer this too, because everyone has problems”, P8	Requires personal exposure The self-completion format may lead to misleading or incomplete answers	“We want to hide our real problems for fears of being judged (…) if the words are already written by someone else, it is easier to just say yes or no”, P7
PQ	Opportunity for self-reflection Oral format encourages to talk about personal problems	“When a person encourages us to talk, we become more comfortable and open. I talked about my drinking problem but on paper I wouldn’t have said a thing” P7	Patients reported none.	“It is fine as it is”, P1

Notes. “P”, followed by a number (e.g. “P3”) is an anonymous designator for each focus group participant.

Discussion

The purpose of this study was to explore the thoughts of a sample of patients in substance use disorder treatment about the process of clinical assessment. It also aimed to hear those patients' voices about the characteristics of four evaluation measures that all of them used at treatment intake, and some also later in treatment. Among these were two individualised measures, in addition to two traditional and widely used standardised measures.

Our first goal was to investigate patients' general views about the evaluation process and the findings were encouraging. We learned that patients not only welcomed clinical assessment, but also perceived it as a valuable task for their therapeutic journey. Patients were satisfied with the duration of the evaluation protocol (which included six A4 size pages) and there was even openness for the inclusion of further items. Previous studies (Blount, Evans, Birch, Warren, & Norton, 2002; Crawford et al., 2011) have shown that patients tend to be concerned about the brevity of several measures, for being "too simplistic". In contrast, studies of services and therapists, report that evaluation measures can become a burden for patients and potentially interfere with the time assigned for the consultations and treatment (Sales, Goncalves, Fragoeiro, Noronha, & Elliott, 2007).

There was a general preference to have therapists administering the evaluation protocol, making it a meaningful part of the therapeutic process and potentially leading to a greater commitment with the task. As such, we believe that clinical assessment could be formally included as part of treatment, which has already been proposed by authors such as Valderas (2008). The major advantage of this is that using evaluation measures would not require extra human and time resources from the service, making it a potentially more feasible task in real clinical settings. As a downside, one must bear in mind that when therapists administer the protocol directly, patients' answers are likely to be biased, particularly in oral interviews. In such cases, patients may feel the need to provide desirable answers and underreport undesirable behaviours, to satisfy their therapist, as reported by Bowling (2005). However, unless patients are under court-ordered treatment, they tend to be disposed and motivated to disclose personal and clinically relevant information to their therapists. Hence, we believe that if the interviewer is also the therapist, the risk of offering socially desirable answers is likely to decrease. Considering that most research about social desirability in mental health has been conducted with non-clinical samples (Bowling, 2005) further studies are needed to ascertain the pros and cons of having therapists as interviewers in clinical assessment, which is something that, as we have seen, patients seem to prefer.

Our second main goal was to learn what was helpful and hindering about the measures in the evaluation protocol, from the patient perspective. There was a tension regarding service users' preferences about the delivery format of measures, with some favouring the simplicity of ticking boxes, and others keener on talking about their problems. This suggests that a one-size-fits-all approach to evaluation is not enough and flexibility is desirable, so that patients' preferences can be considered. Such flexibility had already been suggested by Gordon and colleagues (2013). As such, we need to further explore to what extent the psychometric properties of an instrument remain unaltered in multiple formats of application, i.e. allowing a flexible administration of measures while providing reliable information for treatment evaluation.

However, when it came to eliciting personalised information, most patients in our group preferred the dialogue, oral format of PQ, rather than describing their problems in writing, as required by the PSYCHLOPS questionnaire. This is consistent with the study by Ashworth and colleagues (2005), where therapists felt that PSYCHLOPS was challenging because patients not only had to identify problems on their own, but also to use their own words to write their problems down.

In our study, standardised and individualised measures were seen as relevant for clinical assessment, despite having certain disadvantages. TOP and CORE-OM were perceived as useful and relevant for this population, suggesting a good level of acceptability among patients. Nevertheless, not all contents covered by these two standardised measures were regarded as meaningful or appropriate (e.g. rating psychological health in a 20-point scale). Also, service users expressed some reservations about the disclosure of sensitive personal information in certain TOP and CORE-OM items, as shown in other studies (Stone & Elliott, 2011). One potential consequence of patients feeling uncomfortable or dissatisfied with the evaluation questionnaires is the likelihood of misleading responses and/or missing. Thus, further research is needed to ascertain which topics are likely to trigger negative reactions to the evaluation process.

As expected, patients appreciated the freedom given by both individualised measures, PSYCHLOPS and PQ, to express any type of personal concern, regardless of topic. This was in line with Duong and colleagues (2016), who demonstrated that recipients of mental health care consider individualised measures to be less confining than their standardised counterparts. Hence, our findings indicate that accommodating a great diversity of topics is important to patients, since misusing substances can lead to / or be the consequence of problems that drug-focussed instruments might not address. Future research should compare the topics elicited from standardised and individualised measures, so that we understand if the former tend to overlook aspects of relevance for patients that the latter are able to capture.

Finally, it is also worth emphasizing that patients who responded to the evaluation measures at treatment intake and later in treatment valued the opportunity to focus on other aspects besides outcomes. This could be overcome by including items about the treatment process, giving patients the opportunity to share their thoughts about the care they are receiving. Such feedback about treatment could be used by clinicians to adjust the intervention to match the patient's needs, as well as to increase therapeutic alliance (Flückiger et al., 2012).

This study is not without limitations. To have a female only, small sample size means that the findings are less generalisable and conclusions should be interpreted with caution. Also, the presence of the patients' therapist in the group may have overstated their positive views about the evaluation process and the measures included in our study.

Conclusions

This study suggests that service users can actively contribute to improving the process of clinical assessment, guiding researchers and professionals towards developing evaluation measures that are more meaningful and relevant for patients with alcohol dependency. Individualised outcome measures have the potential to broaden the range of viewpoints captured from patients compared to the more narrowly focussed standardised instruments.

Ethics approval and consent to participate

Ethics approval for this study was granted by the clinical director of the therapeutic community where the study was held, Dr. Ana Cruz. Even though the participants of this study were residing in the community, their participation was completely voluntary and informed consent forms were completed by each participant. Participants were also ensured that in case of non-participation, their treatment or daily activities at the community would not be affected in any way.

Availability of data and materials

All materials, i.e., the evaluation instruments used in this study are freely available for widespread use and can be downloaded at no cost from the internet. However, contacting the authors of each instrument is highly recommended, not only for networking purposes, but also to inform the authors about how, where and under which conditions their questionnaires are being used. Regarding the data, the authors of this manuscript have decided not to make the focus group's transcript available to ensure that all participants remain de-identified.

Competing interests

PA and CS, the first and second author, respectively, declare that they have no competing interests in this manuscript. MA, the third author, chaired the mental health research group which developed PSYCHLOPS but has no financial interest in its use.

Funding

This study was funded by two fellowships, one awarded to PA by the Portuguese Foundation for Science and Technology (FCT SFRH/BD/87308/2012) and the second to CS by the Center for Psychology at the University of Porto, Portuguese Foundation for Science and Technology (FCT UID/PSI/00050/2013) and EU FEDER and COMPETE programs (POCI-01-0145-FEDER-007294).

Authors' contributions

All authors have made substantial contributions to this manuscript. In particular, PA, CS and MA have all contributed to the conception and design of the study. All authors have been actively involved in drafting the manuscript and revising its intellectual content. PA was responsible for the acquisition and analysis of data, supervised by CS and MA. All authors have given final approval of the manuscript's version to be published and confirm the accuracy and integrity of all the work being presented.

Acknowledgements

The authors of this paper would like to thank Dr. Ana Sofia Cruz, the clinical director and therapist of the therapeutic community in which this study was carried out. We would also like to thank Professor Teresa Santos, from the University of Évora, for her help in reflecting about the data analysis.

References

Alves, P., Sales, C., & Ashworth, M. (2015). Personalising the evaluation of substance misuse treatment: a new approach to outcome measurement. *International Journal of Drug Policy*, *26*, 333-335. doi: 10.1016/j.drugpo.2014.11.014

Ashworth, M., Shepherd, M., Christey, J., Matthews, V., Wright, K., Parmentier, H., Robinson, S., & Godfrey, E. (2004). A client-generated psychometric instrument: the development of "PSYCHLOPS". *Counselling and Psychotherapy Research*, *4*, 27-31. doi: 10.1080/14733140412331383913

Ashworth, M., Robinson, S., Godfrey, E., Parmentier, H., Shepherd, M., Christey, J., Wright, K., & Matthews, V. (2005). The experiences of therapists using a new client-centred psychometric instrument, PSYCHLOPS (Psychological Outcome Profiles). *Counselling and Psychotherapy Research*, *5*, 27-42. doi: 10.1080/14733140512331343886

Blount, C., Evans, C., Birch, S., Warren. F., & Norton. K. (2002). The properties of self-report research measures: beyond psychometrics. *Psychology and Psychotherapy: Theory, Research and Practice*, *75*, 151-164. doi: 10.1348/147608302169616

Bowling, A. (2005). Mode of questionnaire administration can have serious effects on data quality. *Journal of Public Health*, *27*, 281-291. doi: 10.1093/pubmed/fdi031

Bryant, J., Saxton, M., Madden, A., Bath, N., & Robinson, S. (2008). Consumer participation in the planning and delivery of drug treatment services: the current arrangements. *Drug and Alcohol Review*, *27*, 130-137. doi: 10.1080/09595230701829397

Carroll, C., Booth, A., Leaviss, J., & Rick, J. (2013). “Best fit” framework synthesis: refining the method. *BMC Medical Research Methodologies*, *13*, 37-52. doi: 10.1186/1471-2288-13-37

Crawford, M., Robotham, D., Thana, L., Patterson, S., Weaver, T., & Barber, R. (2011). Selecting outcome measures in mental health: the views of service users. *Journal of Mental Health*, *20*, 336-346. doi: 10.3109/09638237.2011.577114

Duong, M., Lyon, A., Ludwig, K., Wasse, J., & McCauley, E. (2016). Student perceptions of the acceptability and utility of standardized and idiographic assessment in school mental health. *International Journal of Mental Health Promotion*, *18*, 49-63. doi: 10.1080/14623730.2015.1079429

Elliott, R., Wagner, J., Sales, C., Rodgers, B., Alves, P. & Café, M. (2016). Psychometrics of the Personal Questionnaire: a client-generated outcome measure. *Psychological Assessment*, *28*, 263-278. doi: 10.1037/pas0000174

Ennis, L., & Wykes, T. (2013). Impact of patient involvement in mental health research: longitudinal study. *British Journal of Psychiatry*, *203*, 381-386. doi: 10.1192/bjp.bp.112.119818

Evans, C., Connell, J., Barkham, M., Mellor-Clark, J., Audin, K. (2002). Towards a standardised brief outcome measure: psychometric properties and utility of the CORE-OM. *British Journal of Psychiatry*, *180*, 51-60. doi: 10.1192/bjp.180.1.51

Flückiger, C., Del Re, A., Wampold, B., Znoj, H., Caspar, F., & Jörg, U. (2012). Valuing clients’ perspective and th effects on the therapeutic alliance: a randomized controlled study of an adjunctive instruction. *Journal of Counselling Psychology*, *59*, 18-26. doi: 10.1037/a0023648

Gilbody, S., House, A., & Shelton, T. (2013). Outcome measurement in psychiatry: a critical review of outcome measurement in psychiatry research and practice. University of York, UK: CRD Report.

Gordon, S., Ellis, P., Siegert, R., & Walkey, F. (2013). Developmet of a self-assessed consumer recovery outcome measure: my voice, my life. *Administration and Policy in Mental Health*, *40*, 199-210. doi: 10.1007/s10488-012-0417-9

Greenfield, S., Sugarman, D., Nargiso, J., & Weiss, R. (2005). Readability of patient handout materials in a nationwide sample of alcohol and drug abuse treatment programs. *Americal Journal of Addictions*, *14*, 339-345. doi: 10.1080/10550490591003666

Hayter, M. (2011). Involving service users in the development and evaluation of health care and services – good practice and the need for a research agenda. *Contemporary Nurse*, *40*, 103-105. doi: 10.1080/10376178.2011.11002577

INVOLVE. (2015, November 20). Strategy 2012-2015. *National Institute for Health Research*. Retrieved from http://www.invo.org.uk

Livingston, J., Milne, T., Fang, M., & Amari, E. (2012). The effectiveness of interventions for reducing stigma related to substance use disorders: a systematic review. *Addiction*, *107*, 39-50. doi: 10.1111/j.1360-0443.2011.03601.x

Marsden, J., Farrell, M., Bradbury, C., Dale-Perera, A., Eastwood, B., Roxburgh, M., & Taylor, S. (2008). Development of the Treatment Outcomes Profile. *Addiction*, *103*, 1450-1460. doi: 10.1111/j.1360-0443.2008.02284.x

McHugh, R., Sugarman, D., Kaufman, J., Park, S., Weiss, R., & Greenfield, S. (2014). Readability of self-report alcohol misuse measures. *Journal of Studies on Alcohol and Drugs, 75*, 328-334. doi: 10.15288/jsad.2014.75.328

Neale, J., & Strang, J. (2015). Blending qualitative and quantitative research methods to optimize patient reported outcome measures (PROMs). *Addiction*, *10*, 1215-1216. doi: 10.1111/add.12896

Neale, J., Tompkins, C., Wheeler, C., Finch, E., Marsden, J., Mitcheson, L., Wykes, T., & Strang, J. (2015). “You’re all going to hate the word ‘recovery’ by the end of this”: Service users’ views of measuring addiction recovery. *Drugs: Education, Prevention and Policy*, *22*, 26-34. doi: 10.3109/09687637.2014.947564

Orford, J. (2008). Asking the right questions in the right way: the need for a shift in research on psychological. *Addiction*, *103*, 875-885. doi: 10.1111/j.1360-0443.2007.02092.x

Perry, A., & Gilbody, S. (2009). User-defined outcomes in mental health: A qualitative study and consensus development exercise. *Journal of Mental Health*, *18*, 415-423. doi: 10.3109/09638230902968175

Rose, D. (2011). Service user views and service user research in the Journal of Mental Health. *Journal of Mental Health*, *20*, 423-428. doi: 10.3109/09638237.2011.613959

Rose, D. (2014). Patient and public involvement in health research: Ethical imperative and/or radical challenge? *Journal of Health Psychology*, *19*, 149-158. doi: 10.1177/1359105313500249

Rose, D., Thornicroft, G., & Slade, M. (2006). Who decides what evidence is? Developing a multiple perspectives paradigm in mental health. *Acta Psychiatrica Scandinavica*, *429*, 109-114. doi: 10.1111/j.1600-0447.2005.00727.x

Rose, D., Evans, J., Sweeney, A., & Wykes, T. (2011). A model for developing outcome measures from the perspectives of mental health service users. *International Review of Psychiatry*, 23, 41-46. doi: 10.3109/09540261.2010.545990

Sales, C., Goncalves, S., Fragoeiro, A., Noronha, S., & Elliott, R. (2007). Psychotherapists' openness to routine naturalistic idiographic research. *Mental Health and Learning Disabilities Research and Practice*, 145-161.

Sales, C., & Alves, P. (2016). Patient centred assessment in Psychotherapy: A review of individualised tools. *Clinical Psychology: Science and Practice*, *23*, 265-283. doi:10.1111/cpsp.12162

Slade, M., Thornicroft, G., & Glover, G. (1999). The feasibility of routine outcome measures in mental health. *Social Psychiatry and Psychiatric Epidemiology*, *34*, 243-349. doi: 10.1007/s001270050139

Stone, C., & Elliott, R. (2011). Clients' experience of research within a clinic setting. *Counselling Psychology Review*, *26*, 71-86.

Tait, L., & Lester, H. (2005). Encouraging user involvement in mental health services. *Advances in Psychiatric Treatment*, *11*, 168-175. doi: 10.1192/apt.11.3.168

Ti, L., Tzemis, D., & Buxton, J. (2012). Engaging people who use drugs in policy and program development: a review of the literature. *Substance Abuse Treatment and Prevention*, *7*, 47-56. doi: 10.1186/1747-597X-7-47

Trujols, J., Iraurgi, I., Batlle, F., Durán-Sindreu, S., Pérez de Los Cobos, J. (2015). Towards a genuinely user-centred evaluation of harm reduction and drug treatment programmes: a further proposal. *International Journal of Drug Policy*, *26*, 1285-1287. doi: 10.1016/j.drugpo.2015.08.012

Valderas, J., Kotzeva, A., Espallargues, M., Guyatt, G., Ferrans, C., Halyard, M., Revicki. A., Symonds, T., Parada, A., & Alonso, J. (2008). The impact of measuring patient-reported outcomes in clinical practice: a systematic review of the literature. *Quality of Life Research*, *17*, 179-193. doi: 10.1007/s11136-007-9295-0

Wu, A., Snyder, C., Clancy, C., & Steinwachs, D. (2010). Adding the patient perspective to comparative effectiveness research. *Health Affairs*, *29*, 1863-1871. doi: 10.1377/hlthaff.2010.0660

“There are things I want to say but you don’t ask”: a thematic comparison between standardised and individualised outcome measures in substance misuse treatment [¤]

Paula C. G. Alves[a,b*], Célia M. D. Sales[c], Mark Ashworth[b], & Luís Faísca[d]

Abstract

In healthcare in general, and substance misuse treatment in particular, there have been increasing calls for patients to be more actively involved with outcome assessment. Such involvement can be achieved through the use of individualised outcome measures, where patients are asked to contribute with their own criteria for evaluation. This is an alternative strategy to the traditional approach based on standardised measures, whose contents are developed by experts and universality used with all patients, in a nomothetic approach. However, little is known about the extent to which individualised measures add information to standardised measures. A cross-sectional survey was conducted, in which we contrasted the problems defined by patients using two individualised measures against the contents of three widely used standardised measures using a thematic comparison approach. We found that 80% of the themes reported in individualised measures were included in at least one of the standardised measures. Nevertheless, half of our sample generated at least one problem whose

---

[¤] Article currently submitted for publication.

[a] Instituto Universitário de Lisboa (ISCTE-IUL), CIS-IUL, Lisboa, Portugal

[b] Division of Health and Social Care Research; Faculty of Life Sciences & Medicine, King’s College London

[c] Centro de Psicologia da Universidade do Porto, Faculdade de Psicologia e de Ciências da Educação, Universidade do Porto.

[d] Departamento de Psicologia, Faculdade de Ciências Sociais e Humanas, Universidade do Algarve.

[*] Corresponding author. E-mail address: paulagomesalves@hotmail.com

theme was not covered by any of the three standardised measures. Our study suggests that individualised measures appear to be a potential strategy to capture issues of importance to substance misuse patients, which may be underestimated by standardised measures.

Keywords: personalised assessment, standardised measures, individualised measures, substance misuse treatment evaluation.

Introduction

A growing body of literature suggests that personalising the assessment of outcome in substance misuse treatment is of central importance (Alves, Sales, & Ashworth, 2015; Neale & Strang, 2015; Trujols et al., 2015). Recent reports have also shown that patients in this population appreciate being actively engaged in outcome assessment (Alves, Sales, & Ashworth, 2016; Neale et al., 2015). Individualised outcome measures are tools that gather each patient's unique perspective about their clinical condition. However, there is little evidence about the extent to which individualised outcome measures may complement traditional standardised questionnaires. In this study we will contrast the contents elicited by patients in individualised outcome measures with standardised measures, as well as comparing two measures with different methods for generating individualised data.

Outcome assessment in substance misuse treatment

The evaluation of patients in substance misuse treatment has been discussed in several international guidelines (e.g. the European Monitoring Centre for Drugs and Drug Addiction, EMCDDA). According to these, evaluation aims "to determine individual needs, to obtain standard somatic, mental and psychological information", and to focus on "the consequences of treatment for the clients" (EMCDDA, 2007). Furthermore, the EMCDDA recommends that evaluation, including outcome assessment, should be based on “instruments that are available and validated” (EMCDDA, 2007).

The instruments recommended for outcome assessment in this field tend to be standardised scales containing quantitative pre-determined items (see the Evaluation Instruments Bank available at http://www.emcdda.europa.eu/eib). These instruments are mostly based on criteria selected by experts, which do not always coincide with what patients deem important (Pulford, Adams, & Sheridan, 2009; Thurgood et al., 2014). A recent study has attempted to overcome this limitation by including patients in the development of a standardised outcome measure, involving them in topic selection (Neale et al., 2016). However, even when patients are involved in such a task, the universal scope of standardised measures limits the understanding of patients’ personal problems. More specifically, these measures do not give patients the freedom to express their personal views and they may contain questions that are not relevant for each patient, or omit questions of relevance.

Why use individualised outcome assessment?

In outcome assessment, capturing the personal issues, concerns or problems is important for several reasons. For instance, Wagner (2002) showed that, in a psychotherapeutic context, nearly 60% of personalised data were not equivalent to any item included in two standardised measures used as comparators. Hunter et al. (2004) carried out a similar study in mental health services, showing that 25% of the information provided by patients was not represented in standardised measures. In 2007, Ashworth and colleagues found that, in the primary care setting, 44% of items in a personalised measure were not covered by a commonly used standardised measure of psychological well-being. These findings indicate that standardised outcome measures potentially fail to capture information about patients that is relevant for evaluation purposes.

Gathering personalised data involves the use of individualised outcome measures. These are open-ended questionnaires, tailored to each individual, and whose items (problems or goals) are generated by patients, in their own words (Ashworth et al., 2004). By doing this, items in the individualised questionnaire reflect the patient's reality (e.g. "I haven't spoken with my daughter for two years"), unlike standardised questionnaires which contain issues that apply to the whole population (e.g. "Talking to people has felt too much for me"). There are two main processes for gathering individualised items: the self-report method, where patients are invited to write their concerns in a pen-and-paper format (e.g. Psychological Outcome Profiles, PSYCHLOPS; Ashworth et al., 2004); and open-ended interviews, where patients are asked, in a dialogue, to talk about their problems (e.g. Personal Questionnaire, PQ; Elliott et al., 2016). Researchers believe that both formats have their own advantages and disadvantages. For instance, self-report individualised measures tend to be briefer, to demand less staff/service resources (e.g. presence of researcher / staff member not necessary), are flexible when it comes to the context of application (e.g. waiting room, private consultation room) and can be administered to multiple patients in the same event (e.g. group therapy). However, as they are meant for self-completion, patients are required to have a minimum level of literacy skills and be physically able to complete the questionnaire unaided. On the other hand, interview-based individualised protocols can be administered to any patient able to communicate verbally, since data collection is conducted by the interviewer. Nevertheless, interview-based individualised outcome measures are normally lengthy (e.g. 30-60 minutes), and require completion in a one-to-one format between patient and interviewer (for a review about individualised outcome measures, see Sales & Alves, 2016).

Using individualised outcome measures in substance misuse treatment

Individualised outcome measures have already been used in other health contexts with promising findings, such as primary care mental health (e.g. Ashworth et al., 2007), counselling and psychotherapy services (e.g. Elliott et al., 2016). However, the use of individualised outcome measures has only recently been applied to substance misuse treatment, and little is known about their potentialities in this field.

We believe that individualised outcome measures may broaden the understanding of outcome assessment in substance misuse treatment. Patients in this population tend to be stigmatised (Livingston, Fang, & Amari, 2012), their perspectives about treatment are seldom taken into account (Orford, 2008) and they are rarely involved in outcome assessment (Alves, Sales, & Ashworth, 2015). In a recent study, we found that patients valued the freedom provided by individualised outcome measures to express personal concerns, even when the topic of concern was unrelated to substance misuse (Alves, Sales, & Ashworth, 2016). Patients also reported that they preferred an interview-based procedure, especially if the interviewer was their own therapist. In contrast, they admitted having difficulties identifying personal problems in self-complete individualised outcome measures (Alves, Sales, & Ashworth, 2016).

Study rationale

In this study, we sought to explore the extent to which individualised outcome measures add personalised information to traditional measures of outcome assessment, in substance misuse treatment. Our aims were the following: 1) to explore the personal problems of patients with individualised outcome measures; 2) to compare the problems elicited from individualised and standardised outcome measures, investigating whether individualised data added information to that obtained from their standardised counterparts; and 3) to contrast the problems elicited from two types of individualised measures (self-report vs. interview-based protocol).

Method

This study followed a cross-sectional design and is part of a larger project (Alves, Sales, & Ashworth, 2013) that aimed to implement the personalised assessment approach in the field of substance misuse treatment. Data were collected in four drug and alcohol treatment services in Portugal; three as outpatients and one an inpatient therapeutic community. Ethics approval was obtained at the Committee for Health of Lisbon and surrounding areas (ARSLVT, Ref. 8251/CES/2012).

Participants

Our sample included patients starting treatment for substance misuse. During the recruitment period, all new patients at the four study sites, who met the inclusion criteria, were invited to participate. The inclusion criteria were: 1) aged 18 years and over; 2) admitted for a first or new treatment episode (i.e. treatment of a relapse); and 3) fluency in Portuguese. A total of 102 patients were invited for the study. Of these, 8 people declined participation and one was excluded on the basis of incomplete data collection. The final sample consisted of 93 respondents, corresponding to a 91% response rate.

Measures

The evaluation protocol included the following outcome measures: 1) Psychological Outcome Profiles (PSYCHLOPS; Ashworth et al., 2004), a self-report individualised outcome measure in which patients are invited to answer three open-ended questions: “Choose the problem that troubles you the most”, “Choose another problem that troubles you” and “Choose one thing that is hard to do because of your problem(s)". PSYCHLOPS includes a fourth standardised 6-point scale question about overall well-being; 2) Personal Questionnaire (PQ; Elliott et al., 2016), an interview-based individualised outcome measure whose items are elicited in a semi-structured format. In the interview, the patient is asked to brainstorm his / her current problems, prompted by the question "Describe the main problems that you are having right now that led you to seek treatment"; 3) Clinical Outcome Routine Evaluation – Outcome Measure (CORE-OM; Evans, Connell, Barkham, Mellor-Clark, & Audin, 2002), a standardised self-report measure about generic psychological distress, which contains 34 items covering four domains: well-being, problems / symptoms, functional capacity and risk/harm; 4) Patient Health Questionnaire – 9 (PHQ-9; Kroenke, Spitzer, & Williams, 2001), a 9-item standardised self-report questionnaire to measure depression; and 5) Treatment Outcomes Profile (TOP; Marsden et al., 2008), a standardised staff-administered scale focusing on drug-related aspects of treatment, i.e., drug and alcohol use, injecting risk behaviours, offending and criminal involvement and health and social functioning.

PQ and PSYCHLOPS were chosen because they are the most frequently used individualised outcome measures in the mental health field (Sales & Alves, 2016); CORE-OM and PHQ-9 are widely used measures of general psychological distress, and have already been administered in combination with PQ and PSYCHLOPS with satisfactory/good convergent validity scores (PQ vs. CORE-OM r =.80 and PQ vs. PHQ-9 r = .44; Elliott et al., 2016; PSYCHLOPS vs. CORE-OM r =.60; Ashworth et al., 2015); and TOP is one of the most frequently used measure for outcome evaluation in substance misuse treatment (see http://www.nta.nhs.uk/top-world-map.aspx).

Data collection

Data were collected between July 2013 and May 2015 by the first author and five research assistants. All selected participants were asked to complete the evaluation protocol prior to their first treatment session, in a private room. Patients were given a Patient Information Leaflet and consent was obtained before proceeding with questionnaire completion. The four measures of general psychological distress (PQ, PSYCHLOPS, CORE-OM and PHQ-9) were presented in random order. TOP was the final measure to be presented and was not randomised because it focussed mainly on drug-related issues. Randomisation was achieved through the use of numbered evaluation packs with each of the 24 possible questionnaire combinations labelled as pack #1 to #24. A random number generator was used to select which pack was administered to each participant.

Data analysis

To achieve our first aim (exploring patients' individualised problems), we analysed the free-text items in PQ and PSYCHLOPS. These were categorised according to their content, or sub-theme, based on a previously validated thematic classification system which comprised of 65 mutually exclusive sub-themes of problems (Robinson et al., 2006; Sales et al., submitted). Use of this classification system allowed us to compare our findings with previous studies. The categorisations were made independently by three researchers, followed by inter-rater reliability calculations. Whenever there was disagreement, discussions with an independent expert in individualised measures took place until consensus was reached.

For the second aim (matching the content of individualised and standardised measures), we categorised the sub-themes found in individualised items according to whether their content overlapped with each standardised item in CORE-OM, PHQ-9 and TOP. A binary yes/no scale was used, where "no" meant "individualised item vague, general or completely different from the standardised item" and "yes" meant "individualised item connected, clearly related or completely overlapped with the standardised item". Content overlap was categorised independently by two researchers and inter-rater reliability was also computed. Frequencies of sub-themes with and without overlap with the three standardised measures were calculated.

