Primary Care Mental Health 2007;4:00–00

International research

In their own words: a narrative-based classification of clients' problems on an idiographic outcome measure for talking therapy in primary care

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ABSTRACT

The perspective of users has become a crucial component of healthcare planning, delivery and evaluation but, within mental healthcare, clients' views of their problem, in their own words, rarely form the basis for measuring the outcome of talking therapy. A new outcome measure, 'PSYCHLOPS' (Psychological Outcome Profiles), invites the client to write down 'the problem that troubles you most', 'another problem' and to 'choose one thing that is hard to do because of your problem'. Responses to these three items enabled us to explore how clients conceptualise their most troubling problem and the consequences of this problem and to provide a typology of these responses. A narrative-based approach was used to analyse PSYCHLOPS data from 235 users of primary care mental health services recruited through four therapists working in southeast England. Seven thematic categories emerged from the analysis of clients' responses to the domain, 'problem': interpersonal; past event; state of mind; somatic; self evaluation; competence/performance; material issues. Responses to the domain, 'consequences of the problem', were categorised under one of six themes: competence/performance; interpersonal; frame of mind; resolution and progression; self-evaluation; somatic. Users of mental health services in primary care offer a rich diversity of narratives, and these represent clients' voices that frame problems within the personal and social contexts in which they are experienced.

Keywords: narratives, outcome measurement, talking therapies users' perspective

Introduction

The perspective of healthcare users has become a crucial component of healthcare planning, delivery and evaluation. In both clinical and policy areas, patients' voices may now be heard, and are expected to be heeded alongside those of professional experts. This move towards assigning value to the perspective of patients is underpinned by the growing recognition of the value of patients' narratives to medicine in general and primary care mental health services in particular.[1–3] A narrative-based approach rests on the understanding that it is important to look at the words, phrases and stories that people use to describe their own experiences, as well as the acceptance that such discourses are neither more nor less accurate representations of the truth than discourses used by professionals.[4]

However, within mental healthcare, clients' own words for their problems rarely form the basis for measuring the outcome of talking therapy. Although many instruments, such as CORE-OM (Clinical Outcomes Routine Evaluation – Outcome Measure),[5] are currently used to measure outcomes in psychological therapies, these are at least partially derived with reference to instruments whose origins lie in the identification and assessment of categories of mental illness (e.g. Beck Depression Inventory (BDI), Hospital Anxiety and Depression Scale (HADS),[6] or in therapists' ideas of what they believe often changes during therapy.[5] The use of instruments like these follows the tradition of placing clients' words within a specific and professionalised linguistic framework, whether psychiatric or psychotherapeutic.[7] Measuring outcomes in talking therapies in primary care using standardised statements may not reflect what individuals feel is important to them in terms of their problem or progress.[8] Clients' voices may be subsumed within the professionals' words and phrases, which the user may experience as signifying psychological disturbance rather than reflecting the personal and social contexts in which their problems are framed and experienced.[9] Further, the development of some of these instruments (e.g. HADS, BDI) has been based on clients in specialist or secondary care services, whose symptom presentation may not be relevant to clients in primary care.[10]

In comparison, exploring outcome evaluation within the context of narrative thinking leads naturally to the use of individualised or patient-generated healthcare measures to capture patients' perspectives on their problems. As Greenhalgh and Hurwitz state, 'the narrative is concerned with individuals' and provides, 'meaning, context and perspective for the patient's predicament'.[2] Therefore, unlike standardised measures that focus on areas deemed important by practitioners, client-generated, idiographic instruments seek to, 'capture individuals' phenomenological experiences', as well as their preferences and priorities.[6]

Patient-generated instruments have been most commonly used in the field of quality of life (QoL) measurement, such as the Schedule for the Evaluation of Individual Quality of Life (SEIQoL),[11] the Patient-Generated Index,[12] and the subsequent Mother-Generated Index for postnatal health and illness.[13] However, they are less frequently used to measure health outcomes. Paterson's MYMOP questionnaire (Measure Yourself Medical Outcome Profile) stands out as one counter-example, as it was designed specifically to measure the outcomes of primary care treatment that patients decided were most important to them, using the categories of symptom, activity and wellbeing.[14]

