Article

Measuring what matters to patients: Using goal content to inform measure choice and development

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Abstract

Introduction: Personalised care requires personalised outcomes and ways of feeding back clinically useful information to clinicians and practitioners, but it is not clear how to best personalise outcome measurement and feedback using existing standardised outcome measures.
Method: The constant comparison method of grounded theory was used to compare goal themes derived from goals set at the outset of therapy for 180 children aged between 4 and 17 years, visiting eight child and adolescent mental health services, to existing standardised outcome measures used as part of common national datasets.
Results: In all, 20 out of 27 goal themes corresponded to items on at least one commonly used outcome measure.
Discussion: Consideration of goal themes helped to identify potential relevant outcome measures. However, there were several goal themes that were not captured by items on standardised outcome measures. These seemed to be related to existential factors such as understanding, thinking about oneself and future planning.
Conclusion: This presents a powerful framework for how clinicians can use goals to help select a standardised outcome measure (where this is helpful) in addition to the use of a goal-based outcome measure and personalise choices. There may be areas not captured by standardised outcome measures that may be important for children and young people and which may only be currently captured in goal measurement. There is an indication that we may not be measuring what is important to children and young people. We may need to develop or look for new measures that capture these areas.

Keywords

Goals, goal setting, outcome measurement, feedback tools, child mental health and wellbeing, Child and Adolescent Mental Health Services, Child Outcomes Research Consortium

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Introduction

A recent review of Child and Adolescent Mental Health Services (CAMHS) in the United Kingdom highlighted several concerns related to a lack of appropriate funding and inadequate provision of services (House of Commons Health Committee, 2014). In response, the children and young people's mental health and wellbeing taskforce has committed to build capacity within evidence-based, outcome-focused services by 2020 and published best practice guidelines, including the use of Routine Outcome Measures (ROMs), particularly those completed by young people and families themselves: Patient-Reported Outcome Measures (PROMs) and Patient-Reported Experience Measures (PREMs; Department of Health (DH), 2015).

PROMs and PREMS are questionnaires regularly administered to service users, from which healthcare professionals are able to collect treatment progress information (Carlier et al., 2012). PROMs have been widely used in services offering provision for emotional and wellbeing difficulties to young people across the United Kingdom and beyond for the past decade (Child Outcomes Research Consortium (CORC), 2015; Fleming, Jones, Bradley, & Wolpert, 2014; and Children and Young People's Improving Access to Psychological Therapies (CYP IAPT), Law & Wolpert, 2014). There are a number of standardised PROMs available, which span clinician-identified presenting difficulties and population groups. The information from these questionnaires is used for two primary purposes: to evidence the impact of a treatment and for service evaluation (DH, 2010). Here, the tools are largely used for operational and management tasks. The second purpose is use as clinical tools that can help facilitate better collaborative practice, to open up discussions about how a young person or family sees progress and their experiences of the work with the practitioner (Law & Wolpert, 2014). In the former use of these tools, they are labelled 'outcome measures', and in the latter, they are 'clinical feedback tools'. In other countries (e.g. North America) tailoring not only the target of treatment but also the tools used to track progress is established (Weisz et al., 2011). The aim of this research was to explore the feasibility of using goals to target the choice of standardised tools for tracking the progress of treatment in the United Kingdom, thereby supporting personalised outcome measurement and care.

Research has shown the use of these tools can prove beneficial for young people with emotional and behaviour difficulties, including increased retention (Hawley & Weisz, 2005; Lambert et al., 2003), better outcomes (Bickman, Kelley, Breda, de Andrade, & Riemer, 2011; Lambert, 2010; Shimokawa, Lambert, & Smart, 2010) and faster improvement (Bickman et al., 2011; de Jong, van Sluis, Nugter, Heiser, & Spinhoven, 2012). Evidence suggests that clinical judgement alone may be less reliable for noting when a young person is not responding to treatment as expected (Hannan et al., 2005). The use of feedback tools counterbalances this by creating more tangible evidence to discuss difficulties and options for an agreed way forward: 'Without direct feedback on how their clients are progressing, clinicians are essentially wearing a blindfold while shooting at a target' (Sapyta, Riemer, & Bickman, 2005; pp. 152–153). Standardised tools may provide additional clinical information that may have otherwise been missed (Worthen & Lambert, 2007). If the tools are used clinically in this way, the information provided can also be used to monitor outcomes, and in most cases, the same tools can be used to serve both purposes.