The third aim (contrasting the two individualised measures) was attained by comparing the number of items and the type of contents generated in PQ and PSYCHLOPS. The similarity between patients' responses in both measures was explored using Jaccard's similarity index (*J*) (Real & Vargas, 1996) to estimate the percentage of patients that reported the same sub-themes in the two measures. We considered values of $J > 0.3$ to indicate strong similarity. Significance of Jaccard's index was determined using *Fisher's exact* test.

Finally, we investigated whether prior exposure to standardised measures could influence (or not) the contents of patient-generated items. To explore this hypothesis, we selected a sub-sample of people ($n = 29$) who responded to standardised measures in between individualised measures (i.e. in the following order: one individualised measure – one or two standardised measures – one individualised measure). Then, we focussed on sub-themes elicited from individualised measures that were and were not featured in standardised measures; and when they were, we analysed if patients mentioned them before or after having contact with the standardised measure. If there was no influence, the proportion of featured sub-themes spontaneously mentioned in individualised measures prior to completing the standardised measure would be at least 50%. To test this hypothesis, we used the one sample *t* test (within-subject analysis).

Results

The mean age of our final sample ($N = 93$) was 43 years old ($SD = 11$) and more than half (57%) were male (see Table 1 for a full summary of socio-demographic information).

Among the study participants, 92 generated a total of 275 items from PQ (one patient did not complete PQ) and 89 generated 214 items from PSYCHLOPS (four patients did not complete the Problem section of PSYCHLOPS).

Table 1

Socio-demographic characteristics of study sample (N = 93)

Socio-demographic criteria	*M* (*SD*)	n (%)
Age	42.9 (11.0)	n/a
Gender		
Male	n/a	55 (59.1)
Female	n/a	38 (40.9)
Marital status		
Single	n/a	45 (48.4)
Married	n/a	19 (20.4)
Divorced	n/a	28 (30.1)
Widowed	n/a	1 (1.1)
Educational level		
Illiterate	n/a	3 (3.2)
Literate, but not completed primary school (years 1-4)	n/a	1 (1.1)
Middle school (years 5-9)	n/a	64 (68.8)
Secondary school (years 10-12)	n/a	15 (16.1)
Undergraduate student	n/a	6 (6.5)
University degree	n/a	4 (4.3)
Employment status		
Full-time employment	n/a	21 (22.6)
Occasional / part-time employment	n/a	5 (5.4)
Unemployment <1 year	n/a	18 (19.4)
Unemployment >1 year	n/a	36 (38.7)
Medically unfit to work	n/a	6 (6.5)
Student	n/a	1 (1.1)
Retired	n/a	6 (6.5)
Treatment status		
First treatment episode	n/a	49 (52.7)
Experience of previous treatment episodes	n/a	44 (47.3)

Notes. In Portugal, the first year of school (which is called primary school) starts at the age of 6. Secondary education ends on the 12th school year. The mean (*SD*) and number, n (%) values are given where applicable.

What problems do patients report in individualised measures?

Individualised items generated from PQ and PSYCHLOPS were classified into 54 of the available 65 sub-themes, with good inter-rater reliability results (Cohen’s kappa between raters ranged from .88 to .93). Altogether, the sub-themes most frequently elicited by patients in individualised measures were ‘addiction’ (73%), ‘work-related problems’ (47%), ‘general relationship difficulties with family’ (22%), ‘money worries’ (19%) and ‘relationship difficulties with family that involve worrying about another person’ (16%) (see Table 2).

Table 2.

Sub-themes elicited from patients’ responses (N=93): comparison between individualised and standardised outcome measures

Sub-themes	Number of patients reporting each sub-theme (%)	Jaccard’s similarity index (*p*)	Content overlap between standardised measures and sub-themes		
			CORE-OM	PHQ-9	TOP
Addiction	68 (73.1)	0.54 (0.01)			✓
Work-related problems	44 (47.3)	0.20 (0.45)			✓
Relationships difficulties: family-general	20 (21.5)	0.05 (1.00)	✓		✓
Money worries	18 (19.4)	0.17 (0.07)			
Relationship difficulties: family - worry about another	15 (16.1)	0.0 (0.99)			
Justice-related problems	13 (14.0)	0.15 (0.09)			✓
Worries about health	13 (14.0)	0.31 (0.01)	✓		✓
Self image/self worth	12 (12.9)	0.0 (0.99)	✓	✓	
Coping: daily living	11 (11.8)	0.0 (0.99)	✓		
Loneliness/being alone	11 (11.8)	0.0 (0.99)	✓		
Global	10 (10.8)	0.10 (0.27)			
Depression/Anxiety	9 (9.7)	0.0 (0.99)	✓	✓	✓
Motivation	9 (9.7)	0.11 (0.24)	✓	✓	✓
Emotions – unspecified	8 (8.6)	0.0 (0.99)	✓	✓	✓
Relationship difficulties: family - breaking up	8 (8.6)	0.13 (0.18)	✓		
Relationships-general	8 (8.6)	0.0 (0.99)	✓		✓
Relationship difficulties: family - conflict	7 (7.5)	0.14 (0.12)	✓		
Socialising	7 (7.5)	0.14 (0.12)	✓		
Agression/irritability	6 (6.5)	0.17 (0.10)	✓		✓
Housing worries	6 (6.5)	0.50 (0.01)			✓

Sub-themes	Number of patients reporting each sub-theme (%)	Jaccard's similarity index (*p*)	Content overlap between standardised measures and sub-themes		
			CORE-OM	PHQ-9	TOP
Relationship difficulties partner - breaking up	6 (6.5)	0.17 (0.12)	✓		
Communication	5 (5.4)	0.0 (0.99)	✓	✓	
Relationship diffculties: family – caring	5 (5.4)	0.0 (0.99)			
Being happy	4 (4.3)	0.0 (0.99)	✓		
Dependence on other people	4 (4.3)	0.0 (0.99)	✓		
Guilt	4 (4.3)	0.0 (0.99)	✓		
Suicidal thoughts	4 (4.3)	0.0 (0.99)	✓	✓	
Understanding self/events	4 (4.3)	0.0 (0.99)			
Existence/existential	3 (3.2)	0.0 (0.99)			
Future	3 (3.2)	0.0 (0.99)	✓	✓	
Relationship difficulties: partner - conflict	3 (3.2)	0.0 (0.99)	✓		
Concentration	2 (2.2)	0.0 (0.99)		✓	
Coping: general	2 (2.2)	0.0 (0.99)	✓		
Fears/panics	2 (2.2)	0.0 (0.99)	✓		✓
Moving on	2 (2.2)	0.0 (0.99)	✓		
OCD	2 (2.2)	0.50 (0.02)	✓		
Personal development	2 (2.2)	0.0 (0.99)		✓	
Sleep problems	2 (2.2)	0.0 (0.99)	✓	✓	✓
Studies-related problems	2 (2.2)	0.0 (0.99)			✓
Victim of abuse/sexual violence	2 (2.2)	0.0 (0.99)			
Achievement	1 (1.1	0.0 (0.99)	✓		
Attempted suicide	1 (1.1)	0.0 (0.99)	✓		
Bereavement	1 (1.1)	0.0 (0.99)	✓		
Coping: feelings	1 (1.1)	0.0 (0.99)	✓		✓
Eating problems	1 (1.1)	0.0 (0.99)		✓	
Going out/travelling	1 (1.1)	0.0 (0.99)			
Having positive outlook	1 (1.1)	0.0 (0.99)	✓	✓	
Having time	1 (1.1)	0.0 (0.99)			
Outlook on life	1 (1.1)	0.0 (0.99)	✓	✓	
Relationship difficulties: partner - development	1 (1.1)	0.0 (0.99)	✓		
Relationship difficulties: partner - general	1 (1.1)	0.0 (0.99)	✓		✓
Relationship difficulties: partner - worry about another	1 (1.1)	0.0 (0.99)			
Self-acceptance	1 (1.1)	0.0 (0.99)	✓	✓	
Sexual problems	1 (1.1)	0.0 (0.99)			
Another person illness	0 (0)	n/a			
Avoiding issues	0 (0)	n/a			
Making decisions	0 (0)	n/a			
Relationship difficulties: family – development	0 (0)	n/a	✓		

Sub-themes	Number of patients reporting each sub-theme (%)	Jaccard's similarity index (*p*)	Content overlap between standardised measures and sub-themes		
			CORE-OM	PHQ-9	TOP
Relationship difficulties: partner - forming	0 (0)	n/a	✓		
Relaxing	0 (0)	n/a	✓		
Self-harm	0 (0)	n/a	✓		
Somatic symptoms	0 (0)	n/a	✓	✓	✓
Thinking rationally	0 (0)	n/a			
Thoughts	0 (0)	n/a	✓	✓	
Traumatic event	0 (0)	n/a	✓		

Notes: In this table, 'n/a' refers to sub-themes that are included in the classification system but were not present in any item elicited by this sample. * indicates strong ($J > 0.3$) and significant ($p < 0.05$) similarity values.

Do individualised measures add information to standardised measures?

For the process of analysing content overlap between individualised and standardised outcome measures, all categorisations achieved satisfactory inter-rater reliability results (Cohen's kappa between raters ranged from .66 to 1.0).

Just over two thirds (38 out of 54) of sub-themes captured by individualised measures were absent from TOP. Among these were sub-themes frequently reported by patients such as 'money worries' (19%), 'relationship difficulties with family – worry about another' (16%) and 'self-image/self-worth' (13%). Among the measures of general psychological distress, a little over one third (19 out of 54) of sub-themes captured by individualised measures were not covered by CORE-OM. A large proportion of sub-themes (40 out of 54) were not covered by PHQ-9. Sub-themes not featuring in CORE-OM and PHQ-9 included topics frequently reported by patients, namely, 'addiction', mentioned by 73% of patients, 'work-related problems' (47%) and 'money worries' (19%).

When considered as a whole, 43 out of 54 sub-themes reported by patients on individualised measures were captured by one or more of the standardised instruments (see figure 1). However, almost half of the patients in our sample (49%) described at least one individualised problem whose content was not covered by any of the three standardised measures. This indicates that even with the inclusion of three standardised measures, certain types of personal problems (e.g. ‘money worries’) were only covered by an individualised measure (see figure 2).

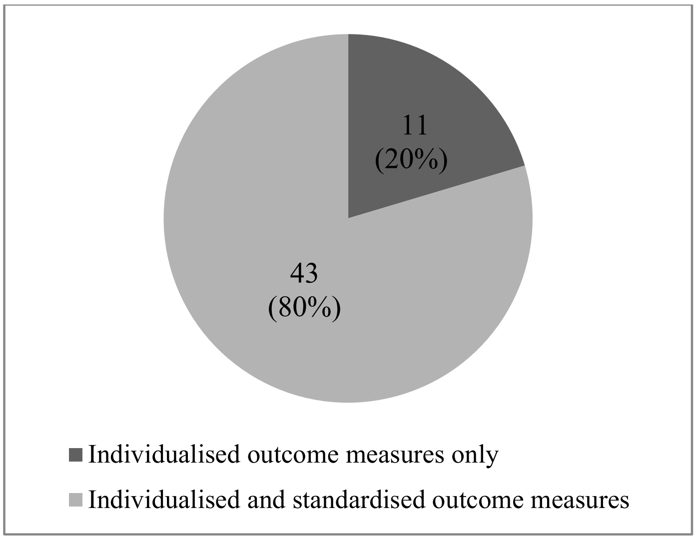


Figure 1. Content overlap between standardised and individualised outcome measures, represented by number of sub-themes (n = 54).

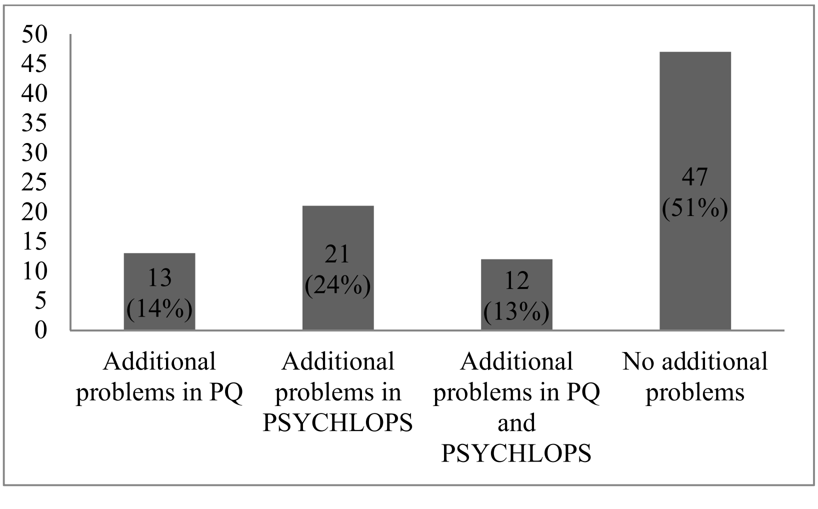


Figure 2. Number of patients (N = 93) with additional problems identified by individualised outcome measures and not featured in standardised measures.

Are there any differences between the two individualised measures?

The mean number of items elicited in PQ was 2.9 (*SD* = 2.1; range 1 to 12) and in PSYCHLOPS was 2.4 items (*SD* = 0.7; range 0 to 3); this difference was significant [t (91) = 3.2, $p < .002$; *Cohen's d* = 0.44]. Twenty-five patients (27%) reported the same number of items in both instruments; 41% (n = 38) reported more items in PQ and 32% (n = 30) reported more items in PSYCHLOPS.

There was little content overlap between the two individualised instruments. Most sub-themes (72%) present in patient-generated items had a Jaccard's similarity index of 0. This means that the responses elicited by PQ tended not to coincide with those elicited by the same patient in PSYCHLOPS, and vice versa. A strong overlap was only found for the following sub-themes: 'addiction' ($J = .5$), 'housing worries' ($J = .5$), 'obsessive compulsive disorder' ($J = .5$) and 'worries about health' ($J = .3$).

Our study showed no evidence that prior completion of a standardised measure influenced the items reported by patients in individualised measures. We found that the proportion of CORE-OM and PHQ-9 sub-themes that were mentioned in patient-generated items prior to completing a standardised measure was 68% (*SD* = 38%). This result was statistically superior to 50% [t (28) = 2.5, $p < .02$], showing that patients spontenously reported items regardless of their content being covered or not by standardised measures.

Discussion

Our study suggests that using individualised measures in substance misuse treatment is a powerful strategy to collect personalised information about patients that would otherwise be overlooked by standardised outcome measures.

It was expected that a sample of patients being admitted for drug and alcohol treatment would be mainly concerned about their addiction problem. However, as patients put it in a previous study (Alves, Sales, & Ashworth, 2016), it was not "just about the alcohol" (p. 4) and drugs. Besides their substance use, people made use of individualised outcome measures to express other concerns, such as their financial situation or difficulties in relating with their family members. To learn that patients who seek substance misuse treatment report problems beyond drug use is a major finding of our study. On the one hand, it confirms the importance of having outcome evaluation protocols that include other aspects, such as psychosocial functioning or stress (Tiffany, Friedman, Greenfield, Hasin, & Jackson, 2012). Both of these domains were expressed by patients in our sample in individualised measures. Moreover, our study also reinforced that is worth involving patients in the selection of criteria to evaluate treatment success, so that it focuses on topics of relevance for patients. As stated by Lee and Zerai (2010), "assuming that [treatment] success itself can be defined, one must accept that is nuanced and, (at least in part), participant-defined" (p. 2423).

When comparing individualised and standardised measures, we were primarily interested in TOP. We expected this measure to have a high content overlap with individualised measures, because it is focussed on problems specific to this population. However, the majority of problems freely reported by patients were overlooked by TOP. By adding two measures of general psychological distress (CORE-OM and PHQ-9), we extended the range of problems covered by the standardised module of the evaluation protocol. We included these measures based on the work of previous authors (Wanigaratne, Davis, Pryce, & Brotchie, 2005) which emphasised the importance of psychological health as a major factor in recovery from drug and alcohol dependence. But even with the inclusion of these three measures, 20% of problems reported by patients were not captured by the standardised measures. These findings have various implications for treatment evaluation in this patient group. The failure of standardised instruments to capture a substantial proportion of reported problems implies that current evaluation protocols may need to be revised in order to accommodate the needs of this population. The wide range of reported problems illustrate the importance of including broadly defined psychosocial criteria in evaluation protocols and not merely focusing on drug and alcohol issues. Additionally, our study indicates that individualised measures can be a valuable increment to the existing evaluation protocols, by capturing aspects that are overlooked by standardised measures, but relevant at an individual level. In other words, the burden of individualised measures (which tend to be lengthy) is potentially overcome by the type, amount and relevance of the information gathered from a clinical perspective.

Patients reported a greater number of items in PQ than in PSYCHLOPS. This finding was expected because PQ imposes no limits on the number of items that patients can create, whereas PSYCHLOPS asks people to generate up to a maximum of three items. This suggests that, if time constraints are not important, one might opt for a questionnaire without a cap on item number. However, although significant, the difference between the mean number of items in PQ and PSYCHLOPS was small (2.9 vs. 2.4, respectively), indicating that the choice of format might be dependent on available resources. Moreover, we found that in self-report individualised measures, some patients did not describe any problems at all, resulting in missing data for outcome assessment. In a previous study, patients reported a preference for someone "pushing them" to facilitate a discussion about their problems rather than documenting their own problems in writing, and thus preferred the format of PQ rather than PSYCHLOPS (Alves, Sales, & Ashworth, 2016).

The two individualised measures elicited different concerns. This discrepancy may have arisen because patients found it easier to express certain problems in one format rather than another. For example, patients may prefer to report sensitive topics, e.g. expression of suicidal thoughts, in a therapist-administered questionnaire; whereas others may prefer a written format to report e.g. communication difficulties. Another explanation is that patients may not have wanted to duplicate reporting across the two measures. If this was the case, we do not know which of the measures elicited the topics of greatest concern for patients. Further research using think-aloud testing would enable us to explore reasons for the unexpected differences in responses elicited by the two individualised measures administered consecutively (Charters, 2003).

This study has several strengths and limitations. Our findings provide the first thematic comparison in substance misuse patients between the contents reported in individualised measures and traditional standardised questionnaires. The comparison of items generated in PQ and PSYCHLOPS has not been previously reported and provides information about their similarities and differences. We were also able to test for contamination of individualised measure completion through prior use of standardised measures, although our findings suggest little if any evidence of bias arising from this source. However, further testing of individualised measures is required in order to establish whether reported differences are related to the structure of the measures or to the mode of administration. Also, it is likely that target problems and treatment goals may change during treatment, hence, future studies should focus of analysing how problems vary after treatment entry, by comparing session-to-session or pre-post data. Even though we chose standardised comparators that were of common use both in mental health and substance misuse treatment, it is possible that other measures, not included in this study, may have a greater content overlap with PQ and PSYCHLOPS than those used in this sample. Another concern relates to the oral administration of self-report measures and the degree to which non-verbal cues may have influenced responses.

Conclusions

Overall, we have demonstrated that individualised measures have the potential to capture qualitative information about personal problems, which is likely to be excluded from standardised psychological outcome measures, even when they are specific to drug and alcohol related problems. This shows that there are benefits, from a qualitative point of view, to combine these measures with traditional standardised tools, so that patient-relevant information is included in outcome assessment and used to personalise treatment provision.

References

Alves, P., Sales, C., & Ashworth, M. (2013). Enhancing the patient involvement in outcomes: a study protocol of personalised outcome measurement in the treatment of substance misuse. *BMC Psychiatry*, *13*, 337-349. doi: 10.1186/1471-244X-13-337

Alves, P., Sales, C., & Ashworth, M. (2015). Personalising the evaluation of substance misuse treatment: a new approach to outcome measurement. *International Journal of Drug Policy*, *26*, 333-35. doi: 10.1016/j.drugpo.2014.11.014

Alves, P., Sales, C., & Ashworth, M. (2016). “It is not just about the alcohol”: a focus group to explore service users’ views about outcome measurement. *Substance Abuse Treatment, Prevention, and Policy*, *11*, 1-7. doi: 10.1186/s13011-016-0070-5

Ashworth, M, Shepherd, M, Christey, J., Matthews, V., Wright, K., Parmentier, H., Robinson, S., & Godfrey, E. (2004). A client-generated psychometric instrument: the development of “PSYCHLOPS”. *Counselling and Psychotherapy Research*, *4*, 27-31. doi: 10.1080/14733140412331383913

Ashworth, M., Robinson, S., Evans, C., Shepherd, M., Conolly, A., & Rowlands, G. (2007). What does an idiographic measure (PSYCHLOPS) tell us about the spectrum of psychological issues and scores on a nomothetic measure (CORE-OM)? *Primary Care and Community Health*, *12*, 7-16. doi: 10.1080/17468840701560805

Charters, E. (2003). The use of think-aloud methods in qualitative research: an introduction to think-aloud methods. *Brock Education*, *12*, 68-82.

Elliott, R., Wagner, J., Sales, C., Rodgers, B., Alves, P. & Café, M. (2016). Psychometrics of the Personal Questionnaire: a client-generated outcome measure. *Psychological Assessment*, *28*, 263-278. doi: 10.1037/pas0000174

Evans, C., Connell, J., Barkham, M., Mellor-Clark, J., & Audin, K. (2002). Towards a standardised brief outcome measure: psychometric properties and utility of the CORE-OM. *British Journal of Psychiatry*, *180*, 51-60. doi: 10.1192/bjp.180.1.51

European Monitoring Centre for Drugs and Drug Addiction. (2007). Guidelines for the evaluation of treatment in the field of problem drug use, EMCDDA Publications, Lisbon.

Hunter, R., McLean, J., Peck, D., Pullen, I., Greenfield, A., McArthur, W., et al. (2004). The Scottish 700 Outcomes Study: A comparative evaluation of the Health of the Nation Outcome Scale (HoNOS), the Avon mental health measure (AVON), and an idiographic scale (OPUS) in adult mental health. *Journal of Mental Health*, *13*, 95-105. doi: 10.1080/09638230410001654594

Kroenke, K., Spitzer, R. L., & Williams, J. B. (2001). The PHQ-9: validity of a brief depression severity measure. *Journal of General Internal Medicine*, *16*, 606-613. doi: 10.1046/j.1525-1497.2001.016009606.x

Lee, H., & Zerai, A. (2010). “Everyone deserves services no matter what”: defining success in harm-reduction-based substance user treatment. *Substance Use & Misuse*, *45*, 2411-2427. doi: 10.3109/10826081003712060

Livingston, J., Milne, T., Fang, M., & Amari, E. (2012). The effectiveness of interventions for reducing stigma related to substance use disorders: a systematic review. *Addiction*, *107*, 39-50. doi: 10.1111/j.1360-0443.2011.03601.x

Marsden, J., Farrell, M., Bradbury, C., Dale-Perera, A., Eastwood, B., Roxburgh, M., & Taylor, S. (2008). Development of the Treatment Outcomes Profile. *Addiction*, *103*, 1450-1460. doi: 10.1111/j.1360-0443.2008.02284.x

Neale, J., & Strang, J. (2015). Blending qualitative and quantitative research methods to optimize patient reported outcome measures (PROMs). *Addiction*, *10*, 1215-1216. doi: 10.1111/add.12896

Neale, J., Tompkins, C., Wheeler, C., Finch, E., Marsden, J., Mitcheson, L., Wykes, T., & Strang, J. (2015). "You're all going to hate the word 'recovery' by the end of this": Service users' views of measuring addiction recovery. *Drugs: Education, Prevention and Policy*, *22*, 26-34. doi: 10.3109/09687637.2014.947564

Orford, J., (2008). Asking the right questions in the right way: the need for a shift in research on psychological. *Addiction*, *103*, 875-85. doi: 10.1111/j.1360-0443.2007.02092.x

Pulford, J., Adams, P., & Sheridan, J. (2009). Client/clinician discrepancies in perceived problem improvement and the potential influence on dropout response. *International Journal of Mental Health Addiction*, *7*, 497-505. doi: 10.1007/s11469-007-9116-2

Real, R., & Vargas, J. (1996). The probabilistic basis of Jaccard's index of similarity. *Systematic Biology*, *45*, 380-385.

Robinson, S., Ashworth, M., Shepherd, M., & Evans, C. (2006). In their own words: a narrative-based classification of clients' problems on an idiographic outcome measure for talking therapy in primary care. *Primary Care & Mental Health*, *4*, 165-174.

Sales, C., & Alves, P. (2016). Patient centred assessment in Psychotherapy: A review of individualised tools. *Clinical Psychology: Science and Practice*, *23*, 265-283. doi:10.1111/cpsp.12162

Thurgood, S., Crosby, H., Raistrick, D., & Tober, G. (2014). Service user, family and friends' views on the meaning of a 'good outcome' of treatment for an addiction problem.

Drugs: Education, Prevention and Policy, *21*, 324-332. doi: 10.3109/09687637.2014.899987

Tiffany, S., Friedman, L., Greenfield, S., Hasin, D., & Jackson, R. (2012). Beyond drug use: a systematic consideration of other outcomes in evaluations of treatments for substance use disorders. *Addiction*, *107*, 709-718. doi: 10.1111/j.1360-0443.2011.03581.x

Trujols, J., Iraurgi, I., Batlle, F., Durán-Sindreu, S., & Pérez de Los Cobos, J. (2015). Towards a genuinely user-centred evaluation of harm reduction and drug treatment programmes: a further proposal. *International Journal of Drug Policy*, *26*, 1285-1287. doi: 10.1016/j.drugpo.2015.08.012

Wagner, J. (2002). Evaluating a core battery: a comparison of standardized, individualized and qualitative approaches to therapy outcome assessment (PhD Dissertation), University of Toledo, Toledo.

Personalising outcome measurement in substance misuse treatment: the practicability and psychometrics of two individualised outcome measures [¤]

Paula C. G. Alves[a,b*], Célia M. D. Sales[c], & Mark Ashworth[b], & Luís Faísca[d]

Abstract

Individualised information in substance misuse treatment complements standardised outcome measures. However, few studies investigate the use of individualised measures and their robustness in terms of quantifying outcomes. In this study we analysed the psychometrics and practicability of two individualised outcome measures (PQ and PSYCHLOPS). We followed a cross-sectional methodology, administering the individualised measures and three additional standardised measures (CORE-OM, PHQ-9 and TOP) to a sample of 93 patients entering substance misuse treatment in four clinical services. The results showed high levels of patient acceptability of the two individualised measures (response rates > 95%). The internal reliability was good for both PQ and PSYCHLOPS (Cronbach's alpha, .79 and .72, respectively). The correlation between PQ and standardised measures was weak: TOP (psychological health) *r* = .21, PHQ-9 *r* = .22 and CORE-OM *r* = .27. In contrast, convergent validity of PSYCHLOPS was moderate: *r* = .40, *r* = .39 and *r* = .50 (TOP, PHQ-9 and CORE-OM, respectively). Convergence between PQ and PSYCHLOPS was weak (*r* = .28). Experience of previous treatment episodes was associated with higher PQ and PSYCHLOPS

[¤] Article currently submitted for publication.

[a] Instituto Universitário de Lisboa (ISCTE-IUL), CIS-IUL, Lisboa, Portugal

[b] Division of Health and Social Care Research; Faculty of Life Sciences & Medicine, King's College London

[c] Centro de Psicologia da Universidade do Porto, Faculdade de Psicologia e de Ciências da Educação, Universidade do Porto.

[d] Departamento de Psicologia, Faculdade de Ciências Sociais e Humanas, Universidade do Algarve.

[*] Corresponding author. E-mail address: paulagomesalves@hotmail.com

scores; PSYCHLOPS but not PQ scores were higher among those opting to complete the questionnaires in written rather than verbal format. Our findings demonstrated that PQ and PSYCHLOPS are reliable and practical individualised outcome measures for use in substance misuse treatment units, even though convergent validity with standardised measures was only weak to moderate. Optimal outcome measurement may involve combining individualised and standardised measures.

Keywords: substance misuse treatment, individualised outcome measures, personalised assessment, PQ, PSYCHLOPS.

Introduction

The evaluation of treatment outcomes has, until recently, been dominated by a nomothetic approach. However, a growing body of expert opinion has recommended that idiographic, or individualised, information should also be used for outcome measurement purposes (Alves, Sales & Ashworth, 2015; Neale & Strang, 2015). Combining nomothetic and idiographic approaches has been described as an “optimal way of understanding and measuring patient reported outcomes of addiction and its related constructs” (Neale & Strang, 2015, p. 1216). However, little is known about whether individualised outcome measures are a viable method for collecting idiographic information and producing reliable quantitative estimates of outcomes in substance misuse treatment.