A new outcome measure, 'PSYCHLOPS' (Psychological Outcome Profiles), has been developed specifically to measure outcomes in talking therapies in primary care, and to base these outcomes on problems that clients identified as most troubling.[15] PSYCHLOPS offers the opportunity to capture a succinct and simplified window into clients' perspectives on their problems. Because individualised measures have not generally been employed in the routine evaluation of talking therapy in primary care, clients' conceptualisations and descriptions of their problems or the consequences of their problems are rarely collected or monitored. The use of PSYCHLOPS provides a unique opportunity to explore how clients conceptualise their most troubling problem and the consequences of this problem, and to provide a typology of these responses.

Method

From its roots in sociolinguistics,[16] narrative analysis has become well established in the social sciences as a means of interpreting qualitative data. However, there appears to be little agreement among those who champion narrative analysis as to its archetypal purpose, method and form, other than its central focus on formalising understanding of the story within the data.[17]

Although the seminal functional analysis model devised by Labov and Waletzky involves matching verbal sequences of clauses to an actual sequence of events in order to identify 'story units',[16] narrative analysis has since evolved to include a range of approaches . In its broadest sense it embraces what Launer calls 'narrative thinking', whereby the focus

is on the words or discourses that people use to describe their experiences.[4] It has also come to encompass various specific methodological techniques suited to analysing different types of data, particularly written documents.

One area in which narrative analysis has been used to identify themes among relatively large cohorts has been in the analysis of occupational injury records.[18–20] Additionally, the nursing profession has used narrative analysis of case notes produced by heart failure nurse specialists to investigate the delivery of care, and of patient records written by advanced practice nurses in the US to examine the problems experienced by their elderly patients.[21,22]

These studies demonstrate that narrative analysis can be used with short, written data as well as with longer, oral stories. However, while narrative analysis embraces an eclectic approach to interpreting data, all studies, including ours, are underpinned by Labov's assertion that for narrative analysis, 'the most reportable event is the semantic and structural pivot on which the narrative is organized'.[23]

Data collection

This study was part of a validation trial of PSYCHLOPS as an outcome measure for use in primary care talking therapy settings.[24] Ethical approval was granted by the NHS Multi-centre Research Ethics Committee (MREC) in 2002.

PSYCHLOPS is a one-page questionnaire that asks the client to write down 'the problem that troubles you most' (termed, 'problem' in this paper), to write down a second problem if there is one (some opt not to give a second problem), and to 'choose one thing that is hard to do because of your problem' (here termed, 'consequence of the problem'). Clients write their answers into freetext boxes during their first therapy session. Each freetext response is followed by a tick box enabling the client to rate the severity of the item in the past week along a 6-point scale. The therapist then transcribes the freetext responses onto the post-therapy form for the client to re-rate at the final session, and to provide the basis for measuring outcome.

Setting and sample

Data were collected between 2002 and 2004 from users of primary care mental health services through four therapists working in southeast England. The therapists represented a range of clinical approaches including counselling, clinical psychology, counselling psychology and psychotherapy.

Therapists asked their clients to complete PSYCHLOPS at the same time as CORE-OM, an outcome measure that they used as part of their usual practice.[5] Clients were given information sheets with the questionnaire, and the therapists ensured that clients were giving fully informed consent for the data to be used in this study. The mean age of respondents was 34 years (range 15–64 years), and 74% were female.

Analysis

The data were used to answer the following research questions:

1 how would clients express their problems on an outcome measure without being guided by questions or options based on professional models of mental distress?
2 what are the similarities among clients' stories and how widely among the sample were they used?
3 how can these words and phrases be consolidated into thematic categories to allow us to identify further links among themes so that the narrative undercurrents contained in the data can be illustrated?