While there are many benefits to using standardised tools, numerous challenges to their use have also been documented (Badham, 2011; Batty et al., 2012; Boswell, Kraus, Miller, & Lambert, 2015; de Jong, 2014; Edbrooke-Childs, Wolpert, Deighton et al., 2014; Hall et al., 2014; Moran, Kelesidi, Guglani, Davidson, & Ford, 2012; Wolpert, 2013), specifically related to three broad areas: the content of standardised tools, the process of using tools and the effective use of data derived from tools (Wolpert, Curtis-Tyler, & Edbrooke-Childs, 2014). Learning collaboratives such as CORC (CORC, 2015; Fleming et al., 2014) and CYP IAPT (Law & Wolpert, 2014) work

with services and clinicians to mitigate barriers and to encourage the meaningful use of the information from these tools at a clinical and service level (MINDFUL approach; Wolpert, Deighton et al., 2014).

Barriers often relate to striking a balance between the need for generalisable evidence and providing personalised care (Wolpert, 2013). The advantages of idiographic measures (measures with an individual focus such as goal-based tools, for example, goal-based outcomes (GBOs); Law & Jacob, 2015) and standardised tools to measure outcomes and gain feedback (e.g. broad symptom or wellbeing measures) have been explored elsewhere (Edbrooke-Childs, Jacob, Law, Deighton, & Wolpert, 2015; Wolpert, Ford, et al., 2012). One key risk of harm is tools becoming a bureaucratic tick-box exercise if they are not seen as clinically meaningful by clinicians or young people (Badham, 2011; Wolpert, Fugard, Deighton, & Görzig, 2012).

While standardised tools are useful to gather information to create norms and benchmark at an aggregate level, evidence suggests that they may be less clinically meaningful to inform practice and may lack a person-centred focus (Bromley & Westwood, 2013; Norman, Dean, Hansford, & Ford, 2013; Ruble, McGrew, & Toland, 2012). In particular, clinicians have referred to standardised tools as at times being depersonalising and too focused on numbers, calling for more individualised measurement (Norman et al., 2013). Mental health and wellbeing difficulties are individual; feedback from young people has highlighted the importance of treating service users as individuals and not simply reducing them to a score on a questionnaire (Badham, 2011). Drawing on social validation theory, for service users to engage and be satisfied with care, they should experience the focus of treatment, techniques and effects personally meaningful to them (Kazdin, 1977). This tension suggests that there is a call for outcome measurement in areas that are not covered by standardised tools, due to the concern that a focus on standardised tools alone may miss areas not included on these tools and may also distort clinical conversations to fit with questionnaire items rather than clinical presentations. Ensuring outcome measurement occurs within a personalised care context, and that we are therefore measuring what matters to patients, is a priority.

Personalised care is a key domain of healthcare quality (DH, 2011; Institute of Medicine, 2001) and is increasingly seen as sitting at the heart of service models, with a call for greater alignment between patients' preferences, research evidence and clinical experience and judgement (Frueh, Ford, Elhai, & Grubaugh, 2012). It involves putting service users at the centre of all decisions about their care, with choice and control based on a collaborative perspective (De Silva, 2012). Evidence suggests that young people have the capacity to be involved in treatment decisions, which may have benefits to self-esteem and the transition to adulthood (Alderson, Sutcliffe, & Curtis, 2006; Costello, 2003; Huffine, 2005). Young people want to be involved in decisions about their treatment (Alderson et al., 2006; Coyne, 2006; Dogra, 2005; Kelsey, Abelson-Mitchell, & Skirton, 2007) and report feeling under-empowered when they have limited involvement (Gyamfi, Keens-Douglas, & Medin, 2007). For example, young people in acute care settings report feeling alienated when clinicians speak only to their parents and that a lack of communication is a barrier to personalised care (O'Brien, Crickard, Rapp, Holmes, & McDonald, 2011). Studies in child mental health settings have found that interventions that include personalised care improve communication and treatment outcome (Asarnow et al., 2009; Westermann, Verheij, Winkens, Verhulst, & Van Oort, 2013). There is an increasing commitment to embedding personalised care in CAMHS (Richter, Halliday, Grømer, & Dybdahl, 2009; Soffe, Read, & Frude, 2004).

DH (2015) recommended a move away from the tiered model of CAMHS, which no longer fits well with the evolving support young people and families seek, receive or need. The THRIVE model (Wolpert, Harris et al., 2014) conceptualises a better approach to organising care, support and personalised care in CAMHS. The model proposes the use of idiographic measures, such as goal setting, to help work towards personalised care and 'goal focused, evidence informed and

outcomes focused intervention' (Wolpert, Harris et al., 2014, p. 7). The use of goal setting to direct interventions and outcome measurement may promote personalised care.