Broadly speaking, outcome measures aim to quantify changes that occur in a patient’s clinical status over the course of treatment. The commonest strategy involves the use of standardised outcome measures, based on pre-set questions administered to a general group of patients. The standardised structure of these measures allows for a mechanisation of the outcome measurement process, since all individuals are presented with the same pre-determined questions (OECD, 2013). The generation of large scale data from standardised instruments has given these measures a golden status in the field of outcome evaluation (Evans, Greenhalg & Connelly, 2000).

In recent years, individualised measures have gained ground in healthcare, due to a number of reasons (Fitzpatrick, Davey, Buxton & Jones, 1998). First, they provide patients with an opportunity to indicate items to evaluate the outcome of their treatment (Barkham, 2016); second, they allow patients to rate the intensity or level of distress caused by their own problem, which correspond to their priorities (Elliott et al., 2016; Sales & Alves, 2012; 2016); third, they have a greater sensitivity to clinical change than standardised outcome measures (Ashworth, Evans, & Clement, 2008; Elliott et al., 2016); fourth, they are likely to capture information overlooked by standardised measures (Alves, Sales, Ashworth, & Faísca, submitted); and fifth, patients value the opportunity to define and express their own range of concerns (Alves, Sales, & Ashworth, 2016).

To be appropriate, outcome measures must be "psychometrically strong, applicable and practical" (Lambert & Hawkins, 2004, p. 493). A growing body of literature has explored these properties among individualised outcome measures. These studies have focussed mostly on the Personal Questionnaire (PQ; Elliott et al., 2016) and the Psychological Outcome Profiles (PSYCHLOPS; Ashworth et al., 2004). PQ and PSYCHLOPS are individualised measures targeting general psychological distress, based on items generated by patients, and widely used in mental health care (Sales & Alves, 2016).

Previous findings stated that PQ and PSYCHLOPS are clinically useful, since they contain items of high relevance for patients (Ashworth et al., 2005; Sales et al., 2007). Therapists have also reported their satisfaction using these two measures for several clinical tasks, including outcome assessment (Sales et al., 2007; Sales & Alves, 2012). On psychometrics, both PQ and PSYCHLOPS have produced reliable and valid scores to measure treatment outcomes in general mental health settings (e.g. university counselling units, mental health primary care) (Ashworth et al., 2008; Elliott et al., 2016). However, further studies, ideally in other clinical populations, are required to decrease the scepticism about individualised measures (Elliott et al., 2016).

Substance misuse treatment is one of the areas where individualised measures have been little explored. In this field, outcome measurement tends to focus on specific drug-related issues, as well as psychosocial variables, including general psychological distress and specific problems such as depression or suicidal thoughts (Darke, Ross, & Teesson, 2007; Gossop, Marsden, Stewart, & Kidd, 2003, Jones et al., 2009; Wanigaratne, Davis, Pryce, & Brotchie, 2005). However, these outcomes tend to be assessed with standardised instruments and it is unknown whether individualised outcome measures are also practical and psychometrically robust for outcome measurement purposes (Alves, Sales, & Ashworth, 2015).

To our best knowledge, PQ and PSYCHLOPS were firstly introduced in substance misuse treatment in 2013, in a larger project where this present study is included (Alves, Sales, & Ashworth, 2013). Preliminary findings demonstrated that patients value these measures by being easy to understand; helping them to reflect about personal difficulties; providing them with freedom to talk about problems, related or not to substance misuse; and making them feel like normal people (Alves, Sales, & Ashworth, 2016). As a downside, patients admitted that the level of self-exposure that these instruments require can be hindering (Alves, Sales, & Ashworth, 2016). This project also revealed that PQ and PSYCHLOPS elicited problems overlooked by standardised measures (Alves, Sales, Ashworth, & Faísca, submitted). For instance, more than two thirds of sub-themes indicated by patients in these individualised measures were absent from the Treatment Outcomes Profile (TOP; Marsden et al., 2008), including problems such as ‘money worries’ and ‘self-image/self-worth’ (Alves, Sales, Ashworth, & Faísca, submitted). The present study builds on these findings by exploring the practicability of PQ and PSYCHLOPS, as well as their psychometric properties in this sample.

Study rationale

The current study focussed mainly on the practicability of PQ and PSYCHLOPS, in contrast with their standardised comparators; and in the psychometric properties of PQ and PSYCHLOPS in this population. Additionally, we also explored potential factors that may influence PQ and PSYCHLOPS scores (e.g. socio-demographic, substance misuse, treatment history and other variables of interest), to gain further knowledge about the quantitative value of these instruments. We also aimed to contrast the scorings obtained with PQ and PSYCHLOPS, since both are individualised measures albeit with different characteristics (e.g. mode of administration). To our knowledge, this is the first study to explore these questions within the context of substance misuse services.

Method

This was a cross-sectional study with a sample of adult patients entering treatment in four services for drug and alcohol substance misuse in Portugal, between July 2013 and May 2015. Approval was granted by the Committee for Health of Lisbon and surrounding areas (ARSLVT, Ref. 8251/CES/2012).

Participants

The sample comprised of patients aged 18 years and older, who were starting a treatment episode (i.e. first episode or treatment of a relapse) and were fluent in Portuguese. We excluded patients that were not motivated to participate or were too distressed to complete the evaluation protocol. This decision was made by researchers in consultation with the administrative/clinical staff available. We calculated our sample size based on previously reported alpha scores of .80 for PSYCHLOPS, with 114 patients, and .86 for PQ, with 72 patients (Ashworth, Evans, & Clement, 2008; Elliott et al., 2016). Based on these findings, we aimed to recruit a sample of approximately 100 patients. Of the 102 individuals who met the inclusion criteria, 94 (92%) consented to participate. One was excluded because of non-completion of PQ and PSYCHLOPS, resulting in a final sample of 93 patients.

Instruments

Personal Questionnaire (PQ; Elliott et al., 2016). A semi-structured interview-based individualised outcome measure that asks patients to describe the main problem(s) that resulted in them seeking treatment. The intention is to prompt patients to elicit an unlimited number of personalised items, without any limitations on topic, where each item represents a unique problem of the patient expressed in their own words. After the item generation process, the patient is asked to rate each item/problem according to how much it troubled him/her over the last week using a 7-point scale (ranging from "1 = not at all" to "7 = maximum possible"); and for how long the problem has been of concern, also recorded on a 7-point scale (from "1 = less than 1 month" to "7 = more than 10 years"). PQ total score corresponds to the sum of the scorings of all items elicited by each patient.

Psychological Outcome Profiles (PSYCHLOPS; Ashworth et al., 2004). A self-report individualised measure in which patients are invited to write down one or two personalised problems in free-text boxes, in response to the question, "choose the problem that troubles you most" (P1) and "choose another problem that troubles you" (P2). Each problem is rated according to how much it has affected him/her over the last week, on a 6-point scale (from "0 = not at all affected" to "5 = severely affected"); and for duration in time on a 5-point scale (from "0 = under one month" to "4 = over five years"). PSYCHLOPS includes a third personalised item prompted by the question, "choose one thing that is hard to do because of your problem or problems" (Functioning), also rated on a 6-point scale (from "0 = not at all hard" to "5 = very hard"). There is a final pre-set item where patients are asked to rate the question “how have you felt in yourself this last week” on a 6-point scale (from “0 = very good” to “5 = very bad”) (Well-being). PSYCHLOPS total score corresponds to the sum of the scores of the two problems, in addition to the scores of functioning and well-being items. In case P2 is missing, the score of P1 should be doubled; whenever P1 and/or the functioning and well-being items are missing, the total score cannot be computed.

Clinical Outcomes in Routine Evaluation – Outcome Measure (CORE-OM; Evans, Connell, Barkham, Mellor-Clark, & Audin, 2002). A self-report standardised 34-item tool to assess the level of psychological distress in four domains: problems (depression, anxiety, physical problems and trauma), functioning (general daily functioning, relationships), subjective well-being (feelings about self and optimism about the future), and risk behaviours (risk to self and to others). All items are scored on a 5-point scale (from “0 = not at all” to “4 = most or all the time”, or the opposite, for reversed items) based on the number of times that each item was experienced by patients in the previous week. CORE-OM total score corresponds to the sum of the 34 items. If more than three items are missing, the total score cannot be computed. Regarding the four domains, if more than one item is missing from problems and well-being, these total scores cannot be computed as well.

Patient Health Questionnaire – 9 (PHQ-9; Kroenke, Spitzer, & Williams, 2001). A self-report standardised 9-item questionnaire to evaluate depression. In this measure patients are asked to score each item in a 4-point scale (from “0 = not at all” to “3 = nearly every day”), according to the frequency that each problem troubled the patient in the last two weeks. PHQ-9 total score corresponds to the sum of the 9 items.

Treatment Outcomes Profile (TOP; Marsden et al., 2008). A standardised questionnaire orally administered by researchers, in an interview, that includes 20 questions about key aspects of substance misuse treatment: substance use, injecting risk behaviour, crime, health and quality of life. In TOP, the items are rated in number of days, yes/no questions and scaling items on 20-point scales.

Procedure

Researchers invited patients attending the treatment centres to take part in the study prior to commencing treatment. Consent was obtained and participants completed the evaluation protocol immediately prior to the first treatment session.

Patients were presented with the evaluation protocol containing the five outcome measures, followed by a socio-demographic and treatment history form. All measures were administered according to their original instructions, unless patients required assistance to complete the questionnaires. We randomised the order in which measures about psychological distress (PQ, PSYCHLOPS, CORE-OM and PHQ-9) were presented to patients. With this, we aimed to control for order effects and avoid patients' responses to be influenced by the contents elicited in the other measures with similar purposes. The presentation order of TOP was not randomised. TOP was invariably presented at the end of the protocol because it focusses specifically in drug-related topics and little or no influence was expected.

Data analysis

Practicability. We focussed on three main parameters to evaluate the practicability of individualised measures: administration duration in minutes (note: we opted for timing the entire protocol, instead of each measure separately, to interfere as little as possible with the evaluation process, considering that only one researcher was present in the room); acceptability, i.e. proportion of patients who completed each instrument; and the preferred mode of administration, i.e. proportion of patients who were able to complete by self-report or who required assistance from an administrator (upon patient's request).

Descriptive analyses of PQ and PSYCHLOPS. PQ and PSYCHLOPS data were analysed in terms of mean number of patient-reported items, mean severity of distress and mean problem duration since onset. Because of the unpredictability of the number of patient-reported items in PQ, overall mean severity and duration was based on the individual PQ mean score for each patient. Data on problem duration was also recorded for the longest duration reported in PQ and PSYCHLOPS.

Internal reliability of PQ and PSYCHLOPS. For PQ, we computed consecutive Cronbach's alpha values, starting with 2 items (PQ item #1 and PQ #2) and then consecutively re-calculating new alphas by adding the next PQ item (one at a time) to the calculation. A total of four alphas were computed until the last item mentioned by at least 15 patients (i.e. PQ item #5) was added. The mean (and respective standard deviation) of the alpha for PQ represents the mean of the four alphas that resulted from this procedure, following the method described by Elliott et al. (2016). For PSYCHLOPS, we opted for two alpha values, one for the three individualised items and one for the total score.

Convergent validity of PQ and PSYCHLOPS. Correlations between instrument scores were calculated using Pearson's *r*. The mean scores of PQ and PSYCHLOPS were correlated with CORE-OM, PHQ-9 and TOP (psychological health, physical health and quality of life scale items). As in Elliott et al. (2016), we expected moderate to strong correlations between individualised and standardised measures. Unlike CORE-OM and PHQ-9, the scale items of TOP have their scores reversed (i.e. "0 = very bad" and "20 = very good") in contrast to PQ and PSYCHLOPS; hence convergent validity would be indicated by a negative correlation.

In addition to practicability and psychometrics of the individualised measures, we also explored the association between PQ and PSYCHLOPS scores with socio-demographics, substance misuse and treatment history variables. The objective of these further analyses was to extend our knowledge about the quantitative data generated by individualised instruments, as well as investigating potential variables that might influence these quantitative scores. PQ and PSYCHLOPS scores were also contrasted according to their mode of administration (interview vs. self-report) and order of instrument administration (severity of scores in the first and second individualised completed by patients). For binary variables, the student's *t-test* was used; for nominal variables with more than two values, *one-way ANOVAs* (followed by Bonferroni *post hoc* analyses) were computed; for continuous data, Pearson's *r* was calculated.

All analyses were conducted in IBM SPSS Statistics 22.

Results

The 93 patients who participated in our study consisted of a higher proportion of men (59%); the mean age was 43 years (*SD* = 11). Tables 1 and 2 (2a and 2b) show further characteristics of the sample, as well as their substance use and treatment history, respectively

Table 1

Patient characteristics (N = 93)

Variable		n	%
Relationship status	Single	45	48.4
	Married/cohabiting	19	20.4
	Divorced/separated	29	31.2
Educational level	Illiterate	3	3.2
	Literate, but not completed primary school	1	1.1
	Basic school (years 1-9)	64	68.8
	Secondary school (years 10-12)	15	16.1
	University (years >12)	10	10.8
Employment status			
	Paid work (full-time/part-time)	26	28.0
	Unemployed	52	55.9
	Retired	8	8.6
	Other (e.g. housewife)	7	7.5

Variable		n	%
Accommodation status			
	Rented/owned house	84	90.3
	Temporary accommodation (e.g. guesthouse)	1	1.1
	Homeless	2	2.2
	Shared supported accommodation (e.g. community shelters)	6	6.5

Table 2a

Substance misuse – age of onset and usage in the last 12 months (N = 93)

Type of substance		Years: Mean (Standard deviation)	n (%)
Alcohol	Age of onset	16.5 (7.7)	
	Used in the last 12 months (yes)		58 (62.4)
Heroin	Age of onset	20.2 (6.7)	
	Used in the last 12 months (yes)		10 (10.8)
Cocaine (powder)	Age of onset	20.3 (6.7)	
	Used in the last 12 months (yes)		4 (4.3)
Crack cocaine	Age of onset	28.0 (12.8)	
	Used in the last 12 months (yes)		1 (1.1)
Cannabis	Age of onset	14.7 (2.5)	
	Used in the last 12 months (yes)		14 (15.1)
Ecstasy	Age of onset	16.3 (1.7)	
	Used in the last 12 months (yes)		1 (1.1)
LSD	Age of onset	16.2 (1.5)	
	Used in the last 12 months (yes)		0 (0)
Tobacco	Age of onset	14.1 (3.3)	
	Used in the last 12 months (yes)		58 (62.4)

Table 2b

Substance misuse treatment history

Substance misuse treatment history		Yes n (%)
	First treatment episode	49 (52.7)
Type of previous treatment	Psychological treatment	15 (17.4)
	Opioid substitution treatment	7 (8.1)
	Alcohol dependence medication	11 (12.8)
	Inpatient therapeutic community	13 (15.1)
	Detoxification unit	17 (19.8)
	Self-help groups	4 (4.7)

Practicability of individualised vs. standardised outcome measures

The mean time required for completion of the evaluation protocol, including the individualised measures, was 30.1 minutes (*SD* = 11.4, range 10-61 minutes). Regarding the acceptability, the proportion of patients who responded to each tool was as follows: PQ, 92 (99%); PSYCHLOPS, 88 (95%); CORE-OM, 92 (99%); PHQ-9, 93 (100%); and TOP, 90 (97%). Concerning the mode of administration, PQ and TOP were delivered in an interview-based format, as required by their instructions. The self-report tools often required administrator completion. PSYCHLOPS was administered orally to 37 (41%) patients; CORE-OM to 36 (40%) patients; and PHQ-9 to 35 (39%) patients. Patients requested assistance because of literacy issues, self-reported anxiety and poor sight.

Descriptive analyses of PQ and PSYCHLOPS mean scores

The mean number of items in PQ was 2.9 (*SD* = 2.1), range 1 to 12. The mean severity score for PQ items was 5.3 (*SD* = 1.7). Eighty-two (89%) patients had mean PQ severity scores above the clinical cut-off value of 3.25 points, as defined in Elliott et al. (2016). Problems described in PQ had lasted 1 to 2 years (*M* = 4.2 points; *SD* = 1.6); however, the longest duration problem was 3 to 5 years (*M* = 5.3 points; *SD* = 1.8).

For PSYCHOPS, the mean number of patient-generated items (P1 + P2 + Function) was 2.3 (*SD* = .8), range 0 to 3 items. The mean item severity scores were: problems, 7.1 (*SD* = 2.9, range 0-10); function, 3.4 (*SD* = 1.7, range 0-5); well-being, 2.3 (*SD* = 1.8). The mean total PSYCHLOPS score was 13.8 (*SD* = 4.9, range 0-20). Even though we collected 92 PSYCHLOPS, the total score could only be computed for 58 patients because of insufficient data (i.e. two problems missing and/or function, and/or well-being item missing). The problems reported in PSYCHLOPS had been troubling patients for a duration of 3 months to 1 year

(*M* = 3.4 points, *SD* = 1.3). In this sample, the PSYCHLOPS problem of the longest duration was 1 to 5 years (*M* = 3.6 points, *SD* = 1.4).

Internal reliability of PQ and PSYCHLOPS mean scores

Both individualised measures showed good internal reliability, with alpha scores for PQ of α = .79 (mean) and for PSYCHLOPS α = .72 (Table 3).

Table 3

Internal reliability (Cronbach's alpha) of PQ and PSYCHLOPS

<table>
<tr><th>Cronbach's <i>alpha</i></th><th>PQ items 1-2</th><th>PQ items 1-2-3</th><th>PQ items 1-2-3-4</th><th>PQ items 1-2-3-4-5</th><th>Mean (<i>SD</i>)</th></tr>
<tr><td>PQ</td><td>.69</td><td>.75</td><td>.83</td><td>.88</td><td>.79 (.09)</td></tr>
<tr><td>PSYCHLOPS</td><td>Problem items 1-2</td><td colspan="2">Problem + functioning items 1-2-3 (individualised component)</td><td colspan="2">All items 1-2-3-4 (individualised items + standardised item)</td></tr>
<tr><td></td><td>.42</td><td colspan="2">.69</td><td colspan="2">.72</td></tr>
</table>

Notes. In PQ, item #1 corresponds to the first item in the PQ item list, i.e. the item identified by the patient as being the problem he/she is most concerned about; item #2 is the second problem that most concerns the patient, etc.

Convergent validity of PQ and PSYCHLOPS vs. standardised outcome measures

Table 4 shows the correlation matrix between the five instruments. We found a weak and significant convergence between PQ and PSYCHLOPS (*r* = .28) scores. Correlations between PQ and PSYCHLOPS problem scores were similar when self-completed (*r* = .28) in contrast to researcher administered (*r* = .25). The correlations between PQ scores and the standardises measures were weak, namely, CORE-OM *r* = .27, PHQ-9 *r* = .22 and TOP (psychological health) *r* = .21 (see Table 4). In contrast, correlations between CORE-OM, PHQ-9 and TOP (psychological health) with PSYCHLOPS were moderate at *r* = .50, *r* = .39 and *r* = .40, respectively.

Table 4

Convergent validity of PQ and PSYCHLOPS with CORE-OM, PHQ-9 and TOP

Measures (Pearson's *r*)		PQ	PSYCHLOPS			
	Domains		Problems	Functioning	Well-being	Total score
PQ						
PSYCHLOPS	Problems	.35**				
	Functioning	.23	.53**			
	Well-being	.17	.39**	.27*		
	Total score	**.28****	.89**	.73**	.70**	
CORE-OM	Problems	.31**	.39**	.38**	.49**	.48**
	Functioning	.12	.20	.31*	.53**	.39**
	Well-being	.30**	.41**	.35**	.52**	.49**
	Risk	.19	.32**	.16	.37**	.37**
	Total score	**.27****	.38**	.37**	.54**	**.50****
PHQ-9		**.22***	.39**	.28*	.52**	**.39****
TOP	Psychological health	**-.21**	-.33**	-.12	-.60**	**-.40****
	Physical health	**-.12**	-.15	-.004	-.26*	**-.07***
	Quality of life	**-.24***	-.30**	-.30*	-.48	**-.44****

Notes. * $p \leq .05$; ** $p \leq .01$. The values highlighted in bold indicate the correlation between PQ and PSYCHLOPS (total, 4 items) and the total scores of the other measures.

Association between PQ/PSYCHLOPS scores, demographic and clinical variables

Socio-demographic data. There were no significant differences in PQ and PSYCHLOPS scores according to gender, educational level, type of accommodation and employment status. No correlation was found between item severity and patient age.

Substance use and treatment history. PQ and PSYCHLOPS scores were correlated with the age of first substance misuse. The later in life people started to use certain substances, the higher were their distress scores on individualised outcome measures. Specifically, we found that PQ mean scores were moderately and positively correlated with the age of first use of LSD (r = .38) and had a perfect positive correlation with crack (r = 1.0); and were moderately, yet negatively related with age of first use of cannabis (r = -.40). Regarding PSYCHLOPS, scores were strongly and positively correlated with age of first use of ecstasy (r = .90) and negatively with age of first use of LSD (r = -.76).

Patients who had received previous treatment for substance misuse were more likely to report a higher level of psychological distress both in PQ [t (90) = -1.9, p < .05] and PSYCHLOPS [t (56) = -2.5, p < .02]. Regarding the type of treatments received, patients with previous psychological outpatient treatment [t (50) = 2.0, p < .04] and in therapeutic communities [t (50) = 2.4, p < .02] had significantly higher problem scores in PSYCHLOPS than those who did not. These effects were not observed in PQ. There were no differences between the mean scores of PQ and PSYCHLOPS problems in those receiving the remaining treatment modalities.

Mode of administration. PSYCHLOPS scores were significantly higher among those who reported free-text items about problems [t (84) = 2.5, p < .01] and functioning [t (56) = 2.4, p < .02] in a written format.

Order of instrument administration. There were no significant differences in problem severity scores relating to the order of individualised instrument completion [t (85) = .69, p < .49].

Discussion

Previous findings have demonstrated the importance of PQ and PSYCHLOPS as a source of qualitative, personalised information about patients undergoing treatment for substance misuse (Alves, Sales, Ashworth, & Faísca, submitted). The present study adds to that body of literature by providing estimates about the practicability, reliability and validity of such individualised outcome measures in this context.

Are individualised measures practicable for use in substance misuse treatment?

We found that the administration of the whole evaluation protocol took approximately 30 minutes (i.e. approximately half the typical duration of a clinical session). This means that individualised measures were completed relatively quickly, suggesting that adopting these measures might not be a burden in real clinical settings. Replicating previous findings in a primary care mental health setting (Ashworth et al., 2005), the completion rates of individualised measures were above 90%, demonstrating high levels of patient acceptability. The completion rates of individualised and standardised measures were similar, showing that both types of measures were equally received by patients. However, nearly half of our sample missed at least two responses in PSYCHLOPS, hindering the calculation of its total score and questioning its practicability. This was a low number in comparison with previous studies, where more than 90% of patients' responses to PSYCHLOPS allowed the calculation of its total scores (Ashworth et al., 2004; Ashworth et al., 2007; Ashworth et al., 2008).

Regarding the mode of administration, although designed to be self-completed, almost half the sample asked for PSYCHLOPS to be administered orally. This may be due to low literacy skills, high levels of patient distress on entering treatment and patients may have felt more supported by being able to talk about their problems during assessment. On the other hand, patients reported higher severity scores in the written format, implying that they might feel less comfortable verbalising their distress or that responses may be moderated by perceptions of socially disapproved, or even illegal, behaviours. Although contradictory, our results were consistent with Bowling's observation (2005) that interviewer-based methods are likely to increase response accuracy, but self-report questionnaires may encourage the sharing of more sensitive information. No difference was observed between self-report or oral format scores on the standardised measures CORE-OM and PHQ-9.

Overall, our findings indicate PQ and PSYCHLOPS are practicable in substance misuse treatment settings. Nearly all patients invited to participate in the study were motivated to complete the individualised measures, even though not all responded to them in the expected format. In particular, there were many patients requesting the instruments to be administered verbally. This suggests that even when self-report measures such as PSYCHLOPS are selected, researchers and clinicians may have to enhance their interview skills to ensure that data collection is not negatively affected, should patients require assistance in this task.

Do individualised measures generate quantitatively robust information?

Both PQ and PSYCHLOPS elicited fewer items than when used in other clinical populations. For instance, in Elliott et al. (2016), the mean number of items created across five samples of patients in general mental health treatment was 10, compared with three items in the present study. Similar findings were reported in the previous section, when we observed that patients in our sample tended to miss PSYCHLOPS items more often than other samples (Ashworth et al., 2004; Ashworth et al., 2007; Ashworth et al., 2008). When combined, these results indicate that substance misuse patients provided less information in individualised measures than other clinical populations. Further research is needed to explore why this occurred. However, we hypothesize that being admitted for a specialist treatment, targeting a specific behaviour, might have led patients to think that it was inappropriate, or unnecessary, to disclose too much information about their lives. On the other hand, item scores and mean problem duration were similar to those reported in previous studies (Ashworth et al., 2005; Elliott et al., 2016), indicating that patients experience similar levels of psychological distress as in other generalist mental health samples, emphasising the importance of addressing psychological health in this population (Wanigaratne, Davis, Pryce, & Brotchie, 2005).

Concerning psychometric properties, our analyses revealed good internal reliability for PQ and PSYCHLOPS in the context of substance misuse therapy. Such reliability values were similar to those previously reported in Elliott et al. (2016) ($\alpha = .86$) and Ashworth et al. (2005) ($\alpha = .79$). On the other hand, the convergence between individualised and standardised outcome measures was weak to moderate. This might reflect the nature of problems experienced by our sample of patients, often unrelated to health and including concerns such as housing or finances not covered by the standardised comparators used (Alves, Sales, Ashworth, & Faísca, submitted). PSYCHLOPS correlated more strongly with standardised measures than PQ did. This might be a feature of the structural characteristics of PSYCHLOPS which is a hybrid instrument containing one standardised well-being item which correlated more strongly with standardised measures; whilst PQ is a pure patient-generated instrument, only containing personalised items.

A weak correlation was found between the two individualised measures. This was expected for several reasons: the different structure of PQ and PSYCHLOPS may have prompted patients to respond differently to both measures; a previous study (Alves, Sales, Ashworth & Faísca, submitted) had already found that patients tend not to repeat items/problems when answering both instruments as part of the same evaluation protocol. Moreover, the original self-report format of PSYCHLOPS was altered to an interview in approximately half of the sample. Considering that the information provided in a questionnaire depends on its administration (Bowling, 2005), it is unknown how much PSYCHLOPS responses were affected when provided orally.

To sum up, even though individualised measures produce reliable measurements, their weak to moderate correlation with standardised measures suggests that they should complement standardised instruments rather than being used alone. This proposal had already been suggested by authors working in other treatment contexts (Barkham, 2016; Sales & Alves, 2012; 2014). Combining both types of measures may enhance their potential for outcome measurement. As Möller put it (2009), whilst standardised measures can objectively quantify psychological constructs, individualised information is able to capture “distinctive characteristics of individuals” (p. 2016), giving a more meaningful context to the numbers obtained with standardised tools.

Which individual/treatment characteristics may influence PQ and PSYCHLOPS scores?

Patients with past experience of substance misuse treatment were more likely to present higher distress in PQ and PSYCHLOPS, in comparison with those starting their first treatment episode. On the one hand, relapse may be particularly associated with distress and disruptive situations; also, patients who dropped out of previous treatment episode(s) without a successful therapeutic result may be more likely to have unresolved personal issues which they report as problems in individualised measures. Ramos & Brown (2008) identified that, among substance misusers, the main reasons leading to substance misuse and relapse are social situations, coping with negative emotions and interpersonal conflicts. These type of concerns were reported by our sample in PQ and PSYCHLOPS (Alves, Sales, Ashworth, & Faísca, submitted), which is in line with what we found in this study.

Regarding the age of onset of drug use, our study was partly in line with the literature, which has reported that the younger individuals start to use drugs, the more severe their drug-related problems are (Hser, Longshore, & Anglin, 2007). In support of this was the negative correlation between age of first use of cannabis and PQ; and first use of LSD and PSYCHLOPS. However, for crack and LSD in PQ, and ecstasy in PSYCHLOPS the reverse was true. For these patients, it is likely that other bio-psycho-social factors may have contributed for their dependence disorder, reinforcing the importance of a multidimensional evaluation of clinical status (Alves, Sales &, Ashworth, submitted).

