Research Article
Ερευνητική εργασία

The development of manualised cognitive behaviour treatment for adults with mild intellectual disability and common mental disorders

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People with intellectual disability are at a greater risk of developing common mental disorders. In the United Kingdom, the National Institute for Health and Clinical Excellence guidelines recommend cognitive behavioural therapy (CBT) as the treatment of choice for such problems. Even though there is growing evidence that people with mild intellectual disability can benefit from CBT, there are no manuals to assist in the delivery of the treatment. Previously published material from journals and books describing both CBT in people with intellectual disability and the general population was reviewed to create the first draft. Further consultations with professionals and service users with intellectual disability on the content, accessibility and language that was used in the manual were carried out. Specific materials were developed for use in the therapy sessions and for homework. The manual, written for trained therapists, provides generic information about communication and thinking styles in people with mild intellectual disability and describes in detail how to conduct each session. It contains also contains the materials and a leaflet to help carers support the treatment. Manualised treatments are helpful in maintaining a consistent approach to treatment and may be more beneficial for hard to reach population groups.

Key words: Cognitive behavioural therapy, manual, intellectual disability.

Introduction

Recent studies have highlighted that people with intellectual disability* are at an increased risk of developing common mental disorders, with depression and anxiety being diagnosed most commonly.[1] Richards et al (2001)[2] and Maughan et al (1999)[3] compared adults with and without intellectual disability in a British birth cohort and found a four- to six-fold increase of common affective disorders in adults with mild intellectual disability.

The National Institute of Health and Clinical Excellence (NICE) in the United Kingdom advocates cognitive behavioural therapy (CBT) as one of the most effective forms of treatment for depression and anxiety disorders in the general population.[4,5] Current policy by the Department of Health[6] states that people with intellectual disability should have the same access to healthcare as those without intellectual disability. However, whilst CBT is extensively being used in the general population, it is not readily available to people with mild intellectual disability who often have cognitive and complex communication needs. Developing a manualised CBT guide would be the first step to ensure that such psychological interventions can be delivered to people with intellectual disability who may access not just specialist but primary and/or secondary mental health services.

Despite previous concerns about the ability of people with intellectual disability to use psychological interventions, there is now growing evidence that CBT is being offered in clinical practice and it is suitable to treat a range of mental health problems in people with intellectual disability. These include psychosis,[7] obsessive-compulsive disorder,[8] anxiety,[9,10] depression[11–13] and anger.[14,15] Prout & Nowak-Drabik[16] conducted a meta-analysis on the efficacy of psychotherapy in people with intellectual disability. They found a total of 92 studies that evaluated the effects of psychotherapy in children and adults with mild to severe intellectual disability from a variety of settings including community and residential care. They reported that 13% of the studies reviewed used cognitive/cognitive-behavioural techniques. Their findings also suggest that cognitive/cognitive-behavioural interventions appear to result in moderate degree of change as reported by the outcome measures and effectiveness in terms of benefit to people with intellectual disability. However, most CBT interventions have previously focused on observable behavioural rather than cognitive aspects of the disorders.[17,18]

Evidence of CBT in depression

A single case study in mild intellectual disability showed improvements in behavioural symptoms of depression, e.g. crying and depressed mood, following CBT.[19] Furthermore, Lindsay et al (1999)[10] found that five individuals with mild to moderate intellectual disability reported a 25% decrease in scores of depression (on the Beck Depression Inventory and Zung Depression Scale) following individual CBT intervention, the results for which were maintained at six months follow-up. McCabe et al (2006)[12] developed a 5-week group treatment programme that was designed to enhance social skills, promote participation in social activities, identify and change negative cognitions using CBT techniques. The treatment group showed significant improvement in scores of depression, positive feeling about the self and reported less negative automatic thoughts compared to a waiting list control group.[12] These positive changes were maintained at 3-month follow up. McGillivray et al (2008)[13] modified McCabe et al (2006)[12] CBT intervention and trained 13 staff members employed at two different community-based agencies to administer a 12-week group CBT program to 47 individuals with mild intellectual disability and symptoms of depression. Results showed significant improvements cognitive and behavioural aspects of depression and changes in automatic negative thoughts for the individuals who received the CBT intervention compared to a waiting list control.[13]

* Intellectual disability is defined (ICD10) as reduced IQ (<70), deficient adaptive capacity and being evident during the developmental period. In Mild intellectual disability IQ ranges from 50 to 69 and the person has sufficient verbal ability and may live independently.