Goal setting and tracking have been used in CAMHS, often referred to as expectations, aims or top problems, for many years (Bradley, Murphy, Fugard, Nolas, & Law, 2013; Kiresuk & Sherman, 1968; Weisz et al., 2011). Some types of mental health treatment concentrate on self-reflection, incorporating identifying and working collaboratively towards goals, for example, psychoanalysis (Gollwitzer & Moskowitz, 1996) and its derivatives (e.g. cognitive behavioural therapy (CBT); Beck, 1997) and family therapy (Diamond, Liddle, Hogue, & Dakof, 1999). In addition, training programmes often have objectives or goals for parents to seek to achieve by the end of the course (Reid, Webster-Stratton, & Beauchaine, 2001). Although setting and tracking goals in therapy have been used for some time, systematically tracking goals as an outcome or feedback tool is a more recent venture.

A focus on agreed goals is often cited as a key component of personalised care, which has been advocated by service users (Chewning et al., 2012) and has also been shown to be an important driver of both positive therapeutic relationships and outcomes (Cooper, 2008). Goal setting as a method to track clinical progress has good face validity whereby young people and clinicians have attested to goal setting helping them to focus and progress treatment (Bromley & Westwood, 2013; Emanuel, Catty, Anscombe, Cantle, & Muller, 2013; Law & Wolpert, 2014; Pender, Tinwell, Marsh, & Cowell, 2013), with mental health service users placing high value in working towards their own goals (Liberman & Kopelowicz, 2002).

The method of goal setting sits well in personalised care as the clinician and service user collaboratively discuss and choose the goals they want to work towards throughout treatment. A focus on that which is central to what the individual wants to achieve moves away from the suggested tick-box exercise nature of some other methods of standardised outcome measurement (Badham, 2011; Wolpert, Fugard et al., 2012). In particular, goal formulation may help to identify the target for interventions and, correspondingly, areas of difficulties to assess and track using standardised tools. Clinicians may not want to use standardised tools that are not perceived to have clinical relevance, and they may have low levels of self-efficacy in choosing and using tools (Edbrooke-Childs et al., 2014; Fleming et al., 2014; Norman et al., 2013).

There is an array of standardised tools from which clinicians can choose (CYP IAPT data spec; see CORC, 2015). This may enable measures to be chosen that best meet patient preferences and presenting difficulties (Law & Wolpert, 2014). However, it may require clinicians to be trained in a greater number of measures so that they can quickly identify the right measure for the patient; this may be particularly problematic as evidence suggests that young people, parents and clinicians may have different perceptions of reasons for attending services (Yeh & Weisz, 2001).

Goal setting as a method of tracking outcomes also addresses some of the challenges discussed; for example, goals capture the individual nature of what someone wants to work on. This is counterbalanced by a lack of norms available, and goals are not easily comparable between people due to the individualistic nature of goals. However, evidence suggests that goal scores may show more change over the course of therapy than standardised measures of psychosocial difficulties and impact on daily life (Edbrooke-Childs et al., 2015). Evidence has also shown that goal commitment is higher for existential goals (Riemer & Bickman, 2011). Such goals were found to be prevalent in routinely collected data from services providing mental health provision to young people and their families (Jacob et al., 2015). This also suggested that goal setting in CAMHS may offer insight into areas of change related to distal factors such as understanding, confidence and coping that are not explored by other standardised measures (Jacob et al., 2015), especially where difficulties are not expected to vastly improve in terms of symptomatology (Batty et al., 2012). To service users, a good outcome has been shown to constitute something that was not a tick-box exercise and

was meaningful to everyday life and to clinicians; as something that needs to be meaningful to the individual, it may be different to each patient. As part of this, empowerment and self-efficacy were identified as key areas of measurement not currently appropriately captured by existing tools (Childs, Deighton, & Wolpert, 2013). Evidence also suggests that goals may capture these areas which are important to young people, parents and clinicians not covered by standardised tools. For instance, children set goals around ability to cope with emotional and behavioural difficulties (Bradley et al., 2013), which may differ to constructs such as coping with stress (Causey & Dubow, 1992) or resilience (Windle, Bennett, & Noyes, 2011) captured in existing questionnaires.

Work on needs-based groupings in child and adolescent mental health supports this by suggesting a move away from assigning children to fixed, prescribed treatment pathways towards a shared formulation decided upon through a collaborative discussion, shared goals and outcomes (Wolpert et al., 2015). The suggestion is that outcome measurement is chosen in line with the agreed focus of treatment. In an example given of a boy whose difficulties related to being anxious in social situations, the agreed way forward through collaborative discussions may be to work on a goal of spending more time with friends (the outcome important to him) alongside tracking anxiety (the symptom important to him) on a standardised outcome measure: see Table 1 (taken from Wolpert et al., 2015; p. 16).

The aim of this research was to build on themes derived from goals set by young people, parents and clinicians at the outset of therapy (Bradley et al., 2013; Jacob et al., 2015) to explore the feasibility of using goals to inform not only the target of treatment but also the target of tracking the progress of treatment, thereby supporting personalised outcome measurement and care. Two research questions were examined:

1. Can goal content be used to shape outcome and feedback tool choices?
2. Are there goal themes not captured by standardised outcome and feedback tools?