Hence, even though PQ and PSYCHLOPS severity scores were higher in patients with previous treatment history, we found that the age in which patients starting using certain substances had different effects in PQ and PSYCHLOPS scores. This is another finding supporting the fact that PQ and PSYCHLOPS do not tend to converge in what they measure and in how their scorings are influenced by other variables, showing that, despite having similar purposes, they may actually be measuring different aspects of patients' distress.

Limitations

The biggest limitation of our study is that it overlooks post-treatment scores. Contrasting pre-post treatment data would have permitted an estimation of further psychometric parameters of PQ and PSYCHLOPS, such as sensitivity to change and temporal structure. Practicability could be further explored by comparing patient and staff preferences for different combinations of instruments. We only collected the administration time for the entire protocol. Separate times would have provided a better estimate of individualised measures' length and how they compare to their standardised counterparts. Moreover, we did not evaluate the quality of the items produced by patients in PQ and PSYCHLOPS. We hypothesise that differences between the quality of the items may have accounted for the divergence in the results obtained between these two measures.

Conclusions

With this study we have confirmed that individualised measures are practical and reliable to use as outcome measures in substance misuse treatment, in line with previous studies on psychometrics of PQ and PSYCHLOPS (Ashworth et al., 2005; Ashworth, Evans, & Clement, 2008; Elliott et al., 2016). Convergent validity between PQ and PSYCHLOPS and standardised measures was not strong, suggesting that individualised measures may be measuring different aspects of patient's distress.

One of our biggest findings was the weak correlation between PQ and PSYCHLOPS and the variability of results produced by them, when in fact these measures were expected to measure similar constructs – patient's individual concerns. Researcher and self-administered modes of completion may have influenced item generation, potentially leading to the differences between the scorings of PQ and PSYCHLOPS.

Overall, our study suggests that PQ and PSYCHLOPS scoring can be used to measure patient's distress in substance misuse treatment. Due to their low to moderate convergence, individualised measures should ideally be used in combination with standardised measures for optimal results. Further research is required to shed light to the psychometric properties of individualised measures, namely, in regards to their validity. Also, future pre-post studies are still needed to clarify whether PQ and PSYCHLOPS are valid, reliable and sensitive to measure clinical changes, a question that our cross-sectional study with pre-treatment data was not able to respond.

References

Alves, P., Sales, C., & Ashworth, M. (2013). Enhancing the patient involvement in outcomes: a study protocol of personalised outcome measurement in the treatment of substance misuse. *BMC Psychiatry*, *13*, 337-349. doi: 10.1186/1471-244X-13-337

Alves, P., Sales, C., & Ashworth, M. (2015). Personalising the evaluation of substance misuse treatment: a new approach to outcome measurement. *International Journal of Drug Policy*, *26*, 333-35. doi: 10.1016/j.drugpo.2014.11.014

Alves, P., Sales, C., & Ashworth, M. (2016). "It is not just about the alcohol": a focus group to explore service users' views about outcome measurement. *Substance Abuse Treatment, Prevention, and Policy*, *11*, 1-7. doi: 10.1186/s13011-016-0070-5

Alves, P., Sales, C., Ashworth, M., & Faísca, L. "There are things I want to say but you don't ask": a thematic comparison between standardised and individualised outcome measures in substance misuse treatment. Manuscript submitted for publication.

Alves, P., Sales, C., & Ashworth, M. Does substance misuse treatment outcome assessment reflect the personal concerns of patients? A scoping review of measures recommended in Europe. Manuscript submitted for publication.

Ashworth, M, Shepherd, M, Christey, J., Matthews, V., Wright, K., Parmentier, H., Robinson, S., & Godfrey, E. (2004). A client-generated psychometric instrument: the development of "PSYCHLOPS". *Counselling and Psychotherapy Research*, *4*, 27-31. doi: 10.1080/14733140412331383913

Ashworth, M., Robinson, S., Godfrey, E., Shepherd, M., Evans, C., Seed, P., Parmentier, H., & Tylee, A. (2005). Measuring mental health outcomes in primary care: the psychometric properties of a new patient-generated outcome measure, 'PSYCHLOPS' ('psychological outcome profiles'). *Primary Care Mental Health*, *3,* 261-270.

Ashworth, M., Evans, C., & Clement, S. (2009). Measuring psychological outcomes after cognitive behaviour therapy in primary care: A comparison between a new patient generated measure 'PSYCHLOPS' and 'HADS'. *Journal of Mental Health*, *18*, 169-177. doi:10.1080/09638230701879144

Barkham, M. (2016). Patient-centered assessment in psychotherapy: toward a greater bandwidth of evidence. *Clinical Psychology: Science and Practice*, *23*, 284-287. doi: doi:10.1111/cpsp.12163

Bowling, A. (2005). Mode of questionnaire administration can have serious effects on data quality. *Journal of Public Health, 27*, 281-291. doi: 0.1093/pubmed/fdi031

Darke, S., Ross, J., & Teesson, M. (2007). The Australian Treatment Outcome Study (ATOS): what have we learnt about treatment for heroin dependence? *Drug and Alcohol Review*, *26,* 49-54

Elliott, R., Wagner, J., Sales, C., Rodgers, B., Alves, P. & Café, M. (2016). Psychometrics of the Personal Questionnaire: a client-generated outcome measure. *Psychological Assessment*, *28*, 263-278. doi: 10.1037/pas000017

Evans, S., Greenhalg, J., & Connelly, J. (2000). Selecting a mental health needs assessment scale: guidance on the critical appraisal of standardized measures. *Journal of Evaluation in Clinical Practice*, *6,* 379-393. doi: 0.1046/j.1365-2753.2000.00269x

Evans, C., Connell, J., Barkham, M., Mellor-Clark, J., & Audin, K. (2002). Towards a standardised brief outcome measure: psychometric properties and utility of the CORE-OM. *British Journal of Psychiatry*, *180*, 51-60. doi: 10.1192/bjp.180.1.51

Fitzpatrick, R., Davey, C., Buxton, M. J., & Jones, D. R. (1998). Evaluating patient-based outcome measures for use in clinical trials. *Health Technology Assessment*, *2*, 1-86. doi: 10.3310/hta2140

Hser, Y., Longshore, D., & Anglin, D. (2007). The life course perspective on drug use: a conceptual framework for understanding drug use trajectories. *Evaluation Review*, *31*, 515-547.

Gossop, M., Marsden, J., Stewart, D., & Kidd, T. (2003). The National Treatment Outcome Research Study (NTORS): 4-5 year follow-up results. *Addiction*, *98,* 291–303.

Gyawali, B., Choulagai, B., Paneru, D., Ahmad, M., Leppin, A., & Kallestrup, P. (2016). Prevalence and correlates of psychological distress symptoms among patients with substance use disorders in drug rehabilitation centers in urban Nepal: a cross-sectional study. *BMC Psychiatry, 16,* 314-324. doi: 10.1186/s12888-016-1003-6

Jones, A., Donmall, M., Millar, T., Moody, A., Weston, S., Anderson, T., Gittins, M., Abeywardana, V. and D'Souza, J., (2009). The Drug Treatment Outcomes Research Study: Final outcomes report. London: Home Office.

Kroenke, K., Spitzer, R. L., & Williams, J. B. (2001). The PHQ-9: validity of a brief depression severity measure. *Journal of General Internal Medicine*, *16*, 606-613. doi: 10.1046/j.1525-1497.2001.016009606.x

Lambert, M. & Hawkins, E. (2004). Measuring outcome in professional practice: considerations in selecting and using brief outcome instruments. *Professional Psychology: Research and Practice, 35,* 492-499. doi: 10.1037/0735-7028.35.5.492

Marsden, J., Farrell, M., Bradbury, C., Dale-Perera, A., Eastwood, B., Roxburgh, M., & Taylor, S. (2008). Development of the Treatment Outcomes Profile. *Addiction*, *103*, 1450-1460. doi: 10.1111/j.1360-0443.2008.02284.x

Möller, H. (2009). Standardised rating scales in Psychiatry: Methodological basis, their possibilities and limitations and descriptions of important rating scales. *The World Journal of Biological Psychiatry*, *10*, 6-26. doi: 10.1080/15622970802264606

Neale, J., & Strang, J. (2015). Blending qualitative and quantitative research methods to optimize patient reported outcome measures (PROMs). *Addiction*, *10*, 1215-1216. doi: 10.1111/add.12896

OECD (2013). *OECD Guidelines on Measuring Subjective Well-being*. OECD Publishing. doi: 10.1787/9789264191655-en

Sales, C., Goncalves, S., Fragoeiro, A., Noronha, S., & Elliott, R. (2007). Psychotherapists' openness to routine naturalistic idiographic research. *Mental Health and Learning Disabilities Research and Practice*, *4*, 145-161. doi:10.5920/mhldrp.2007.42145

Sales, C., & Alves, P. (2012). Individualised patient-progress systems: Why we need to move towards a personalized evaluation of psychological treatments. *Canadian Psychology*, *53*, 115-121. doi:10.1037/a00280537

Sales, C., Alves, P., Evans, C., & Elliott, R. (2014). The Individualised Patient Progress System (IPPS): A decade of international collaborative networking. *Counselling and Psychotherapy Research*, *14*, 181-191. doi:10.1080/14733145.2014.929417

Sales, C., & Alves, P. (2016). Patient centred assessment in Psychotherapy: A review of individualised tools. *Clinical Psychology: Science and Practice*, *23*, 265-283. doi:10.1111/cpsp.12162

Wanigaratne, S., Davis, P., Pryce, K., & Brotchie, J. (2005). The effectiveness of psychological therapies on drug misusing clients. NHS National Treatment Agency for Substance Misuse: London.

Does substance misuse treatment outcome assessment reflect the personal concerns of patients? A scoping review of measures recommended in Europe ¤

Paula C. G. Alves[a,b*], Célia M. D. Sales[c], & Mark Ashworth[b]

Abstract

In substance misuse treatment, outcome measurement tends to rely on estimates of substance misuse and related behaviours (e.g. crime). There is a growing number of authors stating that outcome measurement should go beyond substance misuse and include other bio-psycho-social variables of interest. However, little is known about which topics tend to be covered by outcome measures targeting this specific population, and whether they reflect the typical concerns of this patient group. This study followed a scoping review methodology in which 42 outcome measures were selected for review. Thirty-one domains of problems were identified across 42 measures, with 'substance use' and 'psychological health' among the commonest. The majority of the measures were similar between each other and multidimensional, suggesting a broad understanding of substance misuse disorders. Almost all domains of problems identified in the outcome measures corresponded to concerns reported by patients. On the other hand, we found that several topics of relevance for patients were not covered by any of the measure included in our study. This suggests that existing outcome measures do not always target aspects that affect patients' lives. Our study shows that outcome

---

¤ Article accepted for publication at *Drug and Alcohol Dependence* (date of acceptance: 17th May, 2017).

[a] Instituto Universitário de Lisboa (ISCTE-IUL), CIS-IUL, Lisboa, Portugal

[b] Division of Health and Social Care Research; Faculty of Life Sciences & Medicine, King's College London

[c] Centro de Psicologia da Universidade do Porto, Faculdade de Psicologia e de Ciências da Educação, Universidade do Porto.

assessment needs to adopt a more flexible and comprehensive approach, by taking on board the problems experienced by patients in this population.

Keywords: outcome measurement, evaluation tools, substance misuse treatment, patient perspectives, thematic analysis.

Introduction

In substance misuse treatment, as in any other mental health intervention, outcome assessment plays a crucial role in understanding how interventions work. To date, one of the largest outcome studies in this field was the National Treatment Outcome Research Study (NTORS; Gossop, Marsden, Stewart, & Kidd, 2003), conducted in the United Kingdom in the early 2000s. This study investigated the outcomes of community and residential treatment in a national sample of 418 individuals misusing illicit drugs and alcohol. It revealed reductions in drug use and risk-taking behaviours, as well as improvements in psychological and physical health. Other large scale outcome studies have reported similar findings (e.g. ATOS; Darke, Ross, & Teesson, 2007; DTORS; Jones et al., 2009). Gossop (2008) also referred to a "clinical fallacy", which considers that numerous successful cases are overlooked in reports due to patients leaving the services voluntarily after self-perceived improvements. Although treatment drop-out can also represent treatment failure, these findings indicate that substance misuse treatment works, at least to a certain extent, and for a certain group of patients.

However, for a relatively large proportion of people, substance misuse treatment is not as successful as desired. For instance, in NTORS, after a 5-year follow-up, there was still a 1% mortality rate and the levels of alcohol consumption remained unchanged among those that took part in the study. Moreover, an increase in frequency of alcohol use was observed in patients receiving residential treatment (Gossop, 2003). The latest report published by the National Drug Treatment Monitoring System of Public Health England (PHE, 2015) showed that approximately one third of patients (with opiate, non-opiate, non-opiate/alcohol or alcohol problems only) dropped out of treatment prior to its completion. It also revealed that one third of patients with opiate and/or non-opiate dependence problems remain unchanged after six months in treatment; and considering solely the alcohol problems, nearly half of all patients failed to improve. The reasons for these discouraging results are unclear, but unsuccessful treatment may negatively affect patients' mental, physical and social status, and contribute to mortality excess in this group. With such contradictory findings the first question is: how are we evaluating substance misuse treatment? In other words, there is a need to reflect about the value and relevance of the information which is being used for outcome assessment purposes.

In 2012, Tiffany and colleagues stated that, to be effective, substance misuse treatment outcome measurement should 1) focus on the consequences or strong, concurrent correlates of excessive drug use; 2) cover aspects that are common across abused substances and widespread among people dependent on those substances; and 3) have documented and strong psychometric properties that produce replicable evidence that the outcome can be altered following treatment. Despite providing a good framework, or strategy, for substance misuse treatment evaluation, this proposal does not suggest which aspects should be covered by outcome measures in this field.

There is a great diversity of outcome criteria proposed for substance misuse treatment. However, the literature lacks consensus, with many international organisations (e.g. European Monitoring Centre for Drugs and Drug Addiction, EMCDDA) and authors suggesting different domains, or outcome measurement criteria (Table 1).

Table 1

Examples of domains (i.e. outcome criteria) to use in substance misuse treatment assessment, as suggested by experts

Type of publication	Authors/year	Source	Criteria suggested for outcome assessment
International guidelines	EMCDDA, 2007	EU Agency	Addictive behaviour/consumption of substances, retention/time in treatment, status at discharge (planned / drop-out), risk-taking behaviours for drug-related infection, somatic and psychiatric health, social reintegration (housing, employment, social network, life style, delinquency), and quality of life
Scientific literature	Tiffany, Friedman, Greenfield, Hasin, & Jackson, 2012	Addiction research experts	Self-efficacy, psychosocial functioning, network/social support, craving and quality of life
Scientific literature	Donavan et al., 2011	Addiction research experts	Behavioural functioning and quality of life
Scientific literature	Neale et al., 2015	Addiction research experts	Substance use, treatment/support, psychological health, physical health, use of time, education/training/employment, income, housing, relationships, social functioning, offending/anti-social behaviour, well-being, identity/self-awareness, goals/aspirations and spirituality

Moreover, there is a gap between what is proposed in the literature and what is actually evaluated in research studies and/or practice. Most evaluation protocols focus on drug and/or alcohol use and related behaviours, e.g. injecting, criminal activities (Donavan et al., 2011; Tiffany, Friedman, Greenfield, Hasin, & Jackson, 2012), overlooking psychosocial variables that many authors believe to be highly relevant for patients' recovery (Table 1). These data could be used as markers to adjust the intervention according to treatment response (Tiffany, Friedman, Greenfield, Hasin, & Jackson, 2012), as well as allowing a better understanding of the mechanisms underlying recovery.

The outcome assessment process in this patient group faces another major challenge: most measures are expert-driven, and not primarily sourced from patient perspectives. Failure to involve patients in the process of outcome measurement raises the possibility of overlooking aspects of relevance for patients (Alves, Sales, & Ashworth, 2016) and having over-optimistic reporting of outcomes (Thurgood et al., 2014). Increasingly, studies are seeking the views of patients about outcome assessment criteria (e.g. Ruefli & Rogers, 2004; Neale et al, 2016; see Table 1). For instance, Ruefli and Rogers (2004) revealed that patients in treatment stated the importance of domains covering: 'making money', 'getting something good to eat', 'being housed', 'relating to family', 'getting needed programs/benefits/services', 'handling health problems', 'handling negative emotions', 'handling legal problems', 'improving oneself' and 'handling drug-use problems'. In a similar study conducted in 2015, Neale and colleagues asked patients to define what "being recovered" meant for them. Patients reported that treatment recovery should include improvements in 'substance use', 'material resources', 'outlook on life', 'self-care' and 'relationships'. Another example is the recently developed SURE, a standardised outcome measure for substance misuse treatment (Neale et al., 2016). In this measure, items were generated in collaboration with former and current drug and alcohol service users (Neale et al., 2016). Similarly, our own research group has sought the views of substance misuse patients through the use of individualised outcome measures, enabling patients to report their personal concerns at treatment entry (Alves, Sales, Ashworth & Faísca, submitted). We found that patient priorities were 'addiction', 'work-related problems', 'general relationships with family', 'money' and 'worries about another person'. Additionally, we found that most of the patient-reported topics were not captured by widely used standardised outcome measures of psychological well-being, such as CORE-OM or PHQ-9, or drug-related outcome measures, namely TOP (Alves, Sales, Ashworth & Faísca, submitted). These findings suggest that patients may contribute with new evidence to outcome assessment, providing insight into contradictory findings reported in the literature about the outcomes of substance misuse treatment.

Study rationale

The principal aim of this study was to explore the thematic content of items used by outcome assessment tools in substance misuse treatment in Europe and to understand the extent to which these measures are perceived as relevant to this population. We hope that our findings will contribute to a broader understanding of the attributes of outcome measures and their ability to capture the personalised problems reported by patients.

Method

This study was comprised of three analytical steps. The first was a scoping review (Arksey & O'Malley, 2002) to search for outcome measures and to identify the domains covered by those measures. Secondly, we explored the similarity between the measures according to their domains. Finally, a thematic comparison analysis was conducted to compare the domains covered by standardised instruments with "problem" domains generated by patients, which derived from individualised measures in previous literature (Alves, Sales, Ashworth, & Faísca, submitted).

Search strategy, selection of measures and data extraction

A scoping review is a charting technique used to extract information, from relevant sources, according to key issues or topics (Arksey & O'Malley, 2002). In this study, the key aspects used to chart our data were the general characteristics and domains covered by the outcome measures. We started by hand searching for outcome measures in the Evaluation Instrument Bank (http://www.emcdda.europa.eu/eib) of EMCDDA, until August 2016. This data source was selected because it operates as an information hub collating data about substance misuse across 30 European countries. Twenty-six national agencies for drug and alcohol monitoring were also contacted by e-mail to ensure that all measures recommended for outcome assessment had been identified. No additional tools were identified by the six national agencies that responded to our request. Outcome measures were selected for review according to two inclusion criteria: 1) used to evaluate the outcome of treatment; and 2) used in adults as the target population. The measures were excluded if: 1) they did not target the patient (e.g. measures focusing on significant others); and 2) were not available in English. After selecting the outcome measures, a charting form was created for data recording. We extracted data describing general characteristics of the measures, by identifying their authors, year of publication, focus (drugs, alcohol, drug/alcohol, health, other), type of measure (standardised, individualised, hybrid), delivery format (self-report, interview, mixed) and number/type of items (Likert scales, nominal scales, number of days/times, other).

Data analysis

Part 1: Identification of domains covered by outcome measures. We started by reading the Evaluation Instruments Bank's "User information" sheet of each measure, which included a section about "Domains measured/life areas/problems assessed". If unavailable, the accompanying instructions or main references were consulted. A preliminary list of domains was then created, containing all domains included in each selected measure. In this list, domains were recorded *verbatim* as provided in the description of the measure. We removed duplicate domains and grouped those that referred to similar/equivalent topics, until a complete list of domains was obtained. For instance, 'illegal activities' and 'criminal involvement' were both integrated in the domain 'crime'. In the particular case of 'psychological health', we opted for creating several sub-domains, due to the existence of instruments that either focussed on general or single aspects of psychological health (e.g. 'self-esteem'). This procedure was performed by the first author and the results were discussed with a researcher, independent to the study, until consensus was reached.

Part 2: Similarity between outcome measures in terms of domains covered. Next, we grouped the measures according to the similarity of the domains which they contained, to understand how convergent the tools were. To achieve this goal, we used the MF similarity index (Sales & Wakker, 2009; Sales, Wakker, Alves, & Faísca, 2015) to obtain a similarity matrix, based on the 'absence' or 'presence' of each domain, in each tool. The similarity matrix was analysed with the Hierarchical Cluster Technique (centroid method) in order to obtain groups of measures that shared common features. We used IBM SPSS Statistics 22 and the freeware online MF calculator (http://mfcalculator.celiasales.org/) to conduct this analysis.

Part 3: Matching between outcome measure domains and the problems relevant for patients. The third part of our analysis comprised a thematic comparison between the domains extracted from the outcome measures and 54 previously defined domains of patient-generated problems. These problems represented patient concerns identified in individualised outcome measures, which are tools where patients are asked to report the concerns that led them to treatment, in an open-ended fashion and in their own words. The list of 54 patient-generated domains was identified by patients entering substance misuse treatment in a previous study (Alves, Sales, Ashworth & Faísca, submitted). The thematic comparison was made independently by two researchers using a binary coding system to rate each outcome measure domain as "yes" (i.e. topics connected, clearly related or completely overlapped with patient-generated domains) and "no" (i.e. topics completely different from patient-generated domains). This procedure was followed by calculations of inter-rater reliability, based on Cohen's kappa values. Certain outcome measures selected for review contained sections about socio-demographic/treatment history and treatment process (e.g. readiness for treatment). These sections were excluded from our thematic comparison, as we were interested in outcome criteria only. After completing the content matching, we calculated the number and percentage of patient-generated domains included in each of the outcome measures.

Finally, for data reduction purposes, we re-analysed the data obtained from the aforementioned thematic comparison of patient concerns to identify the presence of underlying constructs featured in the selected outcome tools. We only included those patient-generated domains which were identified in at least a tenth of the outcome measures; less frequently featured domains were not included. This produced a cohort of 20 domains; the remaining 34 domains were discarded from this part of the analysis. In order to explore the structure of underlying constructs in selected domains, we used Multiple Correspondence Analysis (MCA; Carvalho, 2008). MCA is a multivariate technique used to detect underlying dimensions among a group of nominal/categorical data. Factor analysis can also be used for a similar purpose; however unlike factor analysis, MCA makes no assumptions of normality and can be used with categorical data (Carvalho, 2008; Philips, 2009). Using MCA, dimensions are identified on the basis of their discriminatory and contribution values, in a range varying from zero to one.

Results

After removing the duplicates, 74 outcome measures were screened in this study, of which 42 fulfilled the selection criteria (see selection flowchart in Figure 1).

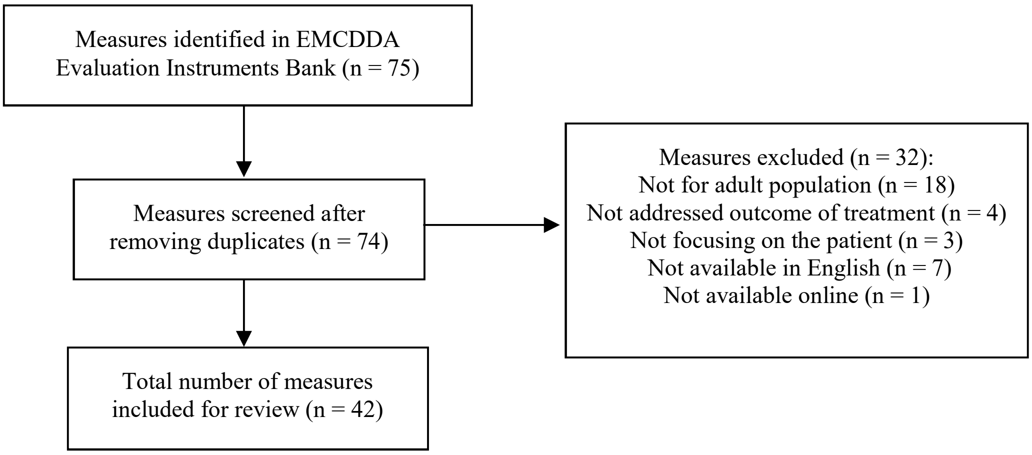


Figure 1. Flowchart showing the selection of outcome measures for review.

Main characteristics of the outcome measures

Among the 42 outcome measures, 25 (60%) focussed on drugs/alcohol, seven (17%) focussed on drugs, six (14%) on alcohol, one (2%) on general health and three (7%) on other aspects (i.e. depression, self-esteem and quality of life). All but one measure were standardised, and only one differed by having an individualised scope, i.e. non-pre-set defined items. On delivery format, 21 (50%) were interview-based protocols, 19 (46%) were self-report measures, one (2%) was an observational scale and one (2%) followed a mixed-methods approach. The mean number of items was 54 (*SD* = 57, range 1-223). Among these measures, 23 (55%) contained nominal items and 34 (81%) had scale-type items (see Table 2).