All qualitative and quantitative data collected were entered into SPSS 13.0. The freetext responses were transferred to Atlas.ti 5, a computer software program for managing qualitative data. Clients' responses contained in each of the three freetext boxes were analysed separately.

Analysis began with 'open coding',[25] to identify the themes emerging from the raw data. This approach differs from content analysis, whose primary purpose is to create statistical data.[26] During open coding, words, phrases or events that appear to be similar were grouped into the same category to form a preliminary framework for analysis. These categories were gradually modified or replaced during the subsequent stages of analysis, so that they were specific, inclusive and representative of responses.

Our main aim for the analysis was to refrain from using codes that echoed professional therapy models, both to retain the client-centredness of the data and to maximise their accessibility to readers from other professional orientations. We felt it was important to ensure that all responses were coded and none left in a left over 'other' category, in order to avoid the possibility of overlooking issues of significance. The codes that we identified are represented by the subthemes within each thematic category.

We went on to re-examine the categories identified and determine how they were linked using 'axial coding',[25] in which the discrete categories

identified in open coding were compared and combined in different ways to help answer the research questions. The resulting themes that were developed for clients' problems, and the consequences of these problems do not represent diagnostic or other professionally driven categories, but are used to illustrate, organise and manage the data. SR, a medical sociologist, conducted the initial analysis, and MA, a general practitioner (GP), checked these categories against the raw data; any analytical variance was discussed and reconciled among all authors.

Qualitative research is characterised by the use of 'voice' in the text, whereby participant quotes illustrate the themes being described. However, it was not possible to attribute extracts to individual respondents, as most are not unique to one person but represent typical or frequently cited narrative phrases used by a number of clients.

Results

Categories of responses to the 'problem' questions

Seven thematic categories emerged from the analysis of clients' responses about their most troubling problem(s): interpersonal; state of mind; somatic; past events; competence/performance; self-evaluation; and material issues. The categories and subthemes within them, and examples of clients' descriptions of their problems in their own words, are given below; categories and sub-themes are summarised in Box 1.

Interpersonal

Interpersonal problems identified by clients could be separated into those relating to relationships, to general social interaction and to others' behaviour/health. Relationship problems spanned both family and partnership issues, such as 'how to maintain my relationships in my family'; 'not coping well with teenage children'; 'family – second husband – not talking'; 'fear of marriage breaking up'; 'not knowing where my wife is'; 'current difficulties in my relationship and feeling unsure how to cope with them'. Social interaction problems dealt with more generalised interpersonal issues, with responses ranging from the most broad ('social problems') to those conveying a general association between self and others ('having to rely on other people'; 'trying to be helpful to all'),

Box 1 Responses to 'problem' by category and sub-themes

Interpersonal

- Relationships
- Social interaction
- Others' behaviour/health

State of mind

- Diagnostic labels
- Unhappiness

Somatic

- Speculative health concerns
- Existing health concerns
- Sleep
- Sex

Past events

- Someone's death
- Traumatic experience

Competence/performance

- Work/employment
- Self-management

Self-evaluation

- Self-esteem
- Self-liking

Material issues

- Finance
- Accommodation

Additionally, around one-third of responses labelled as interpersonal focused explicitly on another person's behaviour or health, for example 'son's drinking'; 'husband's lack of involvement with family'; 'trapped by my husband's behaviour'; 'my daughter's illness'; 'both of my parents being ill'.

State of mind

The category labelled as 'state of mind' included references to psychological, emotional and general disquiet with life. Many clients explicitly used diagnostic terms to describe this uneasiness, such as 'anxiety'; 'depression'; 'panic attacks'; 'agoraphobia'; 'obsessive-compulsive disorder'. Other responses given that may have been describing similar sentiments included 'feeling low all the time with no apparent reason'; 'not understanding why I am so unhappy'; 'constantly feeling tense/worried/nervous/irritable'; 'scared, fearful, alone, unwanted'; and, unequivocally, 'wanting to end my life'.