Evidence of CBT in anxiety

Lindsay et al (1997)[9] used adapted CBT techniques to treat anxiety in two cases with mild intellectual disability and reported positive changes on the Beck Anxiety Inventory and improvements in anxiety related behaviour reported by staff observing the patients. These results were maintained over 18 months. The authors reported significant reduction in self-reported measures of anxiety in 15 individuals with mild/moderate intellectual disability who received an average of 23 individual CBT sessions.

Aim

Despite CBT techniques being used n clinical settings with published reports showing positive changes in symptoms of depression and anxiety, there are no specific guidelines describing how it should be carried out in individual therapy.[20] We report the process by which we developed a cognitive behavioural therapy manual for CBT therapists to administer individual therapy to people with mild intellectual disability who suffer from common mental disorders. This was the first phase of a feasibility study of the evaluation of manualised individual CBT for common mental disorders in people with mild to moderate intellectual disability.

Material and method

We undertook a literature search to find relevant information and drafted a preliminary outline of the manual. We consulted with experts regarding the content before a full draft was produced. Concurrently, we developed accessible materials suitable for people with intellectual disability, which were piloted in a service user consultation group. The developmental process was led by the research team comprising of specialists in the field of intellectual disability, CBT and health interventions (psychiatry, psychology, speech and language therapy, research methodology). An accessible information worker with several years of experience in developing accessible information for people with intellectual disability acted as an advisor to the project.

Literature search

We conducted a literature search using MEDLINE, PsycINFO, PUBMED and EMBASE, in addition to specialist journals including Journal of Applied Research in Intellectual Disability (JARID), Journal of Intellectual Disability Research (JIDR) and the American Journal on Intellectual and Developmental Disability (AJIDD) using the following keywords: "cognitive behav* therap*", "CBT", "learning disabilit*" "intellectual disabilit*", "mental retardation", "depression" and "anxiety". Relevant books and book chapters describing cognitive behaviour interventions in the general population (i.e. children, adolescents and adults) and in people with intellectual disability were hand searched for information and materials. CBT materials for homework tasks were mainly adapted from the following sources: Think Good Feel Good,[21] Wilson and Branch,[22] Alex Kelly[23] and Gulbenkoglu & Hagiliassis.[24]

Suitability for treatment

Several studies have found that people with intellectual disability have the prerequisite skills to understand the concepts of CBT and in order to engage in this form of therapy.[24–26] These include the ability to link situations to emotions,[24] to correctly identify emotions[25] and to have the capacity to differentiate between thoughts, feelings and behaviour.[26] Sams et al[26] found that the identification of behaviours and feelings is linked to verbal ability and thoughts with general IQ. Thoughts, feelings, and behaviours are therefore more likely to be understood and correctly identified by people with higher verbal ability and IQ. People with mild intellectual disability perform better when linking situations to emotions, rather than links involving beliefs, but many may require some training in cognitive mediation before CBT treatment.[24]

The individual's level of comprehension, level of expression, their ability to self-report and self-regulation skills are all important factors in assessing suitability for CBT in people with intellectual disability.[27] Knowledge acquisition requires skills such as controlling attention, and effective memory function.[28] People with intellectual disability may have impairments in both of these domains which may affect concentration span, ability to screen out extraneous information and to attend to relevant stimuli.[28,29] Thus, the therapist needs to control the pace of the session, for example, slowing down to reduce the amount of information the

individual is required to process and repeating information to support retention. The use of visual aids such as pictorial representations, drawings and signs (e.g. Makaton, Walker & Armfield[30]) for certain tasks such as mood monitoring, thought-feeling diaries, presenting temporal concepts and identifying automatic negative thoughts would help facilitate understanding and processing of relevant information.[31] Other modifications include the use of repetition and encouraging "overlearning" in some scenarios, along with a need for flexibility in the number and length of the sessions offered.[20] Previously modified CBT interventions in people with intellectual disability for the treatment of anger have highlighted sections on psycho-education as essential.[32]