Table 2

Review of the outcome measures used in substance misuse treatment (N = 42), including the identification of domains (N = 31)

	Author/Year	Focus	Type of measure	Delivery format	No. items	Type of items	Domains
Addiction Severity Index	McLellan et al., 1979	Drugs/alcohol	Standardised	Interview	161	Nominal, scale	Crime, employment, family/relationships, general health, money, psychological health, substance misuse
Addiction Severity Index Crime	Öberg et al., 1998	Drugs/alcohol	Standardised	Interview	39	Nominal, scale	Crime
Addiction Severity Index Gambling	Öberg et al., 1999	Drugs/alcohol	Standardised	Interview	15	Scale	Gambling
Alcohol Dependence Data Questionnaire	Raistrick, 1983	Alcohol	Standardised	Self-report	15	Scale	Substance misuse
Alcohol Dependence Scale	Skinner, 1982	Alcohol	Standardised	Self-report	25	Nominal	Substance misuse
Depression Scale	Radloff, 1972	Other	Standardised	Self-report	20	Scale	Depression/anxiety/stress, family/social relationships, physical health
Christo Inventory for Substance Misuse Services	Christo, n.d.	Drugs/alcohol	Standardised	Interview	10	Nominal	Crime, employment, general health, psychological health, psychosocial functioning, risk behaviours, substance misuse
Christo Inventory of Drugs	Christo, n.d.	Drugs/alcohol	Standardised	Interview	8	Nominal, scale	Substance misuse
Clinical Opiate Withdrawal Scale	Wesson & Ling, 2003	Drugs	Standardised	Interview	11	Nominal	Substance misuse
Drug Use Screening Test	Skinner, 1982	Drugs/alcohol	Standardised	Self-report	20	Nominal	Crime, employment, family/social relationships, psychological health
Drug Avoidance Self-Efficacy Scale	Martin, 1991	Drugs/alcohol	Standardised	Self-report	16	Scale	Self-efficacy
European Addiction Severity Index	Blacken et al., 1994	Drugs/alcohol	Standardised	Interview	189	Nominal, scale	Crime, employment, family/social relationships, money, psychological health, substance misuse
Evaluate Your Alcohol Consumption	Sobell & Sobell, 1992	Alcohol	Standardised	Self-report	1	Scale	Substance misuse
Evaluate Your Drug Consumption	Sobell et al., 1996	Drugs	Standardised	Self-report	1	Scale	Substance misuse
The Health Questionnaire	Brodman et al., 1949	Health	Standardised	Self-report	144	Nominal	Physical health
Leeds Dependence Questionnaire	Raistrick & Tober, 2000	Drugs/alcohol	Standardised	Self-report	10	Scale	Substance misuse
Lifetime Drinking History	Skinner, 1979	Alcohol	Standardised	Interview	8	Nominal, scale	Substance misuse
Maudsley Addiction Profile	Marsden et al., 1998	Drugs/alcohol	Standardised	Interview	61	Nominal, scale	Crime, employment, family/social relationships, physical health, psychological health, psychosocial functioning, risk behaviours, substance misuse
Measurements in the Addictions for Triage and Evaluation	Schippers & Broekman, 2003	Drugs/alcohol	Standardised	Interview	114	Nominal, scale	Community/civic life, depression/anxiety/stress, domestic life, employment, family/social relationships, money, personality, physical health, school, self-care, social life, substance misuse
Monitoring Area and Phase System – Intake	Öberg et al., 1997	Drugs/alcohol	Individualised	Interview	7	Nominal	Crime, employment, family/social relationships, physical health, psychological health, substance misuse
Monitoring Area and Phase System - Out	Öberg et al., 1997	Drugs/alcohol	Standardised	Interview	223	Nominal, scale	Crime, employment, family/social relationships, physical health, psychological health, substance misuse
Monitoring Area and Phase System - Up	Öberg et al., 1997	Drugs/alcohol	Standardised	Interview	102	Nominal, scale	Crime, employment, family/social relationships, physical health, psychological health, substance misuse
Objective Opiate Withdrawal Scale	Handelsman et al., 1987	Drugs	Standardised	Observational	13	Nominal	Substance misuse
Opiate Treatment Index	Darke et al., 1991	Drugs	Standardised	Interview	104	Nominal, scale	Crime, physical health, substance misuse

	Author/Year	Focus	Type of measure	Delivery format	No. items	Type of items	Domains
Personal Experience Screening Questionnaire	Winters, 1991	Drugs/alcohol	Standardised	Self-report	40	Scale	Psychosocial functioning, substance misuse
Rosenberg Self-Esteem Scale	Rosenberg, 1965	Other	Standardised	Self-report	10	Scale	Self-esteem
Severity of Dependence Scale	Gossop, 1995	Drugs	Standardised	Self-report	5	Scale	Substance misuse
Goals of Treatment Questionnaire	Joosten et al., 2009	Drugs/alcohol	Standardised	Mixed	24	Nominal	Child care, community/civic life, crime, daytime activities, domestic life, family/social relationships, food and nutrition, gambling, housing status, money, physical health, psychological health, school, self-control, sexual functioning, social life, substance misuse, technology and information
Situational Confidence Questionnaire	Annis, 1988	Alcohol	Standardised	Self-report	39	Scale	Emotions, employment, physical health, self-control, social life
Situational Confidence Questionnaire - Heroin	Barber, 1991	Drugs	Standardised	Self-report	22	Scale	Emotions, family/social relationships, physical health, self-control, social life
Subjective Opioid Withdrawal Scale	Handelsman, 1987	Drugs	Standardised	Self-report	16	Scale	Substance misuse
Texas Christian University Follow - Up Interview - Methadone Outpatient	Simpson, 1997	Drugs/alcohol	Standardised	Interview	84	Nominal, scale	Crime, employment, family/social relationships, gambling, general health, leisure activities, money, psychological health, risk behaviours, substance misuse
The Texas Christian University - During Treatment Status - Methadone outpatient	Simpson, 1996	Drugs/alcohol	Standardised	Interview	55	Nominal, scale	Crime, employment, family/social relationships, money, psychological health, risk behaviours, substance misuse, physical/emotional abuse
The Texas Christian University - Initial Assessment - Methadone Outpatient	Simpson, 1995	Drugs/alcohol	Standardised	Interview	58	Nominal, scale	Employment, psychosocial functioning, substance misuse
The Texas Christian University - Initial Assessment - Correctional Residential	Simpson, 1998	Drugs/alcohol	Standardised	Interview	114	Nominal, scale	Employment, psychological health, psychosocial functioning, substance misuse
The Texas Christian University - Intake - Correctional Residential	Simpson, 1998	Drugs/alcohol	Standardised	Self-report	95	Scale	Psychological health, psychosocial functioning
The Texas Christian University HIV/AIDS Risk Assessment	Simpson, 1997	Drugs/alcohol	Standardised	Interview	19	Scale	Risk behaviours
The Texas Christian University Intake - Methadone Outpatient	Simpson, 1997	Drugs/alcohol	Standardised	Interview	119	Nominal, scale	Acculturation, crime, employment, family/social relationships, gambling, general health, money, psychological health, psychosocial functioning, risk behaviours, substance misuse
The Texas Christian University Self Rating at Intake - Methadone Outpatient	Simpson, 1996	Drugs/alcohol	Standardised	Interview	95	Scale	Psychological health, psychosocial functioning
The Texas Christian University- Evaluation of self and treatment	Simpson, 1996	Drugs/alcohol	Standardised	Self-report	126	Scale	Crime, employment, family/social relationships, housing status, risk behaviours, substance misuse
The WHO Quality of Life-Bref instrument	World Health Organisation, 2004	Other	Standardised	Self-report	26	Scale	Family/social relationships, psychological health, social life
Timeline Followback Method	Sobell & Sobell, 1992	Alcohol	Standardised	Self-report	1	Scale	Substance misuse

Domains identified and similarity between outcome measures according to domains covered

From a preliminary group of 196 domains of problems identified across the measures, we obtained a final list of 31 domains by excluding all domains which had overlapping content. The full list of these domains is presented in Figure 2.

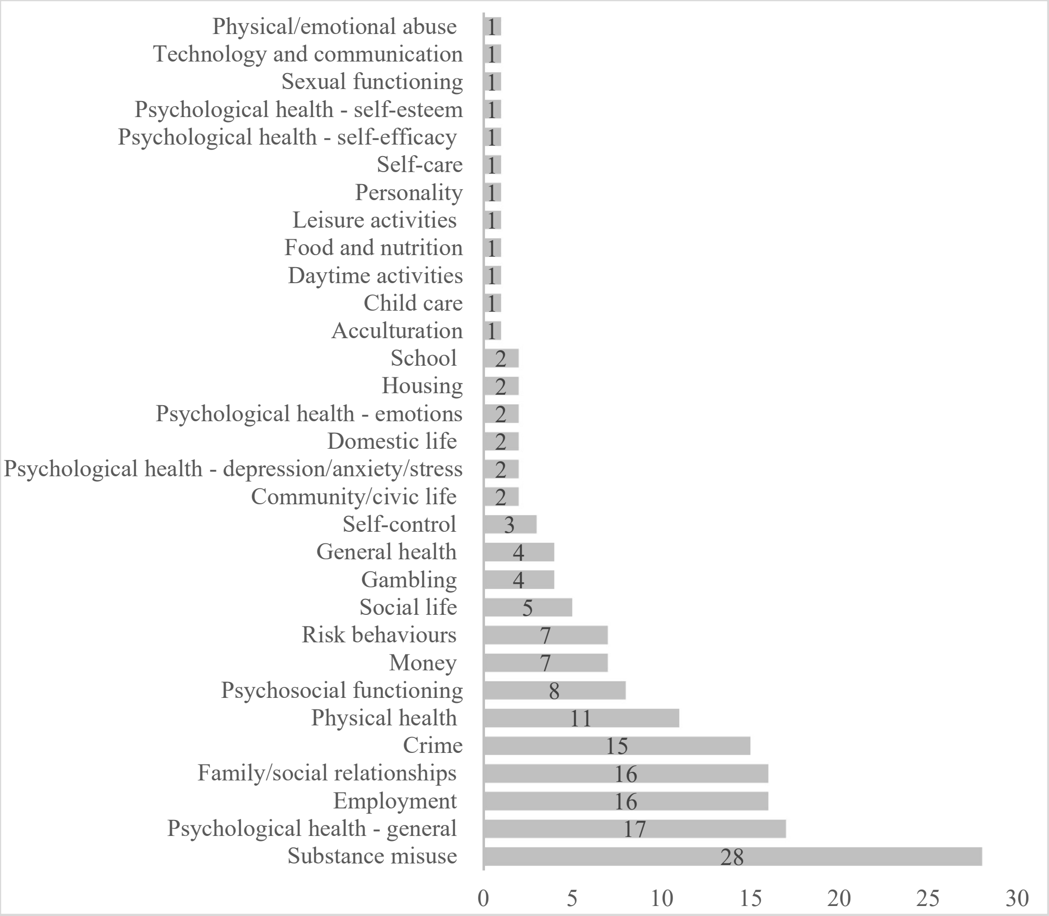


Figure 2. List of domains (N = 31) ordered by frequency of outcome measures featuring each domain.

The mean number of domains per measure was 4 (*SD* = 4, range 1-18); and 43% of measures (n = 18) covered only one domain. The most common domains were: ‘substance misuse’ (67%), ‘psychological health general (40%), ‘family and social relationships’ (38%), ‘employment’ (38%), ‘crime’ (36%) and ‘physical health’ (26%).

When exploring the similarity between the instruments in terms of domains covered, we found two main groups of measures: those that focussed only on substance misuse; and multidimensional measures focusing on substance misuse and other topics. A similarity tree representing these groups is shown in Figure 3.

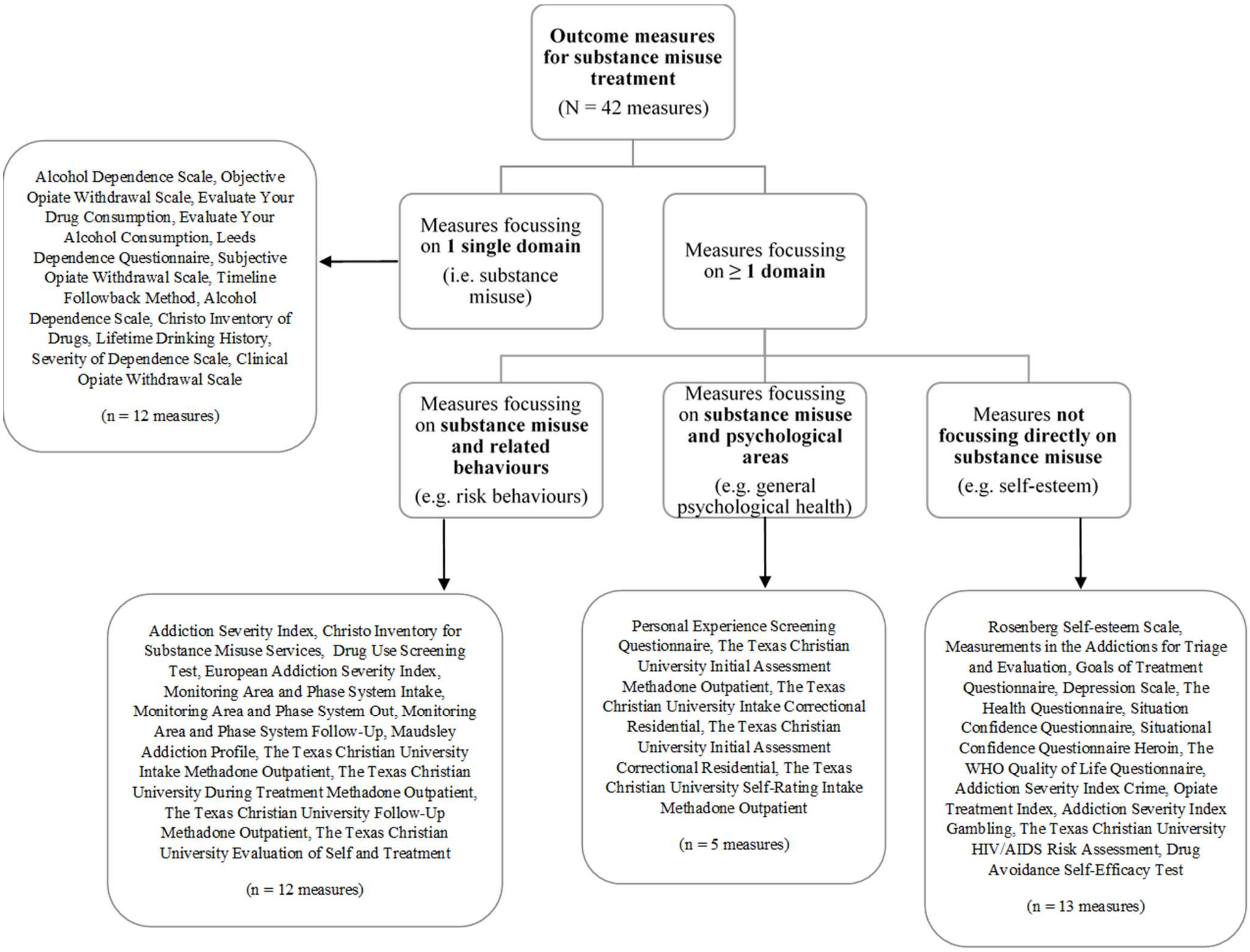


Figure 3. A similarity tree grouping the 42 outcome measures, based on their proximity in terms of domains covered.

Comparison between outcome measure domains and patient-relevant problems

The content matching between the 31 domains and the 54 domains of patient-generated problems was performed with satisfactory inter-rater agreement values (Cohen's kappa between raters ranged from .65 to 1.0). Overall, most patient-generated domains (n = 34, 63%) were represented by a small proportion (10%) of outcome measures (see Table 3). Moreover, 26% of patient-generated domains (n = 14) did not feature in any of the outcome measures. Among the unmatched patient-generated domains were topics such as 'personal development', 'understanding self', 'existence', 'outlook on life', 'moving on', guilt', 'bereavement' and 'dependence on other people'. On the other hand, nearly all 31 domains found in the outcome measures were matched, in terms of topics, to at least one patient-generated sub-theme. The exceptions were the domains: 'domestic life', 'self-care', 'daytime activities', "technology and information' and 'acculturation'. We also found that the patient-generated domains of problems frequently represented in outcome measures tend to focus on four main areas: interpersonal relationships (dimension 1); communication problems (dimension 2); addiction (dimension 3); and social problems (dimension 4) (table 4).

Table 3

Number and percentage of outcome measures featuring the 54 patient-generated sub-theme of problems

Patient-generated sub-themes	No. instruments with sub-theme present (%)	No. instruments with sub-theme absent (%)
Addiction	28 (67)	14 (33)
Relationship difficulties partner - breaking up	15 (38)	27 (64)
Depression/Anxiety	15 (36)	27 (64)
Justice-related problems	15 (36)	27 (64)
Relationship difficulties: family - breaking up	15 (36)	27 (64)
Relationship difficulties: family - worry about another	15 (36)	27 (64)
Relationship difficulties: partner - development	15 (36)	27 (64)
Relationship difficulties: partner - worry about another	15 (36)	27 (64)
Work-related problems	15 (36)	27 (64)
Relationships-general	14 (33)	28 (67)
Relationships difficulties: family-general	13 (31)	29 (69)

Patient-generated sub-themes	No. instruments with sub-theme present (%)	No. instruments with sub-theme absent (%)
Worries about health	10 (24)	32 (76)
Concentration	9 (21)	33 (79)
Socialising	8 (19)	34 (81)
Suicidal thoughts	9 (19)	34 (81)
Coping:daily living	7 (17)	35 (83)
Money worries	7 (17)	35 (83)
Going out/travelling	6 (14)	36 (86)
Relationship difficulties: partner – general	6 (14)	36 (86)
Communication	5 (12)	37 (88)
Attemped Suicide	4 (9) *	38 (91)
Motivation	4 (9) *	38 (91)
Fears/panics	3 (7) *	39 (93)
Being happy	2 (5) *	40 (95)
Emotions – unspecified	2 (5) *	40 (95)
Housing worries	2 (5) *	40 (95)
Loneliness/being alone	2 (5) *	40 (95)
OCD	2 (5) *	40 (95)
Relationship difficulties: partner - conflict	2 (5) *	40 (95)
Sleep problems	2 (5) *	40 (95)
Studies-related problems	2 (5) *	40 (95)
Achievement	1 (2) *	41 (98)
Agression/irritability	1 (2) *	41 (98)
Eating problems	1 (2) *	41 (98)
Relationship diffculties: family – caring	1 (2) *	41 (98)
Relationship difficulties: family - conflict	1 (2) *	41 (98)
Self image/self worth	1 (2) *	41 (98)
Self-acceptance	1 (2) *	41 (98)
Sexual problems	1 (2) *	41 (98)
Victim of abuse/sexual violence	1 (2) *	41 (98)
Bereavement	0 (0) *	42 (100)
Coping: feelings	0 (0) *	42 (100)
Coping: general	0 (0) *	42 (100)
Dependence on other people	0 (0) *	42 (100)
Existence/existential	0 (0) *	42 (100)
Future	0 (0) *	42 (100)
Global	0 (0) *	42 (100)
Guilt	0 (0) *	42 (100)
Having positive Outlook	0 (0) *	42 (100)
Having time	0 (0) *	42 (100)
Moving on	0 (0) *	42 (100)
Outlook on life	0 (0) *	42 (100)
Personal development	0 (0) *	42 (100)
Understanding self/events	0 (0) *	42 (100)

Note. The values highlighted with a * represent sub-themes covered by <10% of outcome measures.

Table 4

Dimensions (of patient-generated sub-themes) covered by the outcome measures, based on the multiple correspondence analysis

	Dimensions							
	1		2		3		4	
Variables (patient-generated sub-themes)	Discrimination	Contribuition (%)	Discrimination	Contribuition (%)	Discrimination	Contribuition (%)	Discrimination	Contribuition (%)
Addiction	.00	0.04	.02	0.67	**.44**	22.04	**.16**	11.06
Communication	.00	0.00	**.59**	18.70	**.25**	12.71	**.08**	5.64
Concentration	.21	2.54	**.36**	11.40	**.25**	12.71	.02	1.71
Coping: daily living	.00	0.02	**.40**	12.61	**.18**	9.08	.00	0.07
Depression/Anxiety	**.46**	5.45	**.24**	7.59	.09	4.29	.00	0.00
Going out/travelling	.01	0.14	**.61**	19.28	**.23**	11.75	.02	1.64
Justice-related problems	**.50**	5.91	.00	0.06	.00	0.05	**.24**	16.85
Money worries	.40	4.71	.05	1.68	.00	0.10	**.10**	7.35
Relationship difficulties partner - breaking up	**.87**	10.29	.07	2.35	.01	0.61	.03	1.93
Relationship difficulties: family - breaking up	**.87**	10.29	.07	2.35	.01	0.61	.03	1.93
Relationship difficulties: family - worry about another	**.87**	10.29	.07	2.35	.01	0.61	.03	1.93
Relationship difficulties: partner – development	**.87**	10.29	.07	2.35	.01	0.61	.03	1.93
Relationship difficulties: partner – general	.27	3.18	.00	0.03	.03	1.46	.03	2.00
Relationship difficulties: partner - worry about another	**.87**	10.33	.07	2.35	.01	0.61	.03	1.93
Relationships difficulties: family-general	**.53**	6.30	.01	0.25	.00	0.15	.03	2.28
Relationships-general	**.58**	6.87	.01	0.35	.02	1.06	.00	0.21
Socialising	.11	1.28	.09	2.73	.08	4.19	**.37**	26.62
Suicidal thoughts	.19	2.22	**.40**	12.70	**.19**	9.48	**.10**	6.78
Work-related problems	**.47**	5.53	.01	0.29	**.13**	6.66	.04	2.50
Worries about health	.37	4.34	.00	0.00	.02	1.21	**.08**	5.50
Active total	8.42	100.00	3.15	100.00	1.98	100.00	1.40	100.00
Inertia / Variance	.42		.16		.10		.07	

Discussion

This study provides an overview of the measures recommended for outcome assessment in substance misuse treatment in Europe. Our goal was to identify the main characteristics of these measures; and also to explore the extent to which they covered individualised problems that bring patients to substance misuse treatment. In the next paragraphs we discuss the lessons derived from our findings.

Lesson 1: Most outcome measures evaluate similar domains and are predominantly multidimensional

In the 1960s professionals felt the need to employ methods to quantify substance use related problems that were being overlooked, which resulted in the proliferation of outcome tools (Dwyer & Fraser, 2015). Our study reveals that there is considerable duplication of the contents of outcome measures with consequent redundancy of measures in terms of topics covered. Hence, careful consideration of the domains worth measuring is required before selecting an outcome measure (Slade & Thornicroft, 2014).

Our study revealed that outcome measures used in substance misuse treatment can be clustered into two main groups. One group included unidimensional measures focussing on substance misuse. This was consistent with the study population and with the fact that most outcome studies focus solely on this topic. A second and larger group contained three types of measures covering: substance misuse and behaviours associated with this disorder (e.g. injection of drugs); substance misuse and psychological health; and domains not directly related to substance misuse (e.g. self-esteem). Psychological health was the second most commonly identified domain, featuring in nearly half the measures. Given the importance of psychological health, these findings suggest that outcome measurement currently adopts a strategy to measure patients' changes from a psychological point of view. These findings show that the “narrow” approach (Bühringer, 2012) that most outcome studies follow is not due to the lack of multidimensional tools, because they are already available. It is the paradigm underlying outcome measurement that could implement a broader approach by using more comprehensive measures. This is consistent with studies where patients in substance misuse treatment reported a need to talk about topics that go beyond their drug-related problems (Alves, Sales & Ashworth, 2016).

Lesson 2: The domains covered by outcome measures are relevant for patients

Considering that outcome measures tend to be standardised and expert-driven, we were particularly interested in exploring the extent to which they reflected the personalised problems of patients in substance misuse treatment. We found that the majority of domains (e.g. addiction, work-related problems, relationship difficulties, money worries) covered by outcome measures were relevant for patients in substance misuse treatment, because they were equivalent to domains of problems reported by patients in free-text items. This had already been highlighted by patients in a previous study, who stated that outcome measure targeting substance misuse helped them to think about the negative consequences of their addictive behaviour (Alves, Sales, & Ashworth, 2016). Moreover, the patient-generated domains covered by outcome tools tend to focus on interpersonal and/or social relationships, which are concerns reported by 20% of patients in substance misuse treatment (Alves, Sales, Ashworth, & Faísca, submitted). This reinforces that outcome measures are tackling topics of interest to this population.

Lesson 3: The outcome measures available are overlooking areas of concern to this population

Our study revealed that only 10% of outcome measures contained half or more of the patient-generated domains identified by our study. The remaining 90% of measures contained few of those domains, which means that most fail to capture the full diversity of patient-generated themes. Some patient-generated domains overlooked by outcome measures reflected specific concerns likely to be experienced by a small minority (e.g. ‘bereavement’). However, more universally experienced psychological factors or distressing events such as ‘guilt’, ‘dependence of other people’ or ‘housing problems’, which are topics of relevance to this population, were rarely included in outcome measures. None of the measures included worries about the self (e.g. ‘personal development’, ‘existence’, ‘outlook on life’, ‘having time’) even though these were frequently reported in individualised measures (Alves, Sales, Ashworth, & Faísca, submitted). Some of these topics, namely, ‘self-care’ and ‘outlook on life’, have also been identified by patients as topics to be included in the standardised measure SURE (Neale et al., 2016). This suggests that patients seeking substance misuse treatment are likely to have a greater diversity of concerns than has previously been acknowledged by experts in the process of designing outcome measures. For this reason, we suggest the use of a more open-ended approach to outcome assessment which elicits a broader range of information from patients.

Implications for outcome assessment in substance misuse treatment

We believe that our study has provided some insight into the limitations of current outcome measures and how we can improve outcome assessment by producing more informed (and less contradictory) findings about treatment outcomes. Based on our study of measures used in Europe, we recommend that international bodies identify a core-set of outcome criteria for use in treatment evaluation, facilitating the selection of outcome tools. However, it is important that both researchers/professionals and patients are engaged with this task. Although standardised outcome measures tend to cover relevant domains, they also overlook relevant information about individual distress. As Slade & Thornicroft (2014) put it, “any attempt to squeeze personal identity into predefined boxes can be justifiably criticised for its loss of meaning” (p. 120). This problem could be overcome through the use of a more patient-centred approach to outcome assessment, by using individualised measures (see Sales & Alves, 2016, for a review about these tools), which allow patients to express their personal problems. We advocate that individualised measures are used in combination with existing standardised measures, which provide population reference data. If the use of individualised measures is not feasible, a standardised PROM designed with a high level of patient input may be a suitable alternative. Although “imperfect measures are better than no measures at all” (Scheyett et al, 2013), the addition of items deemed important by patients has the potential to improve outcome assessment.

Limitations

This study is not without limitations. First, we accept that some outcome measures may have been omitted from our study, since we only searched for outcome measures included in the EMCDDA database. However, our goal was to confine our search to measures recommended by this European agency. Restriction of our search to Europe may have restricted our findings although measures have to be culturally applicable (Mann, 2012). A further limitation is that our review excluded adolescents, since the patient-generated domains used for comparison purposes were derived from an adult population, whose concerns may differ from those of younger individuals. We believe, though, that this present study adds up to an increasing body of literature showing the importance of multidimensional outcome assessment in substance misuse and the inclusion of patient perspectives. Such an approach would acknowledge the multiplicity of problems associated with substance misuse disorder, as well as taking into account the concept that recovery is an individual journey.

References

Alves, P., Sales, C., & Ashworth, M. (2016). “It is not just about the alcohol”: a focus group to explore service users’ views about outcome measurement. *Substance Abuse Treatment, Prevention, and Policy*, *11*, 1-7. doi: 10.1186/s13011-016-0070-5

Alves, P., Sales, C., Ashworth, M., & Faísca, L. “There are things I want to say but you don’t ask”: a thematic comparison between standardised and individualised outcome measures in substance misuse treatment. Manuscript submitted for publication.

Arksey, H., & O'Malley, L. (2005) Scoping studies: towards a methodological framework. *International Journal of Social Research Methodology*, *8*, 19-32. doi: 10.1080/1364557032000119616

Bühringer, G. (2012). The mountain roared and brought forth a mouse: comments on the results of an expert panel on standardisation of drug dependence treatment trial outcome variables. *Addiction*, *107*, 722-723. doi: 10.1111/j.1360-0443.2011.03689.x

Carvalho, H. (2008). Análise Multivariada de dados qualitativos. Lisboa: Edições Sílabo.

Darke, S., Ross, J., & Teesson, M. (2007). The Australian Treatment Outcome Study (ATOS): what have we learnt about treatment for heroin dependence? *Drug and Alcohol Review*, *26,* 49-54. doi: 10.1080/09595230601036986

Donovan, D., Bigelow, G., Brigham, G., Carroll, K., Cohen, A., Gardin, J., Hamilton, J., Huestis, M., Hughes, J., Lindblad, R., Marlatt, A., Preston, K., Selzer, J., Somoza, E., Wakim, P., & Wells, E. (2011). Primary outcome indices in illicit drug dependence treatment research: systematic approach to selection and measurement of drug use end-points in clinical trials. *Addiction*, *107*, 694-708. doi: 10.1111/j.1360-0443.2011.03473.x

Dwyer, R., & Fraser, S. (2015). Addiction screening and diagnostic tools: ‘Refuting’ and ‘unmasking’ claims to legitimacy. *International Journal of Drug Policy*, *26*,1189-1197. doi: 10.1016/j.drugpo.2015.08.016

Gossop, M. (2012). The clinical fallacy and treatment outcomes. *Addiction*, *103*, 89-90. doi: 10.1111/j.1360-0443.2007.02093.x

Gossop, M., Marsden, J., Stewart, D., & Kidd, T. (2003). The National Treatment Outcome Research Study (NTORS): 4-5 year follow-up results. *Addiction*, *98,* 291–303. doi: 10.1046/j.1360-0443.2003.00296

Jones, A., Donmall, M., Millar, T., Moody, A., Weston, S., Anderson, T., Gittins, M., Abeywardana, V. and D’Souza, J., (2009). The Drug Treatment Outcomes Research Study: Final outcomes report. London: Home Office.

Neale, J., Tompkins, C., Wheeler, C., Finch, E., Marsden, J., Mitcheson, L., Rose, D., Wykes, T., & Strang, J. (2015) ‘You’re all going to hate the word ‘recovery’ by the end of this”: service users’ views of measuring addiction recovery’. *Drugs: education, prevention and policy*, *22*, 26-34. doi: 10.3109/09687637.2014.947564

Neale, J., Vitoratou, S., Finch, E., Lennon, P., Mitcheson, L., Panebianco, D., Rose, D., Strang, J., Wykes, T., & Marsden, J. (2016) ‘Development and validation of ‘SURE’: A patient reported outcome measure (PROM) for recovery from drug and alcohol dependence’. *Drug and Alcohol Dependence*, *165*, 159-167. doi: 10.1016/j.drugalcdep.2016.06.006

Public Health England (2015). Adult substance misuse statistics from the National Drug Treatment Monitoring System (NDTMS). London: Public Health England.

Ruefli, T., & Rogers, S. (2004). How do drug users define their progress in harm reduction programs? Qualitative research to develop user-generated outcomes. *Harm Reduction Journal, 1*, 8-13. doi:10.1186/1477-7517-1-8

Sales, C., & Wakker, P.P. (2009). The Metric-Frequency Measure of similarity for ill-structured data sets, with an application to family therapy. *British Journal of Mathematical and Statistical Psychology, 62*, 663-682. doi: 10.1348/000711008X376070

Sales, C., Wakker, P.P., Alves, P., & Faísca, L. (2015). MF Calculator: a web-based application for analyzing similarity. *Journal of Statistical Software, 65*. doi: 10.18637/jss.v065.c02

Sales, C., & Alves, P. (2016). Patient centred assessment in Psychotherapy: A review of individualised tools. *Clinical Psychology: Science and Practice*, *23*, 265-283. doi:10.1111/cpsp.12162

Scheyett, A., DeLuca, J., & Morgan, C. (2013). Recovery in severe mental illnesses: a literature review of recovery measures. *Social Work Research*, *37,* 286-302. doi: 10.1093/swr/svt018

Thurgood, S., Crosby, H., Raistrick, D., & Tober, G. (2014). Service user, family and friends' views on the meaning of a 'good outcome' of treatment for an addiction problem. *Drugs: education, prevention and policy*, 1-9. doi: 10.3109/09687637.2014.899987

Thornicroft, G., & Salde, M. (2014). New trends in assessing the outcomes of mental health interventions. *World Psychiatry*, *13*, 118-124. doi: 10.1002/wps.20114

Tiffany, S., Friedman, L., Greenfield, S., Hasin, D., & Jackson, R. (2012). Beyond drug use: a systematic consideration of other outcomes in evaluations of treatments for substance use disorders. *Addiction*, *107*, 709-718. doi: 10.1111/j.1360-0443.2011.03581.x

GENERAL DISCUSSION

Main findings

When presenting the background for this manuscript, a question was raised that would guide the theoretical and empirical work that followed: are we missing something when we measure the outcomes of substance misuse treatment? We also questioned ourselves about how could we shift the current paradigm, towards a personalised outcome measurement approach that enables patients to contribute with topics of personal relevance.

According to what was found, the answer to our main question is that outcome measurement is, indeed, potentially missing the opportunity to capture the whole range of patient's problems. Paraphrasing an individual from our focus group, whose quote entitled one of our articles, there are things patients want to say but we (i.e. researchers, professionals) do not ask. Our proposal to shift the paradigm was the adoption of I-PROMS as a strategy to provide patients with freedom to express their personal problems. This strategy yielded encouraging findings, demonstrating that I-PROMS were well accepted by patients, allowed the identification of topics overlooked by standardised measures and permitted a quantification of patient's personal distress.

In this section we provide an in depth discussion of what we learned from our project, the implications of its findings for practice and future research and a preliminary set of recommendations for personalised measurement in substance misuse treatment. Finally, an overview of the strengths, limitations and concluding remarks of this project is presented. Figure 1 highlights the main conclusions of this work.

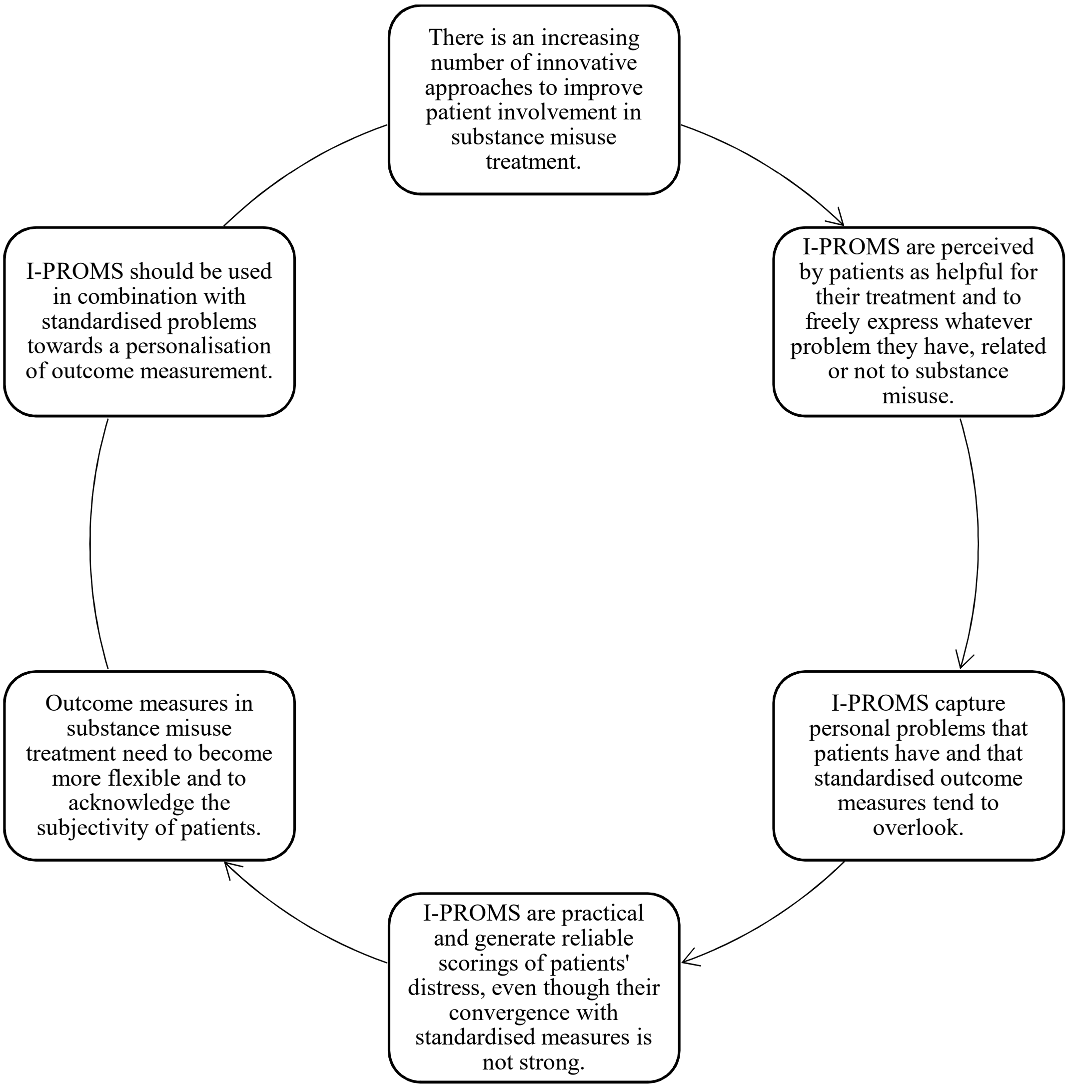


Figure 1. Summary of main findings from this project.

How was our theoretical proposal to personalise outcome measurement in substance misuse treatment received by the scientific community?

We started our thesis by providing a pragmatic answer to the call of various addiction research experts about the need to increase patient involvement in this field (Neale & Strang, 2015; Orford, 2008). Even though this research project had an empirical scope, the lack of guidelines on how to translate this recommendation into practice challenged us to present our approach to the scientific community, in a structured and visible manner. Hence, we sought not only to explain the framework that was going to be used throughout the project; but also to motivate the wider scientific community to contribute with other perspectives about this topic.

From our point of view, we succeed drawing attention to the need for a greater personalisation of outcome measurement in substance misuse treatment. International researchers responded directly, and promptly to our call, by building on our proposal with further considerations about personalised measurement. An example is the article by Trujols, Iraurgi, Battle and Cobos (2015), entitled 'Towards a genuinely user-centred evaluation of harm reduction and drug treatment programmes: a further proposal'. We conceptualised standardised measures as tools that are expert-driven and that target a more or less general population. Nevertheless, Trujols and his colleagues highlighted that standardised measures can also be developed with patient input, covering topics of relevance to a specific patient group and using methods such as participatory research (Rose, Evans, Sweeny, & Wykes, 2011). For instance, the drug-related standardised outcome measure SURE (Neale et al., 2016) is an example of a tool whose topics were selected by patients. But even under these circumstances, it is still possible that measures contain items of little or no relevance at an individual level, which is the greatest advantage of I-PROMS. Nevertheless, the reactions to our first article, and the parallel emergence of literature about patient involvement in substance misuse treatment, demonstrates how rapidly this field is evolving. It also shows an effort for the development of practical solutions to overcoming the poor engagement of patients with treatment-related tasks, in an environment of international collaboration and confluence of ideas/approaches.

Did patients provide relevant input about outcome measures and the outcome measurement process?

Approximately 30-80% of patients with substance misuse disorders experience several forms of cognitive impairment, including decreased insight and lower self-efficacy (Copersino et al., 2009). The present research did not include an evaluation of patients' cognitive skills. However, we found that patients in this population were not only able to respond to I-PROMS and the other standardised measures, but were also capable to think about the impact of these measures and what makes outcome measurement a helpful and/or hindering experience. This reinforced that, similarly to what occurred in other populations (Crawford et al., 2011; Stone & Elliott, 2011), patients with substance misuse disorders should be actively involved in treatment-related tasks, including the selection of outcome measures and the decision about whether I-PROMS are, or not, a valuable addition to outcome measurement.

As we listened to patients' first-hand experiences with our evaluation protocol, we learned that certain topics (e.g. suicidal thoughts) were too sensitive and may trigger negative emotions. The literature also shows that questionnaires characteristics such as length or question wording are likely to affect the quality of individuals' responses (Ganassali, 2008). This does not mean that I-PROMS, or any outcome measure for that matter, should exclude distressful topics. In fact, outcome measures that target psychological distress will, undoubtedly, tackle situations or symptoms that are unpleasant to reflect about. However, precisely because of this, it is important to gather patient's feedback whilst developing outcome measurement protocols. This would not only help us to improve the conditions that make outcome measurement a more appreciated experience for patients; but also raise (our) awareness and minimise the negative impact of discussing potentially critical issues.

By gathering patients' perspectives about I-PROMS, we understood that, like therapists and researchers, patients favour the use of these measures as a means of freely expressing their problems. Patients view I-PROMS as an opportunity to talk about significant aspects in their lives, without being confined to discussing issues around their substance use disorder. The following quote, which partly became the title of the focus group study, is an illustration of this: ‘it is not just about the alcohol, we feel bad about many other things in life. My sister doesn’t drink alcohol but could answer this too, because everyone has problems’. From a normalisation theory approach, an experience such as this can have a positive impact on patients’ well-being, by making them feel less stigmatised and closer to the general population (Kraynak, 2013).

From our research emerged concerns that should be addressed in future studies to ensure that I-PROMS do not become hazardous for patients. The first of them is the high level of personal exposure that I-PROMS require to be completed. Obviously, talking therapies involve information sharing about one’s personal problems in a secure and private setting. Hence, the novelty of I-PROMS is not to elicit personalised data; but to collect it in such a way that is usable beyond the clinical, one-to-one setting, namely, outcome measurement. Unlike standardised measures which allow patients to rate their level of distress in a relatively neutral manner, I-PROMS involve disclosure of intimate aspects about their lives and the lives of their significant others. Even though patients are free to choose what they want to include in I-PROMS, the dilemma about omitting or not certain information can be, in itself, a distressful experience that should be avoided. Based on this, it is paramount to further explore how comfortable patients are in exposing aspects of their private lives for outcome measurement purposes. From this point of view, it would be worth investigating to what extent should I-PROMS be completely open-ended; or to have a hybrid structure by including open and closed questions, similarly to PSYCHLOPS. We hypothesise that such hybrid measures would give patients a choice to decide which type of information (personalised vs. standardised) they wish to share.

What did we gain, in terms of qualitative information, from using I-PROMS?

Knowing that both professionals and patients acknowledge I-PROMS as a good strategy to measure treatment outcome is paramount. However, when this project was planned, we did not know whether I-PROMS generated qualitative information that was not already present in standardised measures.

As our project has shown, using standardised measures alone may not be enough to capture everything that is distressing patients. More specifically, our findings indicate that patients seeking treatment for substance misuse are likely to present a great variety of problems, ranging from psychosocial situations frequently associated with this population (e.g. justice-related problems), to more inner conflicts (e.g. being happy). This shows that substance misusers are anything but a homogenous patient group and that tools such as I-PROMS are needed to take each person's concerns on board. Hence, even though a greater attention is being paid to the personalisation of treatment offered to substance users (e.g. Marsden et al., 2014), these initiatives rely on standardised measures which, according to our project, may not be enough.

To acknowledge that patients in this group are individuals with very specific and diverse problems creates a need to widen the scope of outcome measurement, so that the whole spectrum of patients' distress may be captured. Previous literature (e.g. Donavan et al., 2012; Tiffany, Friedman, Greenfield, Hasin, & Jackson, 2012) is also in support of such a proposal. This would not only ensure that outcome measurement reflects the reality of each patient as accurately and as comprehensively as possible; but would also allow patients to report more problems than those typically addressed in substance misuse treatment (e.g. personal development). The present study limited the comparison of I-PROMS with three standardised measures only. However, I-PROMS items such as 'I am afraid to acknowledge my feelings for my ex-husband' or 'the price of my medication for epilepsy has gone up so I drink to fall asleep', reported by our sample, indicate that those concerns were unlikely to be part of any standardised measure that could have been included.

By capturing patient's individuality, I-PROMS are likely to reduce the gap between the outcome measurement process and psychological interventions. In other words, I-PROMS provide the possibility to measure treatment outcomes based on personal information that patients naturally discuss with their therapists and that was used to shape their therapeutic journey. Without I-PROMS, this patient-relevant information would undoubtedly be captured by clinicians, but could be lost for outcome measurement purposes.

There are however challenges in using I-PROMS to capture patient's individualised problems. The first is the ever changing nature of an individual clinical picture. More specifically, new problematic situations may emerge in patients' lives during the course of treatment and concerns that were relevant in the beginning of treatment may cease to exist or no longer be perceived by patients as a problem. This dynamic structure of patient's clinical situation requires a continuous revaluation to ensure that therapists make informed decisions based on patients' here-and-now problems (Bickman, Kelley, & Athay, 2012). Even though this is also true for standardised measures, reassessing individualised problems in I-PROMS may imply adjustments in the items' free-text, or even the introduction or deletion of items. There are I-PROMS, such as PQ, that acknowledge the necessity to revise individualised items over time. To date, it is unknown how the variations in individualised items impact the evaluation of outcome. This means that, at least in I-PROMS, the formulae typically used to calculate outcome (i.e. contrasting pre-post treatment item scores) may need to be adjusted, by taking into account that not all problems experienced during the intervention existed at treatment entry.

Capturing the personalised problems of patients is a clear advantage of I-PROMS. As Gough and Madill (2012) put it, psychology researchers still have a discomfort with subjectivity and prefer objective and standardised data collection methods to produce valid knowledge. It is believed that using I-PROMS is a strategy to give back subjectivity to outcome measurement. However, it is important that this growing call for the personalisation of outcome measurement do not result in an overuse of I-PROMS. To have a purely subjective approach of evaluating treatment outcomes is as undesirable as using standardised measures alone. Radicalism should be avoided, regardless of which approach is adopted, and a pluralistic perspective of outcome measurement, in particular, and psychological research, in general, is to be commended (Gough & Madill, 2012). In extreme situations, using I-PROMS as the only means of gathering information about patients may also hamper the progression of health research, by hindering the comparison between individuals, the interpretation of data and the recruitment of large sample sizes.

Were I-PROMS scorings reliable and valid to quantify patients' level of distress?

To this point, we have learned that, in substance misuse treatment, I-PROMS are valuable for patients, and that they are likely to capture qualitative information about patients that is overlooked by their standardised counterparts. However, to be adopted as outcome measures, I-PROMS need to have the capacity to quantify the patient's distress.

As in previous studies (Ashworth et al., 2005; Elliott et al., 2016), we found that both PQ and PSYCHLOPS allowed patients to score their individualised problems with a good reliability. On validity, even though convergence between PQ and standardised measures was weak, moderate correlations between PSYCHLOPS and those same standardised measures were found. Overall, these findings were satisfactory because they not only add to the body of knowledge about the psychometric properties of these measures, but they also help consolidating the status of I-PROMS as tools that serve the purpose of quantitative outcome data collection, as their standardised counterparts do.

However, one must interpret these findings with reservations for two reasons. The first is that our studies cannot be considered as isolated investigations of this topic, but as part of a continuum work towards the understanding of I-PROMS. As Cizek (2013) put it, a single study cannot make dichotomous statements about the validity (“valid/invalid”) of an instrument, and any judgements about this property should derive from accumulated evidences. From this point of view, in the current state of the art, any conclusion about the psychometrics of I-PROMS is preliminary, considering that only a limited number of studies has addressed this issue. Secondly, it is unknown whether the methodology previously used to study the psychometrics of I-PROMS (e.g. Ashworth et al., 2005; Elliott et al., 2016), which we replicated, was the most adequate. We followed the quantitative approach that tends to be adopted with standardised measures. This focussed on validity (i.e. whether an instrument measures what it is supposed to measure) and reliability (i.e. whether an instrument includes items that consistently measure the same construct) as the most important criteria to ascertain if an instrument is usable or not (Kember & Leung, 2008). But as Barkham (2016) recently pointed out, perhaps applying these psychometric standards to I-PROMs is, in a way, contrary to their ultimate purpose: to capture the uniqueness of patients.

As recommended by the literature (Mokkink et al., 2010; Wong, Ong, & Kuek, 2012), to measure I-PROMS validity, we contrasted them with gold standard outcome measures to understand if they were measuring the same construct. When this comparison involves standardised measures only, interpreting the numbers (i.e. Pearson’s correlation coefficients) is a relatively direct and objective procedure because the items are fixed and pre-determined. However, adding I-PROMS to the equation complicates this task. Considering that the contents of I-PROMS items are variable and unpredictable beforehand, it is almost impossible to anticipate the topics that will be covered, hindering the selection of relevant standardised comparators. Even when generalised measures of psychological distress are chosen, as we did in this project, we cannot guarantee that we are comparing similar constructs. This may have been the reason underlying the weak convergence between PQ and other standardised measures of psychological distress. Future research should endeavour alternative methods to evaluate the validity of I-PROMS, by integrating the scores and the contents of the items in these analysis, so that patients' individuality is not lost to psychometrics.

To calculate the reliability of I-PROMS, we analysed their internal consistency based on Cronbach's alpha scores. By definition, internal consistency "describes the extent to which all the items in a test measure the same concept or construct (...), put simply, the correlation of the test with itself" (Tavakol & Dennick, 2011, p. 53). It is generally acknowledged that alpha scores > .7 are considered as acceptable in terms of reliability (Bland & Altman, 1997). In our sample, this was observed for both PQ and PSYCHLOPS. However, because in I-PROMS each individual has a different set of items, any "between subjects" analysis with Cronbach's alpha must be interpreted with caution. To overcome this limitation, Elliott et al. (2016) added a method to estimate "within subjects" reliability, by comparing PQ scores of the same individual at different points in time, although we could not replicate this due to lack of data. Another concern that one faces when estimating the internal consistency of I-PROMS is the unpredictability of the number of items generated by individuals. It is known that an instrument's internal consistency increases with its number of items; but in I-PROMS, it is possible that individuals generate such a small number of items that either hinder the calculation of this parameter, or result in extremely low alpha scores.

Did PQ and PSYCHLOPS generate similar qualitative and quantitative data?

PQ and PSYCHLOPS are two of the most popular I-PROMS and both focus on patient' target complaints (Sales & Alves, 2016). Because of this, when integrated in the same evaluation protocol, similar results were expected in the two measures. This is not what our research demonstrated.

We found that the problems reported by patients in PQ and PSYCHLOPS tended to diverge in terms of content, meaning that patients used the two measures to express different kind of concerns. As such, we were not surprised to observe a weak correlation between the scorings of PQ and PSYCHLOPS during the convergent validity analysis. The reasons for this divergence are unknown, but there are strategies that could be adopted to explore this issue. On the one hand, one could make use of think-aloud approach (Charters, 2003) to ask patients what were the characteristics of the two measures (i.e. self-report vs. interview; unlimited number of problems vs. three blank-boxes; open-ended vs. semi-structured requesting two problems and one function; only individualised items vs. three individualised and one standardised item) that motivated them to provide dissimilar responses to PQ and PSYCHLOPS, when simultaneously administered. For instance, as one patient reported in the focus group, “we can be more honest by using a pen”, suggesting that, at least for some patients, the administration format may have impacted how they responded to each I-PROM. On the other hand, it would also be important to investigate individual expectations towards the measurement process when both measures are used. In our protocol, patients may have been inclined to generate different items in the two measures to avoid repetition. It would be useful to develop a set of instructions for I-PROMS to ensure that patients feel as free as possible to create any items of their choice, regardless of being repetitive. To achieve this, though, the wording of these instructions must be carefully selected to ensure a minimal impact on patients’ responses.

Were I-PROMS practical to implement in substance misuse treatment settings?

The fact that patients perceived I-PROMS as advantageous to their treatment, and that we had response rates higher than 90%, indicates that these measures can be implemented in substance misuse treatment. However, we identified three situations that must be considered when discussing the practicability of I-PROMS.

The first was patients' preference for outcome measures to be administered by therapists, as someone to whom they could confide their problems. It is known that therapists perceive I-PROMS as useful for their clinical work (Sales et al., 2007; Sales, Alves, Evans, & Elliott, 2014). Putting these results together, we endeavour that I-PROMS practicability could be increased if used by therapists as part of their routine therapeutic work, for instance, during initial evaluation sessions. Hence, further initiatives are required to train and support therapists and clinical staff to implement I-PROMS in their practice. Such initiatives must be delivered to emphasise the fact that I-PROMS are not only advantageous, but are also similar, in their format, to informal clinical assessments that therapists already do as part of their clinical intervention (e.g. asking patients what brought them to therapy, similar to what is performed in PQ).

The second aspect to bear in mind was that approximately half of our sample requested that self-report measures, including PSYCHLOPS, to be administered in an oral format. A quote from one patient in our sample illustrates this situation: "if we are forced to talk, it is better because we end up saying something". However, this format alteration may not only have affected patients' responses but also the purpose of the instrument in itself. Previous literature, in other populations, has been published on this topic. For instance, the study by Young, Campbell, Zakanis & Weinstein (2003) showed that measuring insight in schizophrenic patients with researcher-administered and self-report questionnaires generated different results. On the other hand, the study by Lopes and collaborators (2009) found that evaluating physical health through interviews and self-report methods produced similar data.

We did not foresee that such a large proportion of patients would ask for PSYCHLOPS to be orally administered; hence, our methodology was not planned to address this topic. However, finding that its original mode of administration was not practical to half of our sample, and that this affected patients' scores, indicates that this topic needs further consideration. This would allow us to understand how the practicability of instruments could be improved, as well as the impact on altering the original mode of administration on the quality of data collected. For instance, it is unknown whether the psychometrics of a self-report measure are preserved when orally administered.

We also verified that our sample tended to create less items in PQ and PSYCHLOPS than other samples (e.g. Elliott et al., 2016). In the case of PSYCHLOPS, where a minimum of items is required to compute its total score, this resulted in discarding nearly half of the questionnaires for the purposes of quantitative analyses. Ultimately, if I-PROMS fail to devise qualitative and quantitative information to evaluate patients' distress, their practicability as outcome measures is questioned. In other words, even if patients agree to participate in the measurement process, providing missing or unreliable responses leads to an unnecessary burden and waste of human and economic resources. For this reason, future research should focus not only on I-PROMS psychometrics, but also on the improvement of their structure, exploring what would make them more attractive to patients in substance misuse treatments.

Did outcome measurements in substance misuse treatment take the patient's subjectivity into account?

The scoping review suggested a disparity of views between patients and experts, by showing that the topics of concern elicited by patients were not always represented in expert-driven measures. This finding is supported by the literature, with authors such as Trujols and collaborators (2011) having demonstrated that patients and clinicians had a different perspective about the meaning of clinical improvement.

The results of our previous studies pointed towards the benefits of using methods that capture the patient's subjectivity, which standardised measures tend to overlook. But these observations were drawn from a comparison between two I-PROMS and three standardised measures only. Although five outcome measures may seem adequate for a protocol to be implemented in naturalistic settings, more generalised conclusions about the panorama of outcome measurement in this field could not be derived from these findings. Is there an overall tendency for outcome measures to miss aspects of relevance for patients? Was this an artefact, or a type II error (i.e. failure to detect an effect that is present), caused by the type and the limited number of measures included in our measurement protocol?

Our review showed that most outcome measures tend to conceptualise addiction as a multidisciplinary problem that encompasses several areas of patients' lives, as many authors advocate (Tiffany, Friedman, Greenfield, Hasin, & Jackson, 2012). However, the reality is that they tend to be similar in what they address, which makes us question the existence of numerous measures (> 40). To overcome this, it would be important that internationally-relevant bodies, such as the European Monitoring Centre for Drugs and Drug Addiction (Europe) or the National Institute on Drugs Abuse (United States of America) could overview the existing measures, and ideally reduce the number of those that are recommended for outcome measurement. This would not only guide researchers and clinicians selecting the most appropriate measures, but would also avoid the parallel, and unnecessary, development of tools that tackle equivalent topics.

The major finding of our review was that the domains addressed by outcome measures correspond to real concerns of this patient group, as reported in I-PROMS. This showed that outcome measures for substance misuse treatment are applicable to this population, which is a crucial aspect to consider when selecting and using outcome measures (Lambert & Hawkins, 2004). The problem is that, in line with our previous results, we did not find a single measure that matched perfectly all concerns elicited by patients. Even though these results are not exhaustive and there may still be other measures that our project overlooked, we believe that no measure is likely to capture everything that is distressing a patient. Hence, the challenge is not the inadequacy or the lack of outcome measures; but the need to have additional means to accommodate for the diversity of human beings and the subjectivity of each clinical case.

Our findings, therefore, suggest that we do not need to develop new tools, but instead to re-think the strategy that has been used for outcome measurement in this population. In 2013, the North American's Agency for Healthcare Research and Quality published a guiding document on how to develop evaluation protocols for research. It stated that the selection of outcomes "involves the consideration of multiple stakeholder viewpoints (provider, patient, payer, regulatory, industry, academic and societal) and the intended use for decision-making of resulting evidence." (p. 71). To achieve this goal, and because it is impossible to predict the nature of each individual's problems, more flexible tools should be considered. In line with our previous studies, this too points out to a more idiographic approach to evaluate the views and personal features of patients, which is lacking in substance misuse treatment (Neale & Strang, 2015). Unfortunately, supporting the use of an idiographic measurement approach, and I-PROMS in particular, is not enough. Even if these measures are endorsed by national and international health agencies, it is difficult to ensure that they are used in practice, unless it is a mandatory procedure. We expect, though, that those interested or asked to design outcome measurement protocols may explore alternatives to the traditionally used measures and are aware of their advantages and limitations, so that informed decision-making takes place.

To sum up, our scoping review was not exhaustive and was limited to the measures that are recommended in Europe. Hence, it is possible that broadening the scope of this study would have resulted in the selection of different measures, which could have had a higher (or lower) convergence with patients' concerns. It is also true that another sample, with different patients and other kind of problems, may have resulted in a different list of patient-generated domains to use as comparators. Even so, the unpredictability of human beings and their life circumstances still supports the benefits of including I-PROMS in evaluation protocols, as a guarantee that such unpredictability can be accommodated.

Recommendations for personalised outcome measurement in substance misuse treatment

Overall, we aimed to explore the use of I-PROMS in substance misuse treatment, as a strategy to personalise outcome measurement and to involve patients more actively in this process. From our findings, we were able to draw a list of preliminary recommendations to implement this measurement approach in substance misuse treatment settings, in a such a way that is practical, comfortable and meaningful for both therapists and patients.

The main recommendation that emerges from our work is that we should involve patients in all steps of the outcome measurement process, and also to request their feedback about how this process could be improved. This could be achieved through the organisation of periodic patient forums in clinical services or groups of service users that collaborate actively with addiction researchers. An example of this is the Service User Research Group, based in London, (www.kcl.ac.uk/ioppn/depts/addictions/research/SURG/index.aspx), which aims to engage patients in "[thinking about] research problems, designing studies, preparing grant applications and ultimately conducting and disseminating research". We suggest that similar groups can be created in other locations, including Portugal, where, to our knowledge, these kind of initiatives have never been promoted.

Another recommendation suggested by our findings is that in substance misuse treatment, likewise in mental health in general, it is important to develop evaluation protocols that include standardised and individualised outcome measures. According to the studies here presented, the complementary use of both kind of measures allows for the collection of standardised indicators that can be used for large-scale purposes (e.g. evaluating the success rate of a clinical service); as well as taking patients' idiosyncrasies into account. The protocol used in this project is an example of how standardised measures and I-PROMS can be combined, but other measures can be selected according to the needs and characteristics of each sample. The list of patient-generated domains that emerged from our thematic analysis (third article) together with the review of outcome measures presented in the scoping review (fifth article), can be useful resources to help clinicians and researchers selecting the measures that best reflect the problems of patients in this population. The review of Sales & Alves (2016) provides a full list of I-PROMS available, which can also guide those interested in using individualised measures.

Moreover, it is preferable to adopt outcome measures that are flexible in their mode of administration, that can either be used as oral interviews or written self-report measures. Our studies revealed that both formats were welcomed by patients; however, we also found that the mode of administration is likely to influence patients' qualitative and quantitative responses. It is unknown why and how the administration format influences patients' responses (e.g. does written-formats offer more privacy? Are interviews a more interactive and humanised process?). Before future studies shed light to these questions, we propose that patients are asked about their preferred questionnaire format, before evaluation takes place, to ensure that we provide them with a setting adjusted to their personal needs. This is particularly important in pre-treatment evaluations, where patients tend to be anxious and less able to focus in the completion of questionnaires.

We also suggest that outcome measurement processes are conducted by clinicians or any member of the clinical staff who will take part in the patient's therapeutic journey. As we listened to patients in our focus group, we learned that, at least in this sample, they tended to prefer having questionnaires administered by their therapists. The extent to which this might affect patients' responses is uncertain, since there is a risk of obtaining socially desirable responses (Börger, 2013). However, as patients and therapists actively collaborate in these kind of tasks, it is likely that their therapeutic alliance will increase (Flückiger et al., 2012). As such, when looking at this from a cost-benefit approach, we suggest that therapists may still be the best choice in terms of outcome measurement delivery.

It is recommended that future studies explore to what extent I-PROMS are sensitive to change in this population, with pre-post outcome studies, and also the concerns of patients that emerge, or fade, as soon as they enter the treatment system. This is important because it is unknown which kind of data would result from subsequent applications of I-PROMS in this patient group. Most patients reported addiction as their main problem; but it is possible that the nature, and also the quantity, of patients' problems vary throughout treatment. A recent review has stated that patients' level of insight and motivation for treatment are poorly documented in the literature (Linn-Walton & Maschi, 2015). Nevertheless, it is likely that these change whilst patients progress in treatment, consequently affecting their responses to I-PROMS and how they perceive their clinical situation.

Given the vast number of outcome measures available for substance misuse treatment, we advocate that national and international policy makers and health managers may work towards a greater harmonisation of outcome evaluation practices. This would involve developing clear guidance on which topics should be tackled in substance misuse treatment outcome measurement, and the instruments that best fit that purpose, based on the literature. It is also important to develop initiatives to encourage therapists and researchers to personalise outcome measurement as much as possible (for instance, through the use of I-PROMS), ideally promoted by health policy makers to ensure its success.

Finally, it is imperative that physical/virtual facilities and secure storage methods are developed to ensure data protection and patient confidentiality of those completing I-PROMS. When patients respond to I-PROMS, it is likely that identifiable data will be shared, such as names, locations or dates. This is particularly relevant in a patient group such as substance misusers, who may be involved with illegal activities e.g. theft or drug trafficking. Moreover, the rapid advance of information technologies allowed for the development of systems to collect and/or store patient data in digital formats, from computer software to mobile applications, increasing the cost-effectiveness and feasibility of outcome measurement (Locklear et al., n.d., p. 10). Examples of such systems have been created for generalist mental health settings, e.g. Contextualised Feedback System (Bickman, Kelley, & Athay, 2012), as well as specific populations, e.g. Electronic Patient Reported Outcomes for Cancer Survivors (Ashley et al., 2011). Although helpful, the use of these electronic tools posits additional challenges in encrypting data, de-identifying information and protecting any patient-identifiable data with firewalls or any equivalent data security methods (Wilcox et al., 2012).

Access to personalised information provided in I-PROMS should also be given careful consideration. As Smith and Street (2012) pointed out, outcome measurement data can be used by individual clinicians, but also by teams, organisations and entire health systems to monitor the quality of health care provision. When such large-scale investigations are at stake, it is crucial to preserve the patient's identity, ensuring that data is not used for ill purposes and to interfere with individuals' personal freedom, welfare and/or socioeconomic situation.

Strengths and limitations

Combining all of our studies, we have grounds to suggest that I-PROMS can be a viable strategy to collect individualised testimonies of patients in substance misuse treatment, allowing a personalisation of outcome measurement.

Our project was innovative and ground breaking in several ways. To our knowledge, this was the first ever application of I-PROMS in substance misuse treatment. This project was, therefore, a step further from previous approaches that developed evaluation protocols with input from patients, or advocated personalised treatment, but did not collect information at an individual level (Marsden et al., 2014; Neale at al., 2016). From this perspective, we have also provided a pragmatic solution to the challenge highlighted by addiction researchers that outcome measurement in substance misuse treatment should include qualitative, personalised information about patients (Orford, 2008; Neale & Strang, 2008).

We listened to the voices of a population that is often misheard and stigmatised and asked them to contribute with their opinion about outcome measures, which is something that tends to be decided in a top-down philosophy. To take a deeper step in this direction, we opted to conduct our focus group with female patients with alcohol problems in a rural setting, a sub-population of substance misusers who tends to be even more neglected in this field (Olszewski, Giraudon, Hedrich, & Montanari, 2009).

Even though the combination of qualitative and quantitative data is still under debate, mixed-methods designs are being increasingly adopted in healthcare (Östlund, Kidd, Wengström, & Rowa-Dewar, 2009). In line with this, this project followed a mixed-methods approach, by analysing qualitative and quantitative information generated by the same patients, in I-PROMS, and reflecting about the relationship between these two types of information.

Another strength of our project was the contrast of the qualitative and quantitative information derived from two different I-PROMS. There were no reports of such comparison in the literature, and the differences that we found between PQ and PSYCHLOPS suggest that this topic deserves further exploration.

This work has several limitations that must be highlighted as well, the first being the absence of post-treatment data. Such data would have allowed for an estimation of further PQ and PSYCHLOPS psychometric parameters, such as sensitivity to change and consistency of results over time (time-series analysis). Although the collection of post-treatment data was planned, the characteristics of the sample prevented it from taking place, and only a very limited number of patients were traceable and completed the second evaluation (5 out of 93 patients). Reasons for missing the second evaluation were patients dropping out of treatment and being referred to inpatient therapeutic services in remote regions of the country. A larger period assigned to data collection, as well as a larger sample, would have increased the likelihood of collecting a bigger sample of post-treatment evaluations. In the context of this project, the lack of time, funding and human resources impaired those possibilities.

The findings were based in items generated by patients in I-PROMs. These items corresponded to sentences elicited in patients' own words. However, the quality of these items was not explored and it is possible that certain problems were more clearly explained and better formed than others. For instance, problems such as 'my alcoholism' were less informative than 'I cannot stop drinking', although both refer to addiction problems. This may have affected the results of the thematic analysis, by hindering the judge's task of categorising the underlying theme of each item. To ensure that this limitation is overcome in the future, the quality of the items should be evaluated, using a validated and reliable procedure.

In our naturalistic study, only three standardised measures were contrasted with I-PROMs. Our findings supported the idea that these standardised missed topics of importance to patients. We hypothesize that if other measures, or a larger number of measures, had been used, different results could have been achieved. Our biggest concern is that we did not include the measure SURE (Neale et al., 2016) in our protocol. This measure was developed with input from patients and, for that reason, it would have been important to contrast it with I-PROMS. However, when this measure was released (2016), our data had already been collected. Despite these limitations, there was an effort to include measures that addressed topics supported by relevant literature; and also to keep the number of measures in the protocol to a minimum, to ensure feasibility of the protocol. Also, even if different measures would have produced different findings, we believe that we would have reached similar conclusions. Our aim was to illustrate how standardised measures have a limited capacity to capture the individuality of patients, and to our knowledge, it is unlikely that any existing standardised measure included every aspect of a patient’s life that causes him/her with distress.

Another limitation refers to the number of clinical services and the sample of patients that participated in our project. With only four participating research sites, and a sample of 93 patients, the generalisability of our findings is restricted. This is particularly problematic in our qualitative study, which is based in a single focus group, with a very specific population (women with alcohol problems). Nevertheless, this inpatient service was the only setting where gathering a group of patients available for approximately three hours, at the same day/time, was possible. It is expected that future studies can contribute with further data about the use of I-PROMs in mental health in general, and in substance misuse treatment, in particular, so that more evidence on their advantages and drawbacks can be accumulated. Figure 2 summarises the strengths and limitations of this project.

Strengths/Innovations

- Using I-PROMS in substance misuse treatment
- Gathering the perspectives of stigmatised and devalued patients
- Using a bottom-up approach (collaborating with patients) to reflect about outcome measures
- Following a mixed-methods approach
- Proposing a pragmatic response to the lack of patient involvement with treatment
- Comparing two different I-PROMS
- Reviewing a wide range of outcome measures recommended for substance misuse treatment

Limitations

- Lack of post-treatment evaluations
- Quality of I-PROMS items was not evaluated
- Limited number (n = 3) of standardised measures used for comparison purposes with I-PROMS
- Lack of generalisability due to small number of services recruited (n = 4) for data collection
- Small sample size (N = 10) used in the qualitative study

Figure 2. Summary of strengths and limitations of this project.

Concluding remarks

To sum up, this project showed that patients in substance misuse treatment are able to contribute with valuable hints about how outcome measurement can be conducted in this field. It has revealed that using I-PROMS is a practical method to generate important and personalised information about patient's concerns that traditional, standardised outcome measures may overlook. Moreover, I-PROMS were able to produce satisfactory quantitative estimates of patient's level of distress. Our project has also suggested that patients perceive I-PROMS as measures that enable them to talk freely about their problems, including those that were not directly related to substance misuse. When considering a wider range of standardised measures, we found further evidence that measures with pre-set items driven by experts do not always reflect the problems that patients in this population experience. This work has successfully demonstrated that patients can be (more) actively involved in outcome measurement, by contributing with data about their own clinical status through the use of I-PROMS. As a methodology that allows for a personalisation of outcome measurement, I-PROMS are a potential strategy to help therapists delivering a more patient-centred healthcare to those with substance misuse problems, as advocated by scientists and health policy makers.

References

Ashley, L., Jones, H., Thomas, J., Forman, D., Newsham, A., Morris, E., Johnson, O., Velikova, G., & Wright, P. (2011). Integrating cancer survivors' experiences into UK cancer registries: design and development of the ePOCS system (electronic Patient-reported Outcomes from Cancer Survivors). *British Journal of Cancer*, *105*, 74-81. doi: 10.1038/bjc.2011.424

Ashworth, M., Robinson, S., Godfrey, E., Parmentier, H., Shepherd, M., Christey, J., Wright, K., & Matthews, V. (2005). The experiences of therapists using a new client-centred psychometric instrument, PSYCHLOPS (Psychological Outcome Profiles). *Counselling and Psychotherapy Research*, *5*, 27-42. doi: 10.1080/14733140512331343886

Barkham, M. (2016). Patient-centered assessment in psychotherapy: toward a greater bandwidth of evidence. *Clinical Psychology: Science and Practice*, *23*, 284-287. doi: doi:10.1111/cpsp.12163

Bickman, B., Kelley, S., & Athay, M. (2012). The technology of measurement feedback systems. *Couple Family Psychology*, *1*, 274-284. doi:10.1037/a0031022

Bland, J., & Altman, D. (1997). Cronbach’s alpha. *BMJ*, *314*, 572.

Börger, T. (2012). Keeping up appearances: motivations for socially desirable responding in contingent valuation interviews. *Ecological Economics*, *87*, 155-165. doi: 10.1016/j.ecolecon.2012.12.019

Charters, E. (2003). The use of think-aloud methods in qualitative research. *Brock Education, 12,* 68-82.

Cizek, G. (2012). Defining and distinguishing validity: interpretations of score meaning and justifications of test use. *Psychological Methods*, *17*, 31-43. doi: 10.1037/a0026975

Copersino, M., Fals-Stewart, W., Fitzmaurice, G., Schretlen, D., Sokoloff, J., & Weiss, R. (2009). Rapid Cognitive Screening of Patients with Substance Use Disorders. *Experimental and Clinical Psychopharmacology*, *17*, 337-344. doi:10.1037/a0017260

Crawford, M., Robotham, D., Thana, L., Patterson, S., Weaver, T., & Barber, R. (2011). Selecting outcome measures in mental health: the views of service users. *Journal of Mental Health*, *20*, 336-346. doi: 10.3109/09638237.2011.577114

Donovan, D., Bigelow, G., Brigham, G., Carroll, K., Cohen, A., Gardin, J., Hamilton, J., Huestis, M., Hughes, J., Lindblad, R., Marlatt, A., Preston, K., Selzer, J., Somoza, E., Wakim, P., & Wells, E. (2011). Primary outcome indices in illicit drug dependence treatment research: systematic approach to selection and measurement of drug use end-points in clinical trials. *Addiction*, *107*, 694-708. doi: 10.1111/j.1360-0443.2011.03473.x

Elliott, R., Wagner, J., Sales, C., Rodgers, B., Alves, P. & Café, M. (2016). Psychometrics of the Personal Questionnaire: a client-generated outcome measure. *Psychological Assessment*, *28*, 263-278. doi: 10.1037/pas0000174

Fitzpatrick, R., Davey, C., Buxton, M. J., & Jones, D. R. (1998). Evaluating patient-based outcome measures for use in clinical trials. *Health Technology Assessment*, *2*, 1-86. doi: 10.3310/hta2140

Flückiger, C., Del Re, A., Wampold, B., Znoj, H., Caspar, F., & Jörg, U. (2012). Valuing clients' perspective and the effects on the therapeutic alliance: a randomized controlled study of an adjunctive instruction. *Journal of Counselling Psychology*, *59*, 18-26. doi: 10.1037/a0023648

Ganassali, S. (2008). The influence of the design of web survey questionnaires on the quality of responses. *Survey Research Methods, 2,* 21-32. doi: 10.18148/srm/2008.v2i1.598

Gough, B., & Madill, A. (2012). Subjectivity in psychological science: from problem to prospect. *Psychological Methods*, *17*, 374-384. doi: 10.1037/a0029313

Kember, D., & Leung, D. (2008). Establishing the validity and reliability of course evaluation questionnaires. *Assessment & Evaluation in Higher Education, 33,* 341-353. doi: 10.1080/02602930701563070

Kraynak, J. (2013, December 16). Normalize and Normative. *Psych Central*. Retrieved from http://blogs.psychcentral.com/bipolar/2013/09/normative-normalize/

Lambert, M., & Hawkins, E. (2004). Measuring outcome in professional practice: considerations in selecting and using brief outcome instruments. *Professional Psychology: Research and Practice*, *35*, 492-499. doi: 10.1037/0735-7028.35.5.492

Linn-Walton, R., & Maschi, T. (2015). Insight, motivation and outcome in drug treatment for offenders: a review of the recent literature. *Journal of Addiction Research and Therapy*, *6*, 1-8. doi: 10.4172/2155-6105.1000210

Locklear, T., Miriovsky, B., Willig, J., Staman, K., Bhavsar, N., Weinfurt, K., & Abernethy, A. (2013, December 16). Strategies for overcoming barriers to the implementation of Patient Reported Outcomes Measures. *NIH Health Care Systems Research Collaboratory Patient Reported Outcomes Core*. Retrieved from https://www.nihcollaboratory.org/Products/Strategies-for-Overcoming-Barriers-to-PROs.pdf

Lopes, A., Furtado, R., Solva, C., Yi, L., Malfatti, C., & Araújo, S. (2009). Comparison of self-report and interview administration methods based on the Brazilian versions of the western Ontario rotator cuff index and disabilities of the arm, shoulder and hand questionnaire in patients with rotator cuff disorders. *Clinics, 64*, 121-125. doi: 10.1590/S1807-59322009000200009

Marsden, J., Eastwood, B., Ali, R., Burkinshaw, P., Chohan, G., Copello, A., Burn, D., Kelleher, M., Mitcheson, L., Taylor, S., Wilson, N., Whiteley, C., & Day, E. (2014). Development of the Addictions Dimensions for Assessment and Personalised Treatment (ADAPT). *Drug and Alcohol Dependence*, *139*, 121-131. doi: 10.1016/j.drugalcdep.2014.03.018

Mokkink, L., Terwee, C., Patrick, D., Alonso, J., Stratford, P., Knol, D., Bouter, L., & de Vet, H. (2010). The COSMIN study reached international consensus on taxonomy, terminology, and definitions of measurement properties for health-related patient-reported outcomes. *Journal of Clinical Epidemiology*, *63*, 737-745. doi: 10.1016/j.jclinepi.2010.02.006

Neale, J., & Strang, J. (2015). Blending qualitative and quantitative research methods to optimize patient reported outcome measures (PROMs). *Addiction*, *10*, 1215-1216. doi: 10.1111/add.12896

Neale, J., Vitoratou, S., Finch, E., Lennon, P., Mitcheson, L., Panebianco, D., Rose, D., Strang, J., Wykes, T., & Marsden, J. (2016). Development and validation of SURE: a patient reported outcome measure (PROM) for recovery from drug and alcohol dependence. *Drug and Alcohol Dependence*, *165*, 159-167. doi: 10.1016/j.drugalcdep.2016.06.00

Olszewski, D., Giraudon, I., Hedrich, D., & Montanari, L. (2009). *Women's voices: experiences and perceptions of women who face drug-related problems in Europe.* Lisbon: EMCDDA.

Östlund, U., Kidd, L., Wengström, Y., & Rowa-Dewar, N. (2011). Combining qualitative and quantitative research within mixed method research designs: a methodological review. *International Journal of Nursing Studies*, *48*, 369-383. doi: 10.1016/j.ijnurstu.2010.10.005

Orford, J. (2008). Asking the right questions in the right way: the need for a shift in research on psychological. *Addiction, 103*, 875-885. doi: 10.1111/j.1360-0443.2007.02092.x

Rose, D., Evans, J., Sweeney, A., & Wykes, T. (2011). A model for developing outcome measures from the perspectives of mental health service users. *International Review of Psychiatry*, *23*, 41-46. doi: 10.3109/09540261.2010.545990

Sales, C., Goncalves, S., Fragoeiro, A., Noronha, S., & Elliott, R. (2007). Psychotherapists' openness to routine naturalistic idiographic research. *Mental Health and Learning Disabilities Research and Practice*, *4*, 145-161. doi:10.5920/mhldrp.2007.42145

Sales, C. M. D., Alves, P. C. G., Evans, C., & Elliott, R. (2014). The Individualised Patient Progress System (IPPS): A decade of international collaborative networking. *Counselling & Psychotherapy Research*, *14*, 181-191. doi:10.1080/14733145.2014.929417

Sales, C., & Alves, P. (2016). Patient centred assessment in Psychotherapy: A review of individualised tools. *Clinical Psychology: Science and Practice*, *23*, 265-283. doi:10.1111/cpsp.12162

Smith, P., & Street. A. (2013). On the uses of routine patient-reported health outcome data. *Health Economics*, *22*, 119-131. doi: 10.1002/hec.2793

Stone, C., & Elliott, R. (2011). Clients' experience of research within a clinic setting. *Counselling Psychology Review*, *26*, 71-86.

Tavakol, M., & Dennick, R. (2011). Making sense of Cronbach's alpha. International Journal of Medical Education, 2, 53-55. doi: 10.5116/ijme.4dfb.8dfd

Tiffany, S., Friedman, L., Greenfield, S., Hasin, D., & Jackson, R. (2012). Beyond drug use: a systematic consideration of other outcomes in evaluations of treatments for substance use disorders. *Addiction*, *107*, 709-718. doi: 10.1111/j.1360-0443.2011.03581.x

Trujols, J., Siño, N, Iraurgi, I., Batlle, F., Guàrdia, J., & Pérez de los Cobos, J. (2011). Patient and clinician's ratings of improvement in methadone-maintained patients: differing perspectives? *Harm Reduction Journal*, *8*, 23-29. doi: 10.1186/1477-7517-8-23

Trujols, J., Iraurgi, I., Batlle, F., Durán-Sindreu, S., & Pérez de Los Cobos, J. (2015). Towards a genuinely user-centred evaluation of harm reduction and drug treatment programmes: a further proposal. *International Journal of Drug Policy*, *26*, 1285-1287. doi: 10.1016/j.drugpo.2015.08.012

Velentgas, P., Dreyer, N., Nourjah, P., Smith, S., & Torchia, M. (2013, December 2016). Developing a Protocol for Observational Comparative Effectiveness Research: a user's guide. *Agency for Healthcare Research and Quality (US)*. Retrieved from https://www.ncbi.nlm.nih.gov/pubmedhealth/PMH0077792/

Wilcox, A., Gallagher, K., Boden-Albala, B., & Bakker, S. (2012). Research data collection methods: from paper to tablet computers. *Medical Care*, *50*, 68-73. doi: 10.1097/MLR.0b013e318259c1e7

Wong, K., Ong, S., & Kuek, T. (2012). Constructing a survey questionnaire to collect data on service quality of business academics. *European Journal of Social Sciences*, *29*, 209-221.

Young, D., Campbell, Z., Zakzanis, K., & Weinstein, E. (2003). A comparison between an interview and a self-report method of insight assessment in chronic schizophrenia. *Schizophrenia Research*, *63*, 103-109. doi: 10.1016/S0920-9964(02)00378-X

ADDITIONAL MATERIALS

A questionnaire about you and how you are feeling – now that you are starting therapy

Question 1

a **Choose the problem that troubles you most.** *(Please write it in the box below.)*

b **How much has it affected you over the last week?** *(Please tick one box below.)*

	0	1	2	3	4	5		
Not at all affected	☐	☐	☐	☐	☐	☐	Severely affected	☐

c **How long ago were you first concerned about this problem?** *(Please tick one box below.)*

Under one month	Between one and three months	Over three months but under one year	One to five years	Over five years
☐	☐	☐	☐	☐

Question 2

a **Choose another problem that troubles you.** *(Please write it in the box below.)*

b **How much has it affected you over the last week?** *(Please tick one box below.)*

	0	1	2	3	4	5		
Not at all affected	☐	☐	☐	☐	☐	☐	Severely affected	☐

c **How long ago were you first concerned about this problem?** *(Please tick one box below.)*

Under one month	Between one and three months	Over three months but under one year	One to five years	Over five years
☐	☐	☐	☐	☐

Question 3

a **Choose one thing that is hard to do because of your problem (or problems).** *(Please write it in the box below.)*

b **How hard has it been to do this thing over the last week?** *(Please tick one box below.)*

	0	1	2	3	4	5		
Not at all hard	☐	☐	☐	☐	☐	☐	Very hard	☐

Question 4

How have you felt in yourself this last week? *(Please tick one box below.)*

	0	1	2	3	4	5		
Very good	☐	☐	☐	☐	☐	☐	Very bad	☐

Client ID	

This questionnaire is called the Psychological Outcome Profiles questionnaire (PSYCHLOPS), Pre-Therapy, Version 5.

Therapist Assessment Form – pre therapy

To be completed by the therapist and attached to the completed questionnaire.

clinic / surgery ID

client ID or initials

client age or DOB

therapist ID

client gender

referral date

assessment date

date pre-therapy PSYCHLOPS completed

date of first session (unless same as above)

How does the client describe their ethnic group?
(Please tick one of the boxes below)

Asian or Asian British
- Bangladeshi ☐
- Indian ☐
- Pakistani ☐
- Other Asian background (please specify) ☐

Black or Black British
- Caribbean ☐
- African ☐
- Other Black background (please specify) ☐

Chinese or Other ethnic groups
- Chinese ☐
- Other ethnic group (please specify) ☐

Mixed background
- White & Asian ☐
- White & Black African ☐
- White & Black Caribbean ☐
- Other Mixed background (please specify) ☐

White
- British ☐
- Irish ☐
- Other White background (please specify) ☐

client's first language:

Scoring PSYCHLOPS

- PSYCHLOPS has been designed as a mental health outcome measure. As such, the pre-therapy score is compared with subsequent scores (during therapy and post-therapy). The difference is the 'change score'.
- All of the responses in PSYCHLOPS are scored on a six point scale ranging from zero to five. The higher the value, the more severely the person is affected.
- Not every question in PSYCHLOPS is used for scoring. Only the questions relating to Problems (Questions 1b and 2b), Functioning (Question 3b) and Wellbeing (Question 4) are scored. Other questions provide useful information but do not contribute to the change score.
- The questions used for scoring are indicated with the symbol: └__┘ This symbol appears after the scoring boxes. The therapist may find it helpful to insert the score inside this symbol.
- PSYCHLOPS therefore consists of three domains (Problems, Functioning and Wellbeing) and four questions which are scored.
- The maximum PSYCHLOPS score is 20.
- The maximum score for each question is 5.
- If both Q1 (Problem 1) and Q2 (Problem 2) have been completed, the total score is: Q1b + Q2b + Q3b + Q4.
- If Q1 (Problem 1) has been completed and Q2 (Problem 2) has been omitted, the total score is: (Q1b x 2) + Q3b + Q4. In other words, the score of Q1b (Problem 1) is doubled. This ensures that the maximum PSYCHLOPS score remains 20.

Total PSYCHLOPS Pre-Therapy score: ________

Simplified Personal Questionnaire Procedure (9/99)

Robert Elliott, Carol Mack & David A. Shapiro
University of Toledo

The Personal Questionnaire (PQ) is an expanded target complaint measure which is individualized for each client. It is generated from the PQ Problem Description Form, completed by the client during the screening process. It intended to be a list of problems that the client wishes to work on in therapy, stated in the client's own words.

Materials

4″ x 6″ Index Cards
Blank PQ Form (for writing in items)
Problem Description Form (completed)

Procedure

1. Generating Items. The items generated for the PQ should be the most important in the client's view. However, an attempt should be made to include one or two problems from each of the following areas:

- Symptoms
- Mood
- Specific performance/activity (e.g., work)
- Relationships
- Self-esteem

This means that if the client does not list a problem in a particular area, the interviewer should ask the client if s/he has any difficulties in that area that s/he wants to work on in therapy. If, however, the client does not wish to have an item for this area, the researcher does not insist on it.

This part of the procedure should be thought of as a brainstorming session, generating as many potential items as possible (around 15 is preferable). If the client has difficulty coming up with 10 problems, the interviewer can use other screening measures as sources of possible problems. For example, if the client has completed the SCL-90-R, the interviewer can ask the client about items with "3" or "4" ratings.

2. Refining the PQ items. Next, the interviewer helps the client to clarify his/her items and, if necessary, to rephrase the goals into problems. If necessary, the number of items is reduced to around 10.

2a. In this part of the procedure, the interviewer begins by writing each problem onto a separate index card, revising it in the process. Refining PQ items is not a mechanical procedure, but requires discussion with the client to make sure that the PQ reflects his/her chief concerns. It takes careful, patient communication to make sure that the PQ items truly reflect the client's experience of what is problematic.

PQ items should be present problems or difficulties, and should be worded "I feel," "I am," "I can't," "My thinking," and so on. It is useful to think of the list as things the client wants to change through therapy. A good PQ item has the following characteristics:

- It reflects an area of difficulty, rather than a goal (e.g., "I am too shy" rather than "I want to be more outgoing").
- It is something that the client wants to work on in therapy.
- It refers to a specific problem; that is, general, vague problems are specified.
- It refers to a single problem; that is, items referring to multiple problems (e.g., "I'm uncomfortable around other people and have trouble talking about myself.") are divided up into multiple items.
- It is in the client's own words, not the interviewer's.
- It is not redundant with another PQ item.

2b. After the interviewer writes down the items, s/he then asks the client if anything has been left out, adding further items as needed, until the client feels that the list is complete.

2c. The interviewer next reviews the items with the client, asking the client to revise or confirm them. If the client has generated more than 10 items, the interviewer asks the client to delete or combine repetitive items. If there are still more than 10 items, the interviewer asks the client is s/he wants to drop any. The interview should not force the client to generate exactly 10 items; but try to obtain 8-12 items where possible.

3. Prioritizing the items. Next, the interviewer asks the client to sort the index cards into order, with the most important concern first, the next most important second, etc. The rank order of the item is written on the card.

4. Rating the PQ. After prioritizing, the interviewer gives the client a blank PQ form and the rank-ordered index cards, and asks the client to use the blank form to rate how much each problem has bothered him/her during the past week. These ratings become the client's initial baseline score for the PQ.

4a. Optional: Duration ratings. In addition, at this first administration of the PQ, the interviewer may want to find out how long each problem has bothered the client at roughly the same level or higher as it does now, using the Personal Questionnaire Duration Form. This can be useful for establishing a retrospective baseline for the PQ.

5. Prepare the PQ. Finally, the interviewer types or writes the PQ items onto a blank PQ form, making at least 10 copies for future use. In doing so, it is a good idea to leave 2

spaces blank for the client to add more items later, in case his/her problems shift over time.

Your initials:___________________(Client ID:____________)
Today's date:_______________

Problem Description Form: Do this one first!