Somatic

Somatic concerns embraced health issues that were both speculative ('fear of my health – heart, veins'; 'fear of serious illness') and current ('my hair loss'; 'my spasms'; 'devil of a stomach'; 'having lost my sight). Difficulties with sleep ('not sleeping'; 'difficulty sleeping') and sex ('low libido'; 'inability to ejaculate/orgasm during sex'; 'problem keeping erection when having sex') represented physical functional issues.

Past events

Clients also identified events that had happened in the past as their most troubling problem. These events could be divided into those relating to someone's death, and those detailing a traumatic experience. Death, loss and bereavement always referred to a family member, for example: 'loss of son in motor bike accident'; 'the death of my sister and my mother within a short period'; 'felt my life was over since my dad died'. Further, traumatic experiences could be something that happened to the client ('sexual abuse when I was about 10'; 'being attacked violently by ex-boyfriend'), terminations of previous pregnancies ('I've had two abortions'; 'an abortion 4 years ago'), or a reference to a more distant event that had a profound effect on the client's life ('dealing with life after 11 September').

Competence/performance

Problems categorised as competence/performance related to clients' feelings about their ability to achieve, cope and function. These responses most commonly related to work, although education was also an issue. Examples include 'worried about reduced coping at work – feeling stressed'; 'competing tasks at work and repercussions of not completing them'; 'dealing with my new role at work and feeling threatened by possible redundancy'; 'that I am failing my degree and might never make it as a doctor'; 'unable to concentrate on things that are extremely important to me right now, i.e. college work'. More general personal self-management issues were also mentioned: 'being able to cope with general day-to-day things'; unable to focus and function normally'; 'lack of success in life'.

Self-evaluation

Self-evaluation was used to describe problems centring on how clients felt about themselves, or how they thought others felt about them. Summative statements such as 'self-esteem'; 'self-confidence'; 'lack of self-liking' were most commonly used. Other responses drew upon phrases expressing different aspects of these: 'not feeling good enough'; 'being able to love and accept myself'; 'my looks and size, feeling ugly'. This theme differs from 'competence/performance' in that responses grouped together as 'competence/performance' were all about *doing* (or *not doing*) jobs, tasks or other responsibilities, whereas 'self-evaluation' was essentially focused around *being* and did not mention performing any task or role.

Material issues

The final category encompassed material issues, and the main areas within it were finances and accommodation. Clients' responses included: 'Money! Partner being made redundant and me pregnant'; 'finding a job which provides good money'; 'money situation and finding affordable home'.

Categories of responses to the question about consequences of the problem

Responses to the question, 'Choose one thing that is hard to do because of your problem' were categorised under one of six themes: competence/performance; interpersonal; frame of mind; resolution and progression; self-evaluation; and somatic (see Box 2). While there is an overlap in categories for problems and their consequences, the responses from any one individual were not necessarily in the same category. Categories and sub-themes are summarised in Box 2.

Competence/performance

Nearly 30% of responses were categorised as relating to competence and performance, far higher than the equivalent number of problems, suggesting that clients felt that many different types of problems resulted in difficulties in this area. Responses within this category were characterised by references to concentrating and focusing ('It's been hard to concentrate on studying so then I feel guilty and that makes me feel worse'; 'concentrate at work', 'organise and concentrate on work and domestic jobs'; 'keeping focused'; 'stay focused on one activity'). Additionally, being motivated or productive ('get things done/apply self'; 'being productive'; 'motivate myself'; 'to apply myself to do something') was cited, as was coping ('coping with life in general') and working ('work effectively'; 'carrying out the 'leadership' activities – defining a strategy for my team'). Achievement was also a mentioned by respondents both in a general sense ('achieve day-to-day