How to manage homework tasks

Evidence from research in the general population indicates that homework compliance in CBT is associated with improvements in treatment outcomes.[33] This provides the individual with an opportunity to practice new skills and incorporate them into his/her daily routine. Rose et al (2005)[34] found that in group CBT for anger, service users who were accompanied by a member of care staff (either from their residential home, place of work or from a community support team) made better progress in the therapy. By having a carer/support worker in the session helped to provide greater continuity between sessions and staff members were more able to assist the participants in practicing skills outside the session.[35] Compliance with homework tasks depends on a number of factors such as therapist and/or clients' attitudes towards the tasks and task characteristics (such as the difficulty of the task and the length of the task), these factors are further discussed elsewhere.[36]

Developing accessible materials (service user workbook)

We developed the service user accessible materials using easy read guidelines that are based on "Make it clear" guidelines on accessible information by MENCAP,[37] a leading UK wide charity for people with intellectual disability and their carers. The two main components of delivering accessible information are to use simpler language and pictures to support the written message. The language needs to be jargon-free and if a difficult word or concept must be used (i.e. "core beliefs") it should be accompanied by a simple definition. Sentences should be as short as possible. Other guidance suggests that there should be one or two ideas expressed per sentence.[37] Other tips of accessible information can be found in table 1.

In our manual we use pictures from the Photosymbols Version 3 (www.photosymbols.com) which is the preferred way of developing accessible information for people with intellectual disability and is the primary symbol resource for many organisations that produce easy read information. The Photosymbols collection contains 3000 pictures and many of their models are people with intellectual disability themselves. These images are easier to recognise and understand because they are photorealistic and in colour. They work well as symbols because they have been cut out to remove the extraneous detail often found in photographs. The text and supporting images should be seen as a starting point in the communication of the information in the workbook. Talking around the information, giving different examples and checking back for evidence of understanding should all be part of the therapist's approach.

Consultations

Consultation with experts

Once a draft of the therapist's manual was completed components were consulted upon in a two hour session with 17 participants (10 consultants and seven senior trainee psychiatrists) who have had several years of clinical experience in working with

Table 1. Tips on accessible information.

- Text in an easy to read Sans Serif font (e.g. Arial)
- Main body of the text should be size 16 point or higher
- Document should be laid out so that the pictures are on the left side of the page and the text on the right; it allows the service user information to be placed first as the English language is read from left to right
- Use bullet points for lists
- Text should be laid out so that there is white space between the sentences and the text is not densely together (this usually occurs naturally when pictures are inserted into the document)

this client group. The participants discussed the content of the draft manual sections and provided comments and other amendments for sections. Details of the feedback received are shown in table 2. We also asked the CBT course tutor of an English University that provides CBT training to professionals working in intellectual disability to comment on the manual contents and layout.

Consultation with service users

The worksheets and homework materials were taken to a service user consultation group that has previously helped with producing several service related accessible materials over a five year period. The group members represent a range of people with intellectual disability and levels of communication. They have previously worked on many of the Camden Intellectual Disability Service publications such as brochures, leaflets, the intellectual disability pages of the Local Authority website, complaint forms, posters and subtitles for audio/visual materials developed for the wider service users group.

The two consultation sessions with the service users focused on the use of language, the use/appropriateness of photosymbols, the layout of the documents and the content of the information, to check that adaptations and modifications to the CBT materials were suitable and could be understood. We discussed the materials to ensure that abstract concepts were successfully presented in a tangible manner. Each consultation consisted of seven participants with mild- moderate intellectual disability. The group was first briefed on the purpose of the consultation by KA using guidelines to accessible information to structure the discussion and facilitated by RL (accessible information worker). Five worksheets including the cognitive model, the body map of symptoms of anxiety, the concept of "future" in relation to the cognitive triad, the concept of core beliefs and the assertiveness scale were selected for consultation. Participant feedback indicated that the information in the documents was understood when text was read out and explained with further examples. Further details are shown in table 3.

Table 2. Expert consultation feedback.

- Inclusion of visual aids
- Inclusion of list about therapist skills
- Describe session duration and content
- Describe possible outcomes

Results

The manual describes a step by step approach to CBT for depression and anxiety in people with mild to moderate intellectual disability. It is divided into two separate parts.

Part 1 provides a review of depression, anxiety, the cognitive behavioural approach to therapy, and the

Table 3. Service user consultation feedback.

- The CBT model: the participants were consulted on the adapted CBT model illustration developed for with people with intellectual disability in the project. The participants understood that thoughts, feeling and behaviour were linked when the model talked through with lots of examples
- Body map of symptom of anxiety: The group went through the symptoms one-by-one and were asked if they understood the symptoms. For abstract symptoms such as "butterflies in the stomach", the group was asked to describe it in their own words. The term was understood and alternative words used where, "funny feeling inside the tummy" and "feeling nervous". The group also raised concerns that even though they understood the symptom "tingling feeling in your fingers and toes" they knew others who might not understand it
- The concept of future (the cognitive triad): It was agreed in the group that people would generally find it difficult to understand the term "future". The group decided on an alternative term which was "ahead" or "doing new things"
- The concept of core beliefs: One of the principles of accessible information is that if a substitute word is not found, the term needs to be explained. Since the idea of "core beliefs" in very important in CBT, it would be important to teach/familiarise the client with the term. Therefore, it was important to see if the explanation was accessible. The service users were able to easily grasp the concept and understand the term core beliefs with examples
- Assertiveness scale: The terms (assertive, aggressive and passive), the definitions and the layout of the continuous scale were consulted upon, and agreed to use in the manual

therapeutic relationship in the context of intellectual disability. The latter half of this section focuses on communication and explains how the therapist can modify their communication in a therapeutic setting to more effectively address the needs of the clients. Furthermore, to assess the service user's communication and cognitive skills, we have decided to include a language assessment that the therapist is required to administer in the initial sessions to gauge the service user's strengths and verbal limitations, in order to aid appropriate engagement in the treatment. The Test for Receptive Grammar (TROG-2; Bishop[38]) is a receptive language test that is commonly used by Speech and Language Therapists, in assessing understanding of receptive grammar and helps tease apart possible reasons for failing to understand what is said.

Part 2 describes in detail the process of therapy over 18 sessions; the first five sessions are about the introduction of the service user to the treatment and the assessment of his/her level of communication and cognitive level. The intermediate phase comprises sessions six to 15 and the final phase sessions 16–18. The manual focuses on cognitive aspects of treatment such as thinking style errors, the cognitive triad, core beliefs and linking thoughts, feelings and behaviours (i.e. using the ABC form in an accessible format). We have also included a chapter on psychoeducation with accessible information on symptoms of depression and anxiety and exercises that can help the service user recognise his/her symptoms effectively. All materials are included on a CD within the manual so they can be reproduced as needed.

Discussion

The manual is designed for therapists who have CBT training, but have little to no experience in working with clients who have intellectual disability. It outlines a therapeutic protocol that can be applied in treatment. The accessible work/homework sheets are incorporated into the manual along with an outline on how they could be used during the sessions. The work/homework sheets are designed as stand alone tasks to provide even greater flexibility in how they can be used.

Homework and carer support

McVilly et al (1997)[39] reported that it is useful to provide educational support and additional information for the carer to improve his/her ability to provide support in therapy. Availability of a carer/support worker is an integral part of the treatment to help the service user with homework tasks, promote adherence to treatment and prepare for the sessions. Where necessary the carer/support worker should also be involved in the sessions to offer encouragement and motivation. We also see the involvement of the carer/support worker as essential for the service users to move successfully through the treatment programme. However, Willner (2006)[40] argued that the therapist also needs to be aware of the support worker's level of engagement and motivation in addition to that of the service user's.

Advantages and limitations of manualised interventions

As CBT in intellectual disability is relatively new in clinical practice and research, manuals can be advantageous and helpful as they allow for consistency in the delivery of the intervention, facilitate training professionals in specific clinical techniques and strategies and assist therapist supervision.[41] Wilson (1998)[42] argued that treatment manuals encourage a pragmatic approach to therapy without hindering clinical practice. A manualised treatment does not supersede clinical judgment but allows a consistent evidence based perspective which may be more likely to have a successful outcome.

Implications for research and clinical practice

This is still a developing area in research and clinical settings and a manual would be a valuable tool for training professionals in the therapeutic skills required to work with this population group. This manual has been developed for accredited CBT therapists; however the manualised treatment program requires further evaluation if it is to be used by other health professionals or frontline staff who have a regular contact with the service users but may not have received training in CBT.

Η ανάπτυξη εγχειριδίου γνωσιακής-συμπεριφορικής θεραπείας για ενηλίκους με ήπια νοητική υστέρηση και ψυχικές διαταραχές

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Άτομα με νοητική αναπηρία ευρίσκονται σε μεγαλύτερο κίνδυνο να αναπτύξουν κοινές ψυχικές διαταραχές, όπως κατάθλιψη ή άγχος. Στο Ηνωμένο Βασίλειο, το Εθνικό Ινστιτούτο Υγείας και η Κλινική Αριστείας συνιστά γνωσιακή-συμπεριφεριολογική θεραπεία (CBT) ως τη θεραπεία επιλογής για αυτές τις παθήσεις. Η υπάρχουσα βιβλιογραφία και η Κλινική εμπειρία δείχνουν ότι η CBT χρησιμοποιείται αρκετά σε υπηρεσίες για άτομα με νοητική υστέρηση παρόλο που δεν υπάρχει ικανοποιητική ερευνητική βάση όσον αφορά στα θετικά αποτελέσματα της μεθόδου. Επίσης δεν υπήρξε μέχρις πρόσφατα εγχειρίδιο που να περιγράφει με λεπτομέρεια την εφαρμογή της σε Κλινικό περιβάλλον. Στο άρθρο περιγράφουμε το πρώτο στάδιο μιας ερευνητικής μελέτης που μας επέτρεψε να αναπτύξουμε το θεραπευτικό εγχειρίδιο. Δημοσιευμένο υλικό από περιοδικά και βιβλία που περιγράφει τόσο CBT σε άτομα με ήπια νοητική υστέρηση όσο και στον γενικό πληθυσμό επανεξετάστηκε για τη δημιουργία του πρώτου σχεδίου. Δύο περαιτέρω διαβουλεύσεις πραγματοποιήθηκαν με: (α) Ψυχιάτρους, ψυχολόγους και άλλους ειδικούς στη νοητική υστέρηση και (β) με τους χρήστες υπηρεσιών για νοητική υστέρηση ώστε να ελέγξουμε αν το περιεχόμενο, η προσβασιμότητα και η γλώσσα που χρησιμοποιήθηκε στο εγχειρίδιο ήταν κατάλληλα. Συγκεκριμένα υλικά που στηρίζονται σε εικόνες και απλοποιημένο λόγο αναπτύχθηκαν για χρήση στη διάρκεια της θεραπείας και για ασκήσεις στο σπίτι ή σε άλλους χώρους. Το εγχειρίδιο, γραμμένο για εκπαιδευμένους θεραπευτές περιέχει κεφάλαια τα οποία περιέχουν γενικές πληροφορίες σχετικά με τον τρόπο επικοινωνίας και σκέψης των ατόμων με ήπια νοητική υστέρηση και περιγράφουν λεπτομερώς τον τρόπο με τον οποίο ο θεραπευτής διαχειρίζεται τη συνεδρία. Περιέχει επίσης ένα CD με τα υλικά και το φυλλάδιο για τους υποστηρικτές ή τα μέλη της οικογένειας ώστε να βοηθήσουν το άτομο στη θεραπεία. Ατομική CBT που στηρίζεται σε εγχειρίδιο βοηθά στη διατήρηση της ποιότητας και τη συνεπή προσέγγιση της θεραπείας σε διάφορα περιβάλλοντα. Παράλληλα, προσφέρεται στο να έχουν καλύτερη εμπειρία αυτής της αντιμετώπισης ειδικοί πληθυσμοί που συνήθως έχουν δυσκολία στην πρόσβαση υπηρεσιών ψυχικής υγείας.

Λέξεις ευρετηρίου: Γνωσιακή-συμπεριφορική θεραπεία, εγχειρίδιο, νοητική υστέρηση

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