Method

This research involved secondary analysis of data derived from a dataset comprising 933 goals set at the outset of therapy for 180 children and young people aged between 4 and 17 years, who were seen by eight CAMH services between 2007 and 2010. The goals data were collected routinely as part of ongoing practice by practitioners and others offering provision for children and young people with mental health and wellbeing difficulties and their families. All members of a learning collaboration focused on improving provision through the appropriate use of outcome information were invited to submit the descriptive content of their recorded goals for research purposes. The goals data received were collated for analysis. Each of the eight services that provided data were required to follow their own ethical guidelines as advised by their information governance team; no other ethical permission was required for this research as it involved secondary analysis of routinely collected data (National Health Service (NHS), 2015).

Goal themes were taken from previous research (Bradley et al., 2013; Jacob et al., 2015) whereby three (child-led, parent-led and jointly agreed) goal frameworks were created by an iterative process of thematic analysis (Braun & Clarke, 2006), also drawing on an existing framework of goals derived from psychotherapy research (Grosse Holtforth, & Grawe, 2002). This research demonstrated through axial coding that all goal themes that emerged from the child-led framework mapped onto themes from the other perspectives (parent-led and jointly agreed). However, there were themes that emerged from the parent-led and jointly agreed goal frameworks that were not present in the child-led data, that is, (parent) co-operation, being calmer and inappropriate behaviour, and (jointly agreed) family support and guidance. An amalgamated version of the child-led,

Table 1. Needs-based grouping and outcome indicator choices: some brief worked examples.

Basic info	Key problems identified in Current View Tool	Needs-based grouping suggested by the algorithm	Collaborative consideration of choices in terms of needs-based groupings and specific approaches within these	Outcome indicators chosen	Needs-based grouping assigned following shared decision-making	Agreement with algorithm's suggestion?
Boy 15 years old Seen without parents though with parental knowledge	Anxious in social situations: 'moderate'	Getting Help: Social Anxiety Disorder (Guided by NICE Guideline 159)	Practitioner and young person discuss the effect of the anxious feelings on social activities. A goal of spending more time with friends is agreed. The options of either individual or group CBT are considered and the pros and cons of involving parents, and the decision is made to try eight sessions of individual CBT, without involving parents.	Goal-based outcome: spend more time with friends Social Anxiety subscale of Revised Child Anxiety and Depression Scale (RCADS)	Getting Help: Social Anxiety Disorder (Guided by NICE Guideline 159)	Yes
Girl 5 years old Two biological parents seen	Carer management of CYP behaviour: 'moderate' Difficulties sitting still or concentrating: 'mild' Peer relationship difficulties: 'mild'	Getting Advice: Signposting and Self-management Advice (NICE Guidance as Relevant)	Parents are finding it hard to manage their child's frequent tantrums and would like to cope better with these. Potential participation in a parenting group is discussed, and the parents think attendance would be difficult given their work and home commitments. They are happy to get advice and signposting towards relevant factsheets and websites. Advice for the child's teacher is also offered.	Experience of Service Questionnaire (ESQ) – satisfaction with advice received	Getting Advice: Signposting and Self-management Advice (NICE Guidance as Relevant)	Yes
Boy 11 years old Foster parents	Behavioural difficulties: 'moderate' Anxious generally: 'moderate'	Getting Help: Co-occurring Behavioural and Emotional Difficulties (NICE Guidance as Relevant)	Clinician and foster parents consider that the primary intervention should target the externalising behaviours, as the child does not wish to engage with individual sessions on anxiety. The foster parents see merit in attending a Webster-Stratton parenting group and working with the clinician and school to manage their child's frequent exclusion from class, the reduction of which was a goal agreed by both child and parents.	Goals Based Outcome: increase number of days per week when no exclusions from class Brief Parental Self-Efficacy Scale (BPSES) No of days when excluded from class	Getting Help: Behavioural and/or Conduct Disorders (Guided by NICE Guideline 158)	No

Table 1. (Continued)

Basic info	Key problems identified in Current View Tool	Needs-based grouping suggested by the algorithm	Collaborative consideration of choices in terms of needs-based groupings and specific approaches within these	Outcome indicators chosen	Needs-based grouping assigned following shared decision-making	Agreement with algorithm's suggestion?
Girl 14 years old Mother and step father	Self-Harm: 'moderate'	Getting Help: Self-harm (Guided by NICE Guidelines 16 and/or 133)	Young person unwilling to engage in treatment and together with carers agrees a plan to safely manage self-harm. Follow-up appointment and advice to mother and step father is offered. The young person agrees to a meeting with an identified member of school staff and the clinician to discuss how the safety plan might be implemented at school, where peer conflict seems to be a common trigger for the young person's distress.	Experience of Service Questionnaire (ESQ) – satisfaction with advice received	Getting Advice: Signposting and Self-management Advice (NICE Guidance as Relevant)	No

NICE: The National Institute for Health and Care Excellence; CBT: cognitive behavioural therapy; CYP: Children and Young People.
Taken with thanks from: Wolpert, Harris et al. (2014) p.16.

parent-led and jointly agreed goal frameworks was created, with outstanding themes from the parent-led and jointly agreed goals included in and referenced as such (Jacob et al., 2015); this version was used for this analysis.

Analytic strategy

The items from a set of standardised feedback tools and outcome tools (questionnaires) widely used in UK CAMHS (CORC, 2015; see appendix (http://www.researchgate.net/publication/282846533_Jacob_et_al_2015_CCPP_Measuring_what_matters_to_patients_appendix) for a complete list) were selected for coding, comprising 192 items in total. Two coders (J.J. and M.W.) coded items from the standardised questionnaires using the amalgamated goal themes from previously published studies of child-rated, parent-rated and jointly agreed goals as described above (Bradley et al., 2013; Jacob et al., 2015) using the constant comparative method of grounded theory (Glaser & Strauss, 1967) with selective coding (Corbin & Strauss, 1990). This iterative process involved the coders first analysing which goal theme code(s) applied to each questionnaire item separately before meeting to compare and integrate any differences in coding. For example, the goal theme 'co-operation' could be mapped onto questionnaire items on measures about behavioural difficulties (Oppositional Defiance Disorder Parent rated (ODDp) ('*My child actively defies or refuses to comply with adults' requests or rules*', '*My child argues with adults*') and Strengths and Difficulties Questionnaire (SDQ) ('*Generally obedient, usually does what adults request*')). Codes for individual items were then aggregated for each questionnaire subscale (in the example given, the SDQ conduct subscale); the relevant codes for the subscale items are reported in Table 2 (appendix [http://www.researchgate.net/publication/282846533_Jacob_et_al_2015_CCPP_Measuring_what_matters_to_patients_appendix]).
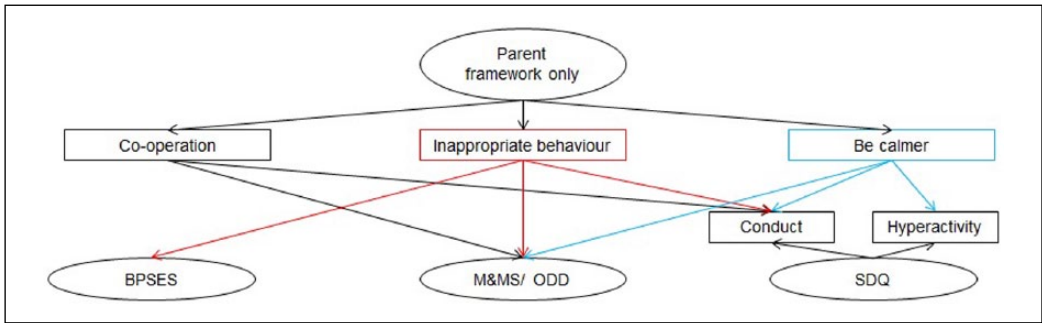
Figure 1. Parent framework goal themes mapped to corresponding items on standardised tools.

Results

Overall, 20 out of the 27 goal themes had corresponding items on at least one of 13 commonly used standardised outcome/feedback tools. See Figures 1 to 4 for a full breakdown.

Of the 27 goal themes explored, 7 did not correspond to any item on the standardised outcome and feedback tools considered:

1. Talking about feelings and thoughts;
2. Letting people know what help I need;
3. Understanding my anger;
4. I would like to . . . (goals with personal meaning or related to a hobby);
5. To be more responsible for myself (including care of myself) or to be more independent;
6. Feeling more confident or feeling better within myself;
7. Thinking about me and understanding my past.

Figure 1 demonstrates that from goal themes that were derived from parent-led goals only, themes related to 'co-operation', 'inappropriate behaviour' and 'being calmer' mapped to items on standardised tools focused on parental self-efficacy (Brief Parental Self-Efficacy Scale (BPSES); inappropriate behaviour), behaviour management and conduct (Me and My School (M&MS), ODDp, SDQ conduct subscale; co-operation, be calmer, co-operation, inappropriate behaviour) and hyperactivity (SDQ hyperactivity subscale; be calmer).

Figure 2 demonstrates that from goal themes derived from all perspectives, themes related to listening and communication mapped to items on standardised tools focused on general wellbeing (Child Outcome Rating Scale [CORS], SDQ impact subscale; make more friends, make family situation better, get on better with mum/dad); impact of events (post-traumatic stress disorder (PTSD), the impact of event scale (IES), be able to communicate more); behaviour management and conduct M&MS, ODDp, SDQ conduct subscale; make more friends); social anxiety (Revised Child Anxiety and Depression Scale (RCADS) subscale, make more friends); family functioning (SCORE-15; be able to communicate more, make family situation better, get on better with mum/dad); and prosocial and peer (SDQ subscales; make more friends).

Figure 3 demonstrates that from goal themes derived from all perspectives, themes related to personal growth and functioning mapped to items on standardised tools focused on general wellbeing (CORS, SDQ impact subscale, Young Persons/Clinical Outcomes in Routine Evaluation (YP-CORE/-10), Short/Warwick-Edinburgh Mental Well-being Scale (S/WEMWBS); feeling comfortable at school, doing better at school, enjoying life); depression (Patient Health Questionnaire
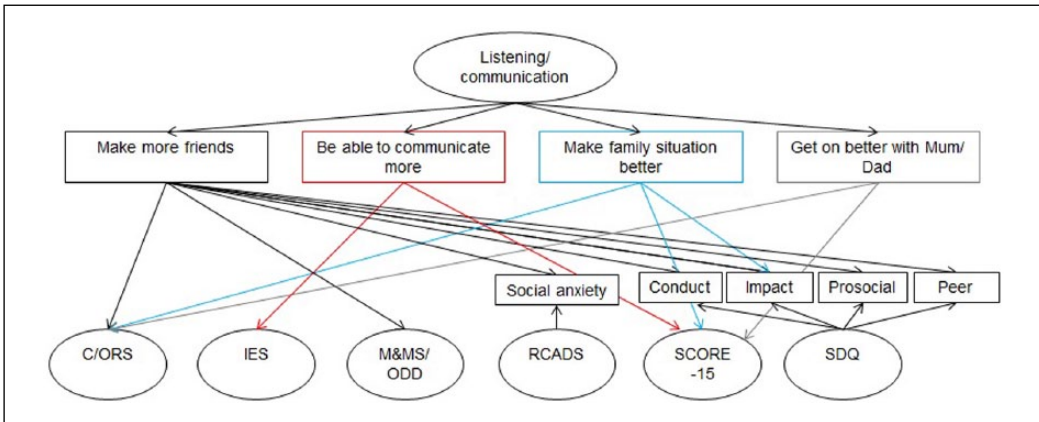
Figure 2. Listening and communication goal themes mapped to corresponding items on standardised tools.
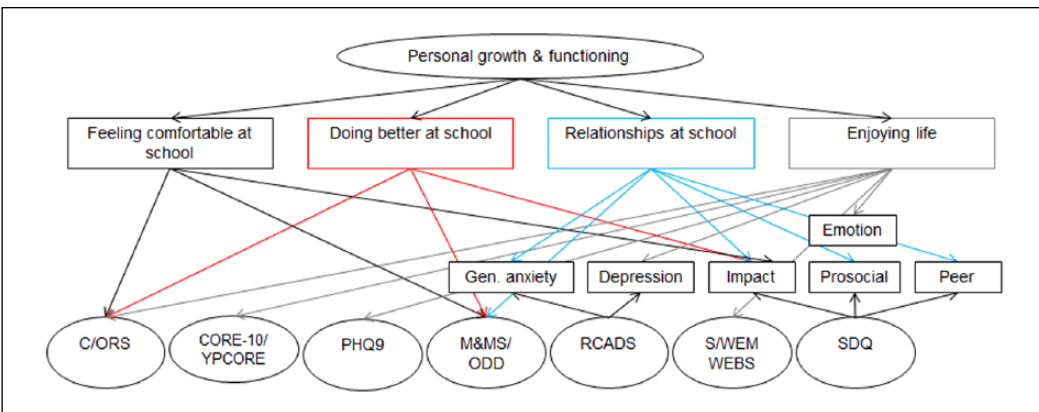

Figure 3. Personal growth and functioning goal themes mapped to corresponding items on standardised tools.

(PHQ)-9, RCADS subscale, SDQ emotional subscale; enjoying life); behaviour management and conduct (M&MS, ODDp; feeling comfortable at school, doing better at school, relationships at school); general anxiety (RCADS subscale; relationships at school); and prosocial and peer (SDQ subscales; relationships at school).

Figure 4 demonstrates that from goal themes derived from all perspectives, themes related to coping with specific symptoms mapped to items on standardised tools focused on general wellbeing (CORS, SDQ impact subscale,CORE-10/YP CORE, S/WEMWBS; manage negative mood and negative thoughts and feelings or patterns, be good/help with behaviour, feel happier; control and manage anxiety, worries, stop feeling anxious, stressed, worried, be good/help with behaviour, better sleep); depression (PHQ-9, RCADS subscale, SDQ emotional subscale; manage negative mood and negative thoughts and feelings or patterns, better sleep, feel happier, stop harming myself); behaviour management and conduct (M&MS, ODDp; controlling and managing my anger); anxiety (RCADS social anxiety, general anxiety, social phobia and panic subscales; SDQ
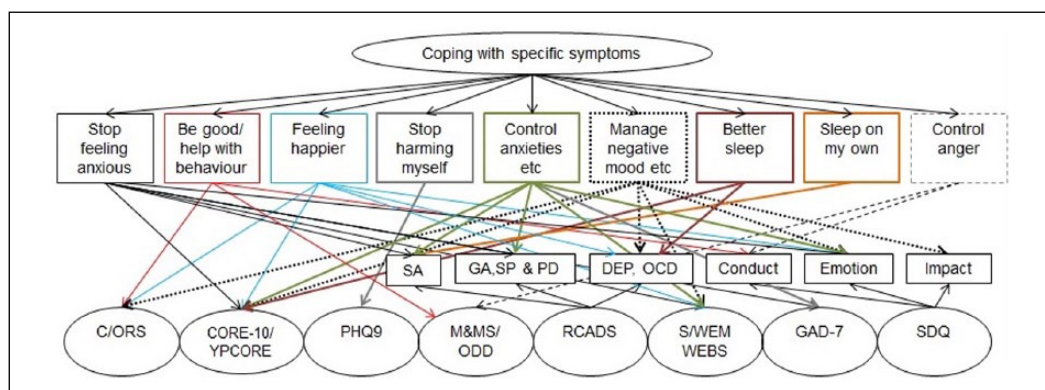
Figure 4. Coping with specific symptoms goal themes mapped to corresponding items on standardised tools.

emotional subscale; generalised anxiety disorder (GAD)-7; control and manage anxiety, worries, stop feeling anxious, stressed, worried, sleep on my own); obsessive–compulsive disorder (OCD) (RCADS subscale; manage negative mood and negative thoughts and feelings or patterns); and prosocial and peer difficulties (SDQ subscales; relationships at school).

Discussion

The aim of this research was to build on previous themes derived from goals set by young people, parents and practitioners at the outset of therapy (Bradley et al., 2013; Jacob et al., 2015) to explore the feasibility of using goals to inform both the target and tracking of the progress of treatment, thereby supporting personalised outcome measurement and care.

Some areas were debated by the two coders. For example, the S/WEMWBS item 'I've been able to make up my own mind about things' was considered a potential comparison of the goal theme 'to be more responsible for myself . . . ' and the S/WEMWBS item 'I've been feeling useful' as a potential comparison of the goal theme 'feeling more confident…'. However, neither was considered enough of a direct comparator without assumptions. This suggests that for the most part, standardised tools could be aligned to young people's and families' goal themes, which is the current way many clinicians are selecting and using these tools with young people (CORC, 2015). Some themes could be thought of as more process-oriented: 'thinking about me and understanding my past' or 'talking about feelings and thoughts', and are less helpful in indicating appropriate types of help than more outcome-oriented goals such as to 'stop harming myself' or 'do better at school'.

Of the 27 goal themes explored, 7 did not correspond to any item on the standardised tools considered. These findings have implications on a number of fronts. When determining which standardised tool to use, clinicians may want to consider the specific goals the person has set, rather than the nature of difficulties as such. This presents a radical reformulation of how these tools should be chosen and used. For example, someone attending with excessive handwashing and severe OCD may agree their goal as 'better family relationships'. The current way of working would be to measure change in symptoms (potentially alone), but what is suggested is a focus on what is important to them, which may be the family relationships and measuring any change in that area. The intervention may remain CBT for handwashing, and you may still be interested in symptom change, but this would be for the purpose of improving relationships: even if the mechanism by which they improve is through work on handwashing. This links to the example of work done

already on needs-based groupings and the suggestion that outcome measurement is chosen based on collaborative discussions to determine what is most important to the service user (Wolpert et al., 2015). This would also suggest that training in the use of standardised tools could focus on using goals to guide measurement choices and agreeing with young people and families around this.

However, building on previous research (Batty et al., 2012; Jacob et al., 2015; Weisz et al., 2011), these findings suggest that there are outcome areas that young people and families find important that are not explored by existing commonly used tools. These areas include more proximal, existential factors such as understanding difficulties, letting people know what help they need, feeling able to talk about things, thinking things through, feeling more confident and talking about thoughts and feelings. This raises a number of issues. Due to this lack of coverage of standardised tools matched to themes identified by goals, we may need to develop or look for new tools that capture these areas. In other countries (e.g. North America), there are established measures for targeting not only the focus of treatment but also the tools used to track treatment progress (i.e. Top Problems; Weisz et al., 2011). The findings of this research provide a framework for clinicians in the United Kingdom to select outcome measures and clinical feedback tools based on goals that have been set, enabling them to personalise care and outcomes within widely used models of routine outcome measurement (CORC, Fleming et al., 2014; CYP IAPT, Law & Wolpert, 2014).

As discussed, available standardised measurement for areas such as coping and understanding is either unavailable or not fit for purpose, for example, coping measures based on stress (Causey & Dubow, 1992); resilience bound by cultural and contextual understandings (Ungar et al., 2008); and youth empowerment and self-esteem questionnaire items being too broad (Childs et al., 2013). This also leads to the question of whether clinicians need to have more explicit conversations with young people and families about what services are there for. For example, is it ever appropriate for a goal to be to understand something, or is it only appropriate for understanding to be a by-product or a mechanism of the goal? Consequently, it is important to continue to consider goals as measurement alongside other tools to ensure a breadth of information is captured (Law & Jacob, 2015).

Limitations

The goals initially analysed were an approximation of a wider clinical conversation, the richness of which was unlikely to have been transferred to the goal description. We cannot be sure of how consistently goals were recorded; some may have been very high-level goals, while others were more specific goals. It also means that the accuracy of the goal content cannot be easily verified. Other research based on a similar dataset suggested that there is a high proportion of missing goals data at the outset of therapy from routinely collected information (Wolpert, Ford et al., 2012). However, this dataset was fairly large and from varied types of services which is positive in terms of sample selection and generalisability, although the effects of the self-selecting sample are unknown.

The goal themes used for this research have not been validated any further than the initial conception study, which has implications on how they can be used in further research. However, in the initial research, the coders did obtain good inter-rater reliability, which is encouraging. As discussed elsewhere (Jacob et al., 2015), the nature of how the data were collated resulted in the inability to link all data to demographic information. Therefore, the analysis was not broken down by age, but some of the standardised tools include age limits for use.

Conclusion

We present a fundamental reformulation of how outcome and feedback tools should be chosen and used, based on our findings that suggest there is a place for using goals as a way to ensure that all

aspects of preferred outcome are covered, which is key to a person-centred focus, leading to better shared decision-making and personalised care (Kazdin, 1977; Mulley, Trimble, & Elwyn, 2012).

Clinical implications

As most of the goal themes matched more than one standardised tool, outcome measurement should be chosen based on collaborative discussions to determine what is most important to the individual. This presents opportunities for more collaboration: suggesting a couple of standardised tools to the young person/family and asking them which one seems to make most sense to them to use to track change in therapy.

When determining which tools to use, clinicians may want to consider the specific goals the person has set, rather than the nature of difficulties. This is a move away from a medical model of outcome measurement that matches tools to diagnosis. We may need to develop or look for new tools that capture the areas identified as not currently in scope of the existing commonly used standardised tools.

Further training may be needed to help clinicians collaborate with young people and families to set more clinically helpful goals that give a focus to the work and also point to more appropriate tools to track progress. For example, process-oriented goal themes such as 'talk about feelings and thoughts' might need more clarity to help decide on an appropriate intervention: a young person may feel that talking about feelings and thoughts might help them feel less depressed (outcome goal); this may be more helpful to focus the work and match the goal with an appropriate tool to use. A good analogy is to think about outcome goals as a destination for travel ('I want to go to America') and process goals as the vehicle to get you there ('I want to go by plane'). Process goals are not much use clinically without outcomes goals. 'I want to take a plane' (process) because 'I want to go to America' (outcome).

There is a question of whether clinicians need to have more explicit conversations with young people and families about what services are there for (particularly public- or insurance-funded services). The THRIVE model (Wolpert, Harris et al., 2015) sets out five areas of need or care that goals may fit into: Thriving (having none or very minor current problems), Coping (having difficulties that pose low risk and the family choose to 'cope' without further direct treatment), Getting Help (the family wants treatment and there is a good evidence-based intervention that fits with the family's goals), Getting More Help (long-term or more intensive treatment is needed to help reach a goal) and Risk Support (the young person has difficulties that present high risk but no suitable treatment is available, either because the young person chooses not to engage with treatment or none is available). A good goal-focused first assessment or choice appointment (The Choice and Partnership Approach [CAPA]; York & Kingsbury, 2013) can help match the family with the right area of care based on their goals as well as match the goal to a standardised tool.

Finally, the suggestion is to continue to consider goals as both useful clinical feedback tools and outcome measurement alongside other standardised tools to ensure a breadth of information.

Declaration of Conflicting Interests

Funding

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