Box 2 Responses to 'consequences of the problem' by category and sub-themes

Competence/performance

- Concentrating/focusing
- Being motivated/productive
- Coping
- Achieving

Interpersonal

- General social interaction
- Relationships

Frame of mind

- Feel mentally well
- Happy
- Relaxed

Resolution and progression

- Being positive
- Moving on
- Personal advancement
- Decision making

Self-evaluation

- Self-esteem
- Confidence

Somatic

- Sleep
- Sex
- Eating

goals'; 'achieving as much as I could achieve'; 'everything I was capable of has gone'), and using specific examples ('get something done in the house'; 'not drinking alcohol'; 'opening my post')

Interpersonal

Responses identified as relating to interpersonal issues conveyed the difficulties that problems created both for interacting with people in general and in intimate relationships. The former included phrases such as 'socialise' or 'socialise confidently'; 'trust people'; 'interact with people I am not actually required to unless I am VERY [sic] close to them'; 'feel part of a social group'. Relationships issues were also cited, for example 'having meaningful relationships'; 'get close to my wife'; 'have a good relationship with husband'; 'think clearly about married life';'I find relationships with partners difficult to deal with and I find forgiveness hard. I have thoughts of hurting the person emotionally'.

Frame of mind (outlook, attitude and wellbeing)

For approximately one-fifth of clients, the main thing that was hard to do related to feeling mentally well, happy and relaxed. Responses overwhelmingly centred on 'be happy'; 'enjoy life'; 'feel relaxed'; 'to be cheerful'. People whose answers fitted into this category felt that their problem prevented them from finding 'peace of mind'; 'enjoying life'; or 'being content'. For one client, 'to have the will to live' was the hardest thing.

Resolution and progression

This category of responses centred on the themes of progression, development and change, with the focus being on the future rather than the past or present. Phrases such as being 'positive' 'focused', 'optimistic' and 'motivated' were repeatedly cited, and represented key approaches to life that were difficult for respondents. Other clients found that the hardest thing to do because of their problem was to 'move forward'; 'put it all behind me and move on'; 'overcome thinking of what could have been'; 'get on with life/move on'. Likewise, personal advancement and realisation was indicated by phrases such as 'progress'; 'develop'; 'to do all the things I want to'; 'live a full life'. Decision making was also an aspect of this category, represented by responses such as 'choose a plan of action correctly'; 'deciding what to do'; 'make a decision'.

Self-evaluation

Clients also considered that the main consequence of their problem was how they felt about themselves. A number of respondents wrote only 'self-worth' or 'self esteem', while others felt it was difficult to 'like myself'; to 'feel okay about myself'; or 'be comfortable with myself'. Confidence was also mentioned several times, such as 'feel confident'; 'have confidence in reactions'; 'have confidence in myself'.

Somatic

Finally, clients' problems also had consequences for somatic functions. These focused exclusively on sleep ('sleep I feel refreshed from – a good night's sleep'), sex ('sleep with my husband'; 'loss of libido'; 'making love with my fiancée') and eating ('eat sensibly, socially'; 'eat in front of people').

Discussion

The aim of this paper was to explore and reveal the written narratives that clients provide on an innovative, client-centred outcome measure (PSYCHLOPS) for evaluating the effectiveness of talking therapy in primary care.

With most outcome questionnaires, clients' narrative descriptions of their problems are usually subsumed within statements based on professional models aligned to diagnostic criteria. In contrast, the purpose of PSYCHLOPS is to allow clients to evaluate their own progress following therapy based on their self-defined problems, and is therefore grounded in clients' own terminology.

Our analysis of responses highlighted that clients interpreted the questions on PSYCHLOPS so that they made sense within the narrative. For example, the term, 'problem', was interpreted widely. Problems cited by clients included the perceived *causes* of their mental distress (past events, another's behaviour or health and material issues), all of which told a story that may have begun many years previously. Conversely, other problems cited by clients included perceived *consequences* such as sleep or sexual problems, or difficulties performing at work, such that consequences were often identified by clients as the problem itself.

Clients also adopted terms traditionally used as labels for mental health problems, such as 'anxiety' and 'depression', to describe their problems. It could be that these clients had previously been given a professional diagnosis, or that there is a lay understanding of what anxiety is, although whether that is the same among respondents is not known. The widespread use of these terms suggests that lay and professional narratives of distress now overlap, rather than representing polarised realities. DeSwann asserts that this apparent blurring of the boundary between lay and expert terminology is both unsurprising and inevitable, and is an illustration of the process of 'proto-professionalisation' whereby people frame their difficulties and distress in expert terms, even before they come into direct contact with professionals.[27]

Some doctors, and perhaps some therapists, might be surprised at how many responses to the question about 'most troubling problem' were focused on another person, either in terms of their health or behaviour. Coulter argues that it is exactly issues such as these that bring lay people into contact with mental health professionals, as they look to such professionals to 'rescue' them from others whom they (the clients) deem to be problematic, either mentally or otherwise.[28]

We also found that clients' interpretations of what their problem made 'hard to do' was a continuation of their narratives and, to some extent, a vision of the future in which they would like to find themselves. Meddings and Perkins note that different stakeholders in the therapeutic relationship may vary in what they see as a desirable outcome, and may include seemingly mundane matters such as housing, money and jobs rather than mental state or medication.[29] Thus, as we found with problem and symptom, the 'hard to do' thing did not necessarily represent what a professional might define as a 'function'; rather, narratives of being and feeling, as well as doing, were all apparent in the responses and served to carry on the story already begun.

Limitations

Data collected using PSYCHLOPS represented succinct stories about the most important problem in respondents' lives during the past week and how this affected them. However, the brevity of PSYCHLOPS means that the stories contained within it can only ever represent snapshots of people's lives during the past week. Undoubtedly, there are stories not yet told that cannot be discerned through the data collected through PSYCHLOPS, and this limits the extent to which the narratives can be analysed on an individual basis.

Further, while our aim was to prioritise the words and phrases that clients used to describe their problems rather than rely on professionally predetermined headings, the classification of individual responses into categories necessarily imposes external interpretation. However, the use of sub-themes derived directly from responses clarifies the meaning of the category label in relation to clients' phrases, and reinforces the privileging of the clients' voice.

Conclusions

Bringing to light clients' conceptualisations of their problems and their problems' consequences is a key skill for primary care clinicians, both doctors and therapists. Based on a qualitative analysis of responses to an idiographic outcome measure, we have categorised these conceptualisations.

The main purpose of PSYCHLOPS is to provide a means of measuring whether a client has benefited from therapy according to the client's self-defined criteria, in line with the assertion of Macran *et al* that it is necessary to elicit, acknowledge and use clients' own conceptualisations of their problems to gain effective measures of change in therapy.[8] This approach is consistent with recommendations that

therapists eschew the 'expert position' and position themselves as working within the client's context and problems, rather than trying to guide the client's understanding of his/her problems to fit with prevailing professional constructions.[30,31] Transferring this principle to measurement, Macran *et al* have described the idea of objective measurement of fundamentally subjective notions as phenomenologically meaningless, and emphasised the uniqueness of a client's perspective and their own sense of personal significance.[8] While we do not hold so strong a position, we do believe that outcome measurement on criteria defined by clients, rather than by professionals, is a valid goal of 'patient-generated' questionnaires.

Our qualitative analysis of responses elicited by PSYCHLOPS shows that users of primary care mental health services offer a diversity of narratives. These represent clients' voices that frame problems within the personal and social contexts in which they are experienced. The narratives provide insight into clients' problems that is unique in relation to outcome measurement and that may have otherwise been concealed on instruments that employ professionals' words and phrases to indicate psychological disturbance.

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FUNDING

Susan I Robinson was supported by a grant from the Joseph Rowntree Foundation.

CONFLICTS OF INTEREST

None.

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Received ?????
Accepted ?????