1. Please describe the main problems you are having right now that led you to seek treatment.

2. If you are seeking psychotherapy, please list the specific problems or difficulties that would like assistance with. Please feel free to add to your list as you fill out other forms.

PERSONAL QUESTIONNAIRE Client ID ______________

Today's date:____________________

Instructions: Please complete before each session. Rate each of the following problems according to how much it has bothered you during the past seven days, including today.

	Not At All	Very Little	Little	Moderately	Considerably	Very Considerably	Maximum Possible
1.	1	2	3	4	5	6	7
2.	1	2	3	4	5	6	7
3.	1	2	3	4	5	6	7
4.	1	2	3	4	5	6	7
5.	1	2	3	4	5	6	7
6.	1	2	3	4	5	6	7
7.	1	2	3	4	5	6	7
8.	1	2	3	4	5	6	7
9.	1	2	3	4	5	6	7
10.	1	2	3	4	5	6	7
Additional Problems: 11.	1	2	3	4	5	6	7
12.	1	2	3	4	5	6	7

Personal Questionnaire Duration Form

Client ID____________

Today's date:

Instructions: Please rate how long each of your problems has bothered you at roughly the same level (or higher) as it does now.

	less than 1 month	1 - 5 months	6 - 11 months	1 - 2 years	3 - 5 years	6 - 10 years	more than 10 years
1.	1	2	3	4	5	6	7
2.	1	2	3	4	5	6	7
3.	1	2	3	4	5	6	7
4.	1	2	3	4	5	6	7
5.	1	2	3	4	5	6	7
6.	1	2	3	4	5	6	7
7.	1	2	3	4	5	6	7
8.	1	2	3	4	5	6	7
9.	1	2	3	4	5	6	7
10.	1	2	3	4	5	6	7
11.	1	2	3	4	5	6	7
12.	1	2	3	4	5	6	7

CLINICAL OUTCOMES in ROUTINE EVALUATION

OUTCOME MEASURE

Site ID ☐☐☐☐☐

letters only ☐☐ numbers only ☐☐☐☐☐☐☐

Client ID

Therapist ID ☐☐☐ numbers only (1) ☐☐☐ numbers only (2) ☐☐☐

Sub codes

D D ☐☐ / M M ☐☐ / Y Y Y Y ☐☐☐☐

Date form given

Age ☐☐

Male ☐

Female ☐

Stage Completed

S Screening
R Referral
A Assessment
F First Therapy Session
P Pre-therapy (unspecified)
D During Therapy
L Last therapy session
X Follow up 1
Y Follow up 2

Stage ☐

Episode ☐

IMPORTANT - PLEASE READ THIS FIRST

This form has 34 statements about how you have been OVER THE LAST WEEK. Please read each statement and think how often you felt that way last week. Then tick the box which is closest to this.

Please use a dark pen (not pencil) and tick clearly within the boxes.

Over the last week

		Not at all	Only Occasionally	Sometimes	Often	Most or all the time	OFFICE USE ONLY
1	I have felt terribly alone and isolated	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4	☐ F
2	I have felt tense, anxious or nervous	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4	☐ P
3	I have felt I have someone to turn to for support when needed	☐ 4	☐ 3	☐ 2	☐ 1	☐ 0	☐ F
4	I have felt O.K. about myself	☐ 4	☐ 3	☐ 2	☐ 1	☐ 0	☐ W
5	I have felt totally lacking in energy and enthusiasm	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4	☐ P
6	I have been physically violent to others	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4	☐ R
7	I have felt able to cope when things go wrong	☐ 4	☐ 3	☐ 2	☐ 1	☐ 0	☐ F
8	I have been troubled by aches, pains or other physical problems	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4	☐ P
9	I have thought of hurting myself	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4	☐ R
10	Talking to people has felt too much for me	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4	☐ F
11	Tension and anxiety have prevented me doing important things	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4	☐ P
12	I have been happy with the things I have done.	☐ 4	☐ 3	☐ 2	☐ 1	☐ 0	☐ F
13	I have been disturbed by unwanted thoughts and feelings	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4	☐ P
14	I have felt like crying	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4	☐ W

Please turn over

Over the last week

		Not at all	Only Occasionally	Sometimes	Often	Most or all the time	OFFICE USE ONLY
15	I have felt panic or terror	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4	☐ P
16	I made plans to end my life	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4	☐ R
17	I have felt overwhelmed by my problems	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4	☐ W
18	I have had difficulty getting to sleep or staying asleep	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4	☐ P
19	I have felt warmth or affection for someone	☐ 4	☐ 3	☐ 2	☐ 1	☐ 0	☐ F
20	My problems have been impossible to put to one side	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4	☐ P
21	I have been able to do most things I needed to	☐ 4	☐ 3	☐ 2	☐ 1	☐ 0	☐ F
22	I have threatened or intimidated another person	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4	☐ R
23	I have felt despairing or hopeless	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4	☐ P
24	I have thought it would be better if I were dead	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4	☐ R
25	I have felt criticised by other people	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4	☐ F
26	I have thought I have no friends	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4	☐ F
27	I have felt unhappy	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4	☐ P
28	Unwanted images or memories have been distressing me	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4	☐ P
29	I have been irritable when with other people	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4	☐ F
30	I have thought I am to blame for my problems and difficulties	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4	☐ P
31	I have felt optimistic about my future	☐ 4	☐ 3	☐ 2	☐ 1	☐ 0	☐ W
32	I have achieved the things I wanted to	☐ 4	☐ 3	☐ 2	☐ 1	☐ 0	☐ F
33	I have felt humiliated or shamed by other people	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4	☐ F
34	I have hurt myself physically or taken dangerous risks with my health	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4	☐ R

THANK YOU FOR YOUR TIME IN COMPLETING THIS QUESTIONNAIRE

	(W)	(P)	(F)	(R)	All items	All minus R
Total Scores	☐	☐	☐	☐ →	☐ →	☐
Mean Scores (Total score for each dimension divided by number of items completed in that dimension)	☐	☐	☐	☐	☐	☐

PATIENT HEALTH QUESTIONNAIRE-9 (PHQ-9)

Over the last 2 weeks, how often have you been bothered by any of the following problems? *(Use "✔" to indicate your answer)*	**Not at all**	**Several days**	**More than half the days**	**Nearly every day**
1. Little interest or pleasure in doing things	0	1	2	3
2. Feeling down, depressed, or hopeless	0	1	2	3
3. Trouble falling or staying asleep, or sleeping too much	0	1	2	3
4. Feeling tired or having little energy	0	1	2	3
5. Poor appetite or overeating	0	1	2	3
6. Feeling bad about yourself — or that you are a failure or have let yourself or your family down	0	1	2	3
7. Trouble concentrating on things, such as reading the newspaper or watching television	0	1	2	3
8. Moving or speaking so slowly that other people could have noticed. Or the opposite — being so fidgety or restless that you have been moving around a lot more than usual	0	1	2	3
9. Thoughts that you would be better off dead or of hurting yourself in some way	0	1	2	3

FOR OFFICE CODING __*0*__ + ______ + ______ + _____

=Total Score: ______

If you ticked any problems, how difficult have these problems made it for you to do your work, take care of things at home, or get along with other people?

Not difficult at all ☐	**Somewhat difficult** ☐	**Very difficult** ☐	**Extremely difficult** ☐

Developed by Drs. Robert L. Spitzer, Janet B.W. Williams, Kurt Kroenke and colleagues, with an educational grant from Pfizer Inc. No permission required to reproduce, translate, display or distribute.

Um questionário sobre si e sobre como se sente – agora que está a iniciar a terapia

Pergunta 1

a **Qual o problema que mais o preocupa?** *(Por favor, escreva na caixa que se segue)*

b **Quanto é que este problema o afectou ao longo da última semana?** *(Por favor, assinale uma das seguintes opções)*

	0	1	2	3	4	5	
Não afectou nada	☐	☐	☐	☐	☐	☐	**Afectou muitíssimo**

c **Quando é que se começou a preocupar com este problema?** *(Por favor, assinale uma das seguintes opções)*

Menos de 1 mês	**Entre 1 e 2 meses**	**Entre 3 meses e 1 ano**	**Entre 1 e 5 anos**	**Mais do que 5 anos**
☐	☐	☐	☐	☐

Pergunta 2

a **Indique outro problema que o preocupa.** *(Por favor, escreva na caixa que se segue)*

b **Quanto é que este problema o afectou ao longo da última semana?** *(Por favor, assinale uma das seguintes opções)*

	0	1	2	3	4	5	
Não afectou nada	☐	☐	☐	☐	☐	☐	**Afectou muitíssimo**

c **Quando é que se começou a preocupar com este problema?** *(Por favor, assinale uma das seguintes opções)*

Menos de 1 mês	**Entre 1 e 2 meses**	**Entre 3 meses e 1 ano**	**Entre 1 e 5 anos**	**Mais do que 5 anos**
☐	☐	☐	☐	☐

Pergunta 3

a **Há alguma coisa que se tenha tornado difícil de fazer devido ao seu problema (ou problemas)?** *(Por favor, escreva na caixa que se segue)*

b **Quanto foi difícil durante a última semana?** *(Por favor, assinale uma das seguintes opções)*

	0	1	2	3	4	5	
Nada difícil	☐	☐	☐	☐	☐	☐	**Extremamente difícil**

Pergunta 4

Como se tem sentido consigo mesmo durante esta semana? *(Por favor, assinale uma das seguintes opções)*

	0	1	2	3	4	5	
Muito bem	☐	☐	☐	☐	☐	☐	**Muito mal**

ID Paciente	

Psychological Outcome Profiles (PSYCHLOPS), Pré-Terapia, Versão Portuguesa 2. www.psychlops.org

Procedimento do Questionário Pessoal Simplificado PQ

Robert Elliott, Mack, & Shapiro (1999)

Adaptado por Célia Sales, Sónia Gonçalves, Daniel Sousa, Eugénia Fernandes, Isabel Silva, Jane Duarte, & Robert Elliott (2007)

O Questionário Pessoal Simplificado (PQ) é um instrumento individualizado de mudança de tipo *target complaint*. Pretende ser uma lista dos pontos que o cliente (ou cada elemento da família) deseja trabalhar em terapia, formulados pelas suas próprias palavras.

O PQ é construído durante uma entrevista individual, cujo procedimento se descreve de seguida.

MATERIAL

- ✓ Cartões de cartolina
- ✓ Folha branca
- ✓ Formulário PQ, por preencher (para escrever os itens)
- ✓ Formulário de Duração dos Problemas

PROCEDIMENTO

1. Confidencialidade

Inicialmente refere-se ao cliente que todos os dados recolhidos na entrevista serão confidenciais, ficando cingidos à equipa de investigação que os está a recolher, e à equipa terapêutica que trabalhará a partir deles, com o intuito de apoiar decisões clínicas ao longo do processo terapêutico.

2. Construir a lista dos itens

Os itens do PQ devem corresponder aos problemas mais importantes, na perspectiva do entrevistado. No entanto, deverá tentar-se a inclusão de 1 ou 2 pontos em cada uma das seguintes áreas:

* Sintomas
* Humor
* Nível de actividade geral (trabalho, etc.)
* Relações interpessoais
* Auto-estima

Se o entrevistado não incluir na sua lista pontos em alguma destas áreas específicas, o entrevistador deve perguntar se existem dificuldades em alguns desses domínios, que o cliente deseje trabalhar em terapia. Se tal não acontecer, o investigador não deve insistir na questão.

Esta fase do procedimento deve considerar-se como uma sessão de *brainstorming*, tentando gerar-se o máximo de itens possível (15 é o ideal). Este *brainstorming* pode ser iniciado com uma instrução verbal do tipo:

"Queria pedir-lhe que me falasse dos motivos que o trouxeram aqui…"

À medida que o cliente fala, o entrevistador escreve numa folha em branco frases que correspondam a queixas ou problemas.

3. Filtrar os itens

Nesta fase, pretende-se ajudar o entrevistado a clarificar os itens listados anteriormente e, se necessário, a redefinir os objectivos em Problemas. Se possível, o número de itens deverá ser reduzido para cerca de 10.

O investigador começa por escrever cada queixa num cartão, confirmando-o com o entrevistado. Redefinir os itens não é, nem deverá ser, um procedimento mecanizado, e requer que se discuta com o entrevistado para garantir que o PQ reflecte as suas principais preocupações. Exige uma comunicação cuidada e paciente, que assegure que os itens evidenciam a perspectiva do entrevistado acerca do que é relevante e pertinente para a terapia.

Um item bem estruturado deverá possuir determinadas características:

* Reflectir uma área de dificuldade ao invés de um objectivo de mudança (por exemplo "sou muito tímido" ao invés de "quero ser mais sociável")

* Ser algo que o entrevistado quer trabalhar em terapia

* Referir-se a um problema concreto, ou seja, os problemas gerais e vagos devem ser especificados

* Referir-se a um único ponto, ou seja, itens que se reportam a problemas múltiplos/vários pontos (por exemplo, "tenho medo de estar com pessoas e tenho muita dificuldade em falar sobre mim") devem ser divididos de forma a constituírem múltiplos itens

* Utilizar as palavras do entrevistado, não do investigador

* Não ser redundante em relação a qualquer outro item.

Depois de escritos os problemas, o entrevistador deve confirmar se o entrevistado não tem mais nada a acrescentar.

4. Priorizar os itens

O investigador pede ao entrevistado que organize os cartões por ordem decrescente de importância dando a seguinte instrução verbal:

"Destes problemas qual é o que lhe causa mais mal-estar?... E a seguir?... E a seguir?..."
(até que todos estejam ordenados)

O número de ordem do item deverá escrever-se no cartão.

5. Classificar o PQ

Depois de priorizar, o investigador preenche o formulário do PQ, colocando os itens pela ordem indicada de importância indicada pelo cliente. Dando o formulário preenchido ao entrevista, solicita:

"Pensando em cada problema, indique o nível de mal-estar (ou "quanto mal-estar") que cada um lhe causou na última semana"

Alternativamente, por exemplo, se o entrevistado não souber / não puder ler, o entrevistado lê em voz alta o item e pergunta o grau de mal-estar, numa escala de 1 a 7.

O investigador deverá tentar perceber se o entrevistado compreendeu o pedido. Se verificar que isto não aconteceu, deve explicá-lo de uma forma o mais claro e simples possível, assegurando que a classificação será o mais aproximada possível das preocupações do entrevistado.

5a. Opcional: Classificação de Duração

Na primeira aplicação do PQ, o investigador pode estar interessado em saber há quanto tempo cada problema tem vindo a preocupar o entrevistado da mesma forma que o preocupa no momento, ou mais. Para obter esta informação, deverá usar o Formulário de Duração PQ. Este pode ser usado para estabelecer uma *baseline* retrospectiva para o PQ.

6. Preparar o PQ

Finalmente, o investigador escreve os itens do PQ num formulário em branco, fazendo pelo menos 10 cópias para uso futuro. Ao fazer esta transcrição, é útil deixar aproximadamente 2 espaços em branco para que o cliente possa adicionar itens posteriormente, se desejar.

(Código do Cliente:______________) Data: ___ / ___ / ______

Formulário para Descrição do Problema: A preencher em primeiro lugar!

1. Por favor, descreva os **principais problemas** que o levaram a procurar ajuda.

2. Por favor, indique os **problemas específicos** que gostaria que fossem abordados na terapia.

QUESTIONÁRIO PESSOAL Data: ___ / ___ / ______ Código Cliente: _________

Instruções: Por favor, indique o grau de mal-estar que cada problema lhe causou na última semana. Muito obrigado.

	Nenhum **Mal-Estar**	Muito Pouco	Pouco	**Mal-Estar** Moderado	Grande	Muito Grande	**Mal-Estar** Total
1.	1	2	3	4	5	6	7
2.	1	2	3	4	5	6	7
3.	1	2	3	4	5	6	7
4.	1	2	3	4	5	6	7
5.	1	2	3	4	5	6	7
6.	1	2	3	4	5	6	7
7.	1	2	3	4	5	6	7
8.	1	2	3	4	5	6	7
9.	1	2	3	4	5	6	7
10.	1	2	3	4	5	6	7

QUESTIONÁRIO PESSOAL Data: ___ / ___ / ______ Código Cliente: _________

Instruções: Por favor, pense desde quando é que estes problemas lhe causam mal-estar, com a mesma intensidade que indicou no quadro anterior, ou com maior intensidade.

	Menos de 1 mês	De 1 a 5 meses	De 6 a 11 meses	De 1 a 2 anos	De 3 a 5 anos	De 6 a 10 anos	Há mais de 10 anos
1.	1	2	3	4	5	6	7
2.	1	2	3	4	5	6	7
3.	1	2	3	4	5	6	7
4.	1	2	3	4	5	6	7
5.	1	2	3	4	5	6	7
6.	1	2	3	4	5	6	7
7.	1	2	3	4	5	6	7
8.	1	2	3	4	5	6	7
9.	1	2	3	4	5	6	7
10.	1	2	3	4	5	6	7

QUESTIONÁRIO PESSOAL Data: ___ / ___ / ______ Código Cliente: _________

Instruções: Preencher antes de cada sessão. Por favor, indique o grau de mal-estar que cada problema lhe tem causado desde a última consulta. Caso existam novos problemas, por favor acrescente-os e indique o grau de mal-estar. Se algum dos problemas já não fizer sentido, por favor risque-o na lista. Muito obrigado.

	Nenhum **Mal-Estar**	Muito Pouco	Pouco	**Mal-Estar** Moderado	Grande	Muito Grande	**Mal-Estar** Total
1.	1	2	3	4	5	6	7
2.	1	2	3	4	5	6	7
3.	1	2	3	4	5	6	7
4.	1	2	3	4	5	6	7
5.	1	2	3	4	5	6	7
6.	1	2	3	4	5	6	7
7.	1	2	3	4	5	6	7
8.	1	2	3	4	5	6	7
9.	1	2	3	4	5	6	7
10.	1	2	3	4	5	6	7

CORE-OM

Identif. Serviço: ☐☐☐☐☐

Identif. Caso: ☐☐☐☐☐☐☐☐☐

Identif. Terapeuta ☐☐☐ ☐☐☐ ☐☐☐

Data de preenchimento ☐☐ ☐☐ ☐☐☐☐
D D M A A A A

Idade: ☐☐ **Género: M** ☐
F ☐

Fase de preenchimento
T Triagem
E Encaminhamento
A Avaliação pré-tratamento
P Pré-primeira sessão
1 Pré-terapia, não especificado
D Durante Terapia
U Última sessão
X Follow up 1
Y Follow up 2

Fase ☐

Episódio ☐

IMPORTANTE – LEIA ANTES DE RESPONDER
Este questionário tem 34 afirmações sobre como se sentiu durante a última semana. Por favor, leia cada afirmação e pense quantas vezes se sentiu assim. Depois, marque a resposta que mais se aproxima da maneira como se sentiu.

Durante a última semana...

		Nunca	Raramente	Às vezes	Muitas vezes	Sempre, ou quase sempre	USO INTERNO, NÃO PREENCHER
1	Tenho-me sentido terrivelmente sozinho/a e isolado/a	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4	☐ F
2	Tenho-me sentido tenso/a, ansioso/a ou nervoso/a	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4	☐ P
3	Senti que tenho alguém a quem posso pedir ajuda, se precisar	☐ 4	☐ 3	☐ 2	☐ 1	☐ 0	☐ F
4	Tenho-me sentido bem comigo próprio/a	☐ 4	☐ 3	☐ 2	☐ 1	☐ 0	☐ W
5	Senti-me totalmente sem energia ou entusiasmo	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4	☐ P
6	Fui violento/a fisicamente com outras pessoas	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4	☐ R
7	Tenho sentido que sou capaz de lidar com as coisas que corremmal	☐ 4	☐ 3	☐ 2	☐ 1	☐ 0	☐ F
8	Tenho-me sentido incomodado/a com dores, mal-estar ou outros problemas físicos	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4	☐ P
9	Pensei em fazer mal a mim próprio/a	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4	☐ R
10	Tem-me custado muito falar com as outras pessoas	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4	☐ F
11	A tensão e a ansiedade não me têm deixado fazer coisas importantes	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4	☐ P
12	Senti-me bem com as coisas que consegui fazer	☐ 4	☐ 3	☐ 2	☐ 1	☐ 0	☐ F
13	Tenho tido pensamentos e sentimentos que não quero ter e que me perturbam	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4	☐ P
14	Tenho sentido vontade de chorar	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4	☐ W

Vire a página, por favor

Durante a última semana…

		Nunca	Raramente	Às vezes	Muitas vezes	Sempre, ou quase sempre	USO INTERNO, NÃO PREENCHER	
15	**Senti pânico ou terror**	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4	☐	P
16	**Fiz planos para acabar com a minha vida**	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4	☐	R
17	**Senti que os meus problemas são demais para mim**	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4	☐	W
18	**Tenho tido dificuldade em adormecer ou em dormir toda a noite**	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4	☐	P
19	**Senti que tenho pessoas de quem gosto**	☐ 4	☐ 3	☐ 2	☐ 1	☐ 0	☐	F
20	**Não consegui pôr os meus problemas de lado**	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4	☐	P
21	**Tenho sido capaz de fazer a maior parte das coisas que preciso**	☐ 4	☐ 3	☐ 2	☐ 1	☐ 0	☐	F
22	**Ameacei ou fiz alguém sentir medo**	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4	☐	R
23	**Senti-me desesperado/a ou sem saída**	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4	☐	P
24	**Pensei que era melhor se eu estivesse morto/a**	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4	☐	R
25	**Tenho-me sentido criticado/a por outras pessoas**	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4	☐	F
26	**Senti que não tinha amigos**	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4	☐	F
27	**Tenho-me sentido triste**	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4	☐	P
28	**Tenho-me sentido perturbado/a por imagens ou recordações que não quero ter**	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4	☐	P
29	**Tenho-me sentido mais facilmente irritável quando estou com outras pessoas**	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4	☐	F
30	**Tenho-me sentido culpado/a pelos meus problemas**	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4	☐	P
31	**Tenho-me sentido optimista em relação ao meu futuro**	☐ 4	☐ 3	☐ 2	☐ 1	☐ 0	☐	W
32	**Tenho conseguido as coisas que queria**	☐ 4	☐ 3	☐ 2	☐ 1	☐ 0	☐	F
33	**Senti-me humilhado/a ou envergonhado/a por outras pessoas**	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4	☐	F
34	**Fiz mal a mim próprio/a fisicamente, ou pus a minha saúde gravemente em risco**	☐ 0	☐ 1	☐ 2	☐ 3	☐ 4	☐	R

OBRIGADO PELA SUA COLABORAÇÃO

TOTAIS	☐	☐	☐	☐ →	☐ →	☐
RESULTADOS MÉDIOS (total de cada dimensão a dividir pelo número de itens respondidos nessa dimensão)	☐	☐	☐	☐	☐	☐
	(W)	(P)	(F)	(R)	Todos os itens	Todos menos R

QUESTIONÁRIO SOBRE A SAÚDE DO PACIENTE- 9 (PHQ-9)

Durante os últimos 14 dias, em quantos foi afectado/a por algum dos seguintes problemas? *(Utilize"✔" para indicar a sua resposta)*	**Nunca**	**Em vários dias**	**Em mais de metade do número de dias**	**Em quase todos os dias**
1. Tive pouco interesse ou prazer em fazer coisas	0	1	2	3
2. Senti desânimo, desalento ou falta de esperança	0	1	2	3
3. Tive dificuldade em adormecer ou em dormir sem interrupções, ou dormi demais	0	1	2	3
4. Senti cansaço ou falta de energia	0	1	2	3
5. Tive falta ou excesso de apetite	0	1	2	3
6. Senti que não gosto de mim próprio/a — ou que sou um(a) falhado/a ou me desiludi a mim próprio/a ou à minha família	0	1	2	3
7. Tive dificuldade em concentrar-me nas coisas, como ao ler o jornal ou ver televisão	0	1	2	3
8. Movimentei-me ou falei tão lentamente que outras pessoas poderão ter notado. Ou o oposto: estive agitado/a a ponto de andar de um lado para o outro muito mais do que é habitual	0	1	2	3
9. Pensei que seria melhor estar morto/a, ou em magoar-me a mim próprio/a de alguma forma	0	1	2	3

FOR OFFICE CODING ___*0*___ + _______ + _______ + _______

=Total Score: _______

Se indicou alguns problemas, até que ponto é que eles dificultaram o seu trabalho, o cuidar da casa ou o lidar com outras pessoas?

Não dificultaram	**Dificultaram um pouco**	**Dificultaram muito**	**Dificultaram extremamente**
☐	☐	☐	☐

Desenvolvido por Robert L. Spitzer, Janet B.W. Williams, Kurt Kroenke e colegas, com uma bolsa de estudos da Pfizer Inc.

Treatment Outcomes Profile

ID Paciente ______ Data de Nascimento (dd/mm/aaaa) ___ / ___ / ___ Terapeuta ______

Data preenchimento TOP (dd/mm/aaaa) ___ / ___ / ___

Sexo: M ☐ F ☐

Fase do tratamento: Pré-tratamento ☐ Durante ☐ Pós-tratamento ☐ Follow-up ☐

Secção 1: Uso de substâncias (Por favor, escreva NR em caso de não resposta.)

Registe a quantidade média e o número de dias em que consumiu cada substância, ao longo das últimas 4 semanas

	Média		Semana 4		Semana 3		Semana 2		Semana 1		Total	
a Álcool		g/dia		0-7		0-7		0-7		0-7		0-28
b Opióides		g/dia		0-7		0-7		0-7		0-7		0-28
c Crack		g/dia		0-7		0-7		0-7		0-7		0-28
d Cocaína		g/dia		0-7		0-7		0-7		0-7		0-28
e Anfetaminas		g/dia		0-7		0-7		0-7		0-7		0-28
f Canabis		charro/dia		0-7		0-7		0-7		0-7		0-28
g Outra substância?		g/dia		0-7		0-7		0-7		0-7		0-28

Nome......................................

Secção 2: Comportamentos de risco com drogas injectáveis (Por favor, escreva NR em caso de não resposta.)

Registe o número de dias em que injectou drogas sem prescrição médica, ao longo das últimas 4 semanas (se a resposta for não escreva zero e N e siga para a secção 3)

	Semana 4		Semana 3		Semana 2		Semana 1		Total	
a Injectou		0-7		0-7		0-7		0-7		0-28

b Injectou com uma seringa ou agulha usada por outra pessoa?	Sim ☐	Não ☐		Escreva S se houver algum sim; se não, escreva N
c Injectou com uma colher, água ou filtro usado por outra pessoa?	Sim ☐	Não ☐		

Secção 3: Comportamentos criminais (Por favor, escreva NR em caso de não resposta.)

Registe o número de dias em que participou em roubos de lojas, tráfico de drogas ou outro tipo de crimes, ao longo das últimas 4 semanas

	Semana 4		Semana 3		Semana 2		Semana 1		Total	
a Roubos de lojas		0-7		0-7		0-7		0-7		0-28
b Tráfico de drogas		0-7		0-7		0-7		0-7		0-28

c Assalto a / ou roubo de carros	Sim ☐	Não ☐		Escreva S se houver algum sim; se não, escreva N
d Outros tipos de roubos a propriedades ou arrombamento de casas	Sim ☐	Não ☐		
e Fraude, falsificação ou movimentação de mercadorias roubadas	Sim ☐	Não ☐		
f Agressões físicas ou violência	Sim ☐	Não ☐		Escreva S ou N

Secção 4: Funcionamento social e de saúde (Por favor, escreva NR em caso de não resposta.)

a Avaliação do paciente sobre o seu estado psicológico (ansiedade, depressão ou problemas emocionais)

Mau 0 1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20 Bom ______ 0-20

Registe o número de dias de trabalho, ou escola, ao longo das últimas 4 semanas

	Semana 4		Semana 3		Semana 2		Semana 1		Total	
b Dias de trabalho remunerado		0-7		0-7		0-7		0-7		0-28
c Dias de comparência às aulas		0-7		0-7		0-7		0-7		0-28

d Avaliação do paciente sobre a sua saúde física (grau de incómodo causado por sintomas físicos e doença)

Mau 0 1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20 Bom ______ 0-20

Situação de alojamento ao longo das últimas 4 semanas

e Problemas habitacionais graves	Sim ☐	Não ☐		Escreva S ou N
f Em risco de despejo	Sim ☐	Não ☐		Escreva S ou N

g Avaliação do paciente sobre a sua qualidade de vida geral (ex. ser capaz de aproveitar a vida, bom relacionamento com família e parceiro)

Má 0 1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20 Boa ______ 0-20

TOP PT v1.1 Março 2013