Co-design and development of an multi-component anxiety management programme for people with an intellectual disability.

Authors

Daniel Acton

Robert Waites

Sujeet Jaydeokar

Steven Jones

1. Cheshire and Wirral Partnership NHS Foundation Trust, UK
2. Centre for Autism Neurodevelopmental Disorders and Intellectual Disability (CANDDID), UK
3. University of Chester, Chester Medical School, UK

Abstract

Purpose

This paper aims to identify the lived experience of anxiety from people with intellectual disabilities and being co-design partners in developing a multi component approach to the management of anxiety.

Design/methodology/approach

The development of an anxiety manual and programme was part of a service development which allowed existing and establish psychological therapies be adapted for people with intellectual disabilities. A qualitative approach was used to understand the views of people who experience anxiety on a daily basis. The feedback generated was used to make modifications to the manuals and anxiety management programme.

Findings

The study has demonstrated the value of involving people with intellectual disabilities in co-production of an anxiety management programme. Additional findings identified the rea life challenges and experiences of the impact anxiety has on people's lives.

Originality

This is the first study to involve people with intellectual disabilities in developing an anxiety management programme as co-production partners. This paper underlines the value of understanding and involving people as co-production partners in developing clinical interventions.

Key words: learning disability, collaboration, involvement, mental health, psychological therapy

Introduction

There is an estimated 1.2 million people with an intellectual disability in England with approximately 30-50% of these people suffering with mental health problems. Anxiety related difficulties ranging from between 7% to 40% (Reid, Smiley, & Cooper, 2011; Smiley, 2005). However, this figure is thought to be higher with underreporting and lack of effective diagnosis impacting on prevalence rates (Cooray & Bakala, 2005). A comparative study identified higher rates of mental illness in people with intellectual disability than the general population (Cooper, Smiley, Morrison, Williamson, & Allan, 2007) with (Deb, Thomas, & Bright, 2001) identifying higher rates of anxiety in older adults.

Anxiety disorders have been found to increase over a person with intellectual disability life course, with exposure to negative life events being a predictive factor for psychological trauma (Tsakanikos, Bouras, Costello, & Holt, 2007; Wigham, Taylor, & Hatton, 2014).

Anxiety related conditions are increasingly prevalent within people with Intellectual disability (Bowring, Painter, & Hastings, 2019; Cooper et al., 2015). However, there is evidence to suggest a greater prevalence of anxiety in people with autism and intellectual disability (Bakken et al., 2010).Furthermore, the co-morbid association between autism and intellectual disability result in a greater propensity for psychiatric disorders (Hill & Furniss, 2006). The presence of anxiety in people with intellectual disability and autism has been found to have a greater association

with specific phobias, social anxiety and obsessive compulsive disorder (Helverschou & Martinsen, 2011).

Despite this high prevalence, there is limited evidence of effective and sustainability of any current treatment interventions (Bailey & Andrews, 2003; Dagnan, Jackson, & Eastlake, 2018; National Institute for Health and Care Excellence, 2016). A meta-analysis examining the effectiveness of psychological therapies for people with mild to moderate intellectual disabilities found limited evidence of efficacy within studies (Koslowski et al., 2016). Modified cognitive behaviour therapy (CBT) for anxiety related problems in people with intellectual disabilities have demonstrated limitations and any sustained therapeutic impact (Hassiotis et al., 2013; Unwin, Tsimopoulou, Kroese, & Azmi, 2016). Although, CBT has demonstrated to have some effect but small samples sizes and lack of scientific rigor were found to be significant in study outcomes (Dagnan et al., 2018). Furthermore, it was noted alternate approaches to psychological interventions are needed to improve clinical practices.

Studies have shown anxiety has a significant negative impact on the daily lives of people with Intellectual disability (Ali, King, Strydom, & Hassiotis, 2015; Cooper et al., 2007). The impact on those people with more significant levels of Intellectual disability with limited verbal communication , can often manifest in behaviours that challenge (Bowring et al., 2019; Challenging Behaviour Foundation, 2021). The health impact is often compounded with people requiring high doses of medications to manage symptoms of anxiety (Axmon, El Mrayyan, Eberhard, & Ahlström, 2019; Deb, Unwin, & Deb, 2015). This is in contrast with national campaigns to 'stop over medicating people with a learning disability and/or autism' and NICE recommended guidance (National Institute for Health and Care Excellence, 2016; NHS England, 2016).

NICE clinical guidelines suggest psychological therapy be adapted for people with intellectual disabilities identifying CBT, relaxation and graded exposure as recommended treatment for anxiety (National Institute for Health and Care Excellence, 2016). Additional, psychological therapies such as ,mindfulness is an effective therapy providing people with intellectual disability are given adequate support and guidance to practice requisite skills (Idusohan-Moizer, Sawicka, Dendle, & Albany, 2015; Robertson, 2011). More recently, a systematic review examined acceptance and commitment therapy for the treatment of anxiety in people with

intellectual disability. This study noted the potential for adapted acceptance and commitment therapy being incorporated into psychological treatment programmes (Byrne & O'Mahony, 2020).

Most therapies for the treatment of anxiety have used a single based therapeutic model, with variable effectiveness (Koslowski et al., 2016; Unwin et al., 2016). The limited evidence of long term sustainability of psychological approaches underlines the need for alternate methods for the treatment of anxiety related issues. Non-pharmacological approaches are needed to deliver a range of effective therapies to support people to improve their self-management skills. . It is considered, further exploration of psychological approaches should be developed to understand the effectiveness for use within clinical practice (National Institute for Health and Care Excellence, 2016).

Aims and objectives

The aim of this study was to make improvements to the treatment of anxiety in people with intellectual disability. Co-producing a treatment programme with people with a lived experience was essential in the development of a multi-component anxiety management programme. The key objectives of the project were:

- To work with an engagement group, refining and adapting psychological therapies to an anxiety management programme manual for people with ID.
- To understand the lived experience of anxiety from people with intellectual disability
- To work alongside an engagement group, refining and adapting psychological therapies to develop an anxiety management programme manual
- To co-design an accessible user guide to allow engagement from people with more severe intellectual disability.
- To explore the thoughts and experiences of participants in co-producing the manual

Method

The study was conducted in a NHS community intellectual disability service. The service provides specialist care and treatment to people with intellectual disability, their families and carers. The service offer a range of multi-disciplinary specialist interventions and support to meet the healthcare needs of people with intellectual disability. .

A total of four people consented to participate in the project. All participants had a mild intellectual disability with an equal number of male and female participants. Two participants had a diagnosis of autism. All participant experienced difficulty with anxiety related issues on a daily basis.

To understand the lived experience of anxiety participants focus groups were used to collect information about how anxiety impacted upon their lives. Content analysis was used to evaluate the feedback from participants to understand areas of the manual which required further modification. The suggested changes included the structure of sessions, changes to graded exposure approach, using alternative images and terminology. The initial feedback formed the basis of development for the multi-component anxiety management programme (M CAMP-ID). By using an iterative approach within the analysis the feedback obtained was used to identify areas of further refinement of the programme content and accessible user guide. Feedback from participants was continually analysed throughout the development process using the information provided to make modification to the manual and user guide.

Figure 1 provides details of feedback questions.

Figure 1.

Are the sessions easy to follow?

Are the words used in the manual and user guide easy to follow and understand?

What do you think of the Images and pictures in the user manual?

Can you think of any changes we could make to help people better understand the information?

Do any of the sessions need changing or is there any information you don't like?

Do both the user and clinician guide work together?

Can you think of any other changes which are needed?

Discussion groups

Two separate discussion groups were completed using open ended questions. This approach was used to gain an awareness of the individual challenges participants experienced in their

everyday lives. We explored how anxiety impacted individuals to gain a better understanding of peoples self-management strategies. Insight into the participants lived experience provided additional insight into the effectiveness of current clinical interventions.

Additional, feedback on the initial draft M CAMP-ID programme was obtained with prior agreement from all participants. The discussion group sessions were used to capture participants thoughts of the proposed session structure, content and accompanying user workbook and programme manual.

Developing the multi component anxiety management programme

Adaptation of several psychological therapies for the development of the anxiety management manual project used a systematic approach by (Hwang, 2009). The adaptation follows a five stage process (Box 1.).

Box 1.

Phase 1: Generating Knowledge and Collaborating with Stakeholders

Phase 2: Integrating Generated Information with Theory and Empirical and Clinical Knowledge

Phase 3: Review of Culturally Adapted Clinical Intervention by Stakeholders and Further Revision

Phase 4: Testing the Culturally Adapted Intervention

Phase 5: Synthesizing Stakeholder Feedback and Finalizing the Culturally Adapted Intervention

A co-production approach was chosen for this project. Co-production is a method of involving people who use healthcare services to design and support developments to treatment interventions (NHS England, 2017). Pivotal to improving healthcare services and treatment interventions is involvement from people with a lived experience (Health Quality Improvement Partnership, 2017). There is clear evidence people with lived experience are ideally placed to advise on the type of support and interventions which are required to make improvements in people's lives (INVOLVE, 2018). An essential element to this approach are the voices of people with a disability in the creation and delivery of healthcare services (Fenney, Wellings, Lennon, &

Hadi, 2022). This approach was adopted for the project and included people with intellectual disability with lived experience of anxiety related disorders as co-production partners.

To support involvement and co-production processes information on the key underlying psychological principles for the sessions was provided to participants. The information enabled discussion and a clear explanation provided to participants of the key psychological principles.

A project task and finish group was created consisting of the four participants who provided valuable feedback from focus groups session to support the initial development of the programme manual. The draft manual was provided to participants who were subsequently asked to consider; treatment principles, optimum session arrangement, presentation of sessions format, accompanying materials and length of each session. Feedback questionnaires were provided in advance of the development sessions to enable facilitators to support participants to prepare feedback.

The anxiety management programme consists of eight therapy sessions, which utilise a range of psychological approaches to achieve an individual's therapy goal. The therapy sessions apply a key focus on the identified area of need with each session revisiting pre-agreed goals.

The multi-component anxiety management programme (M CAMP-ID) uses a goal-based approach to therapy. The goals are used to focus on what the patients wants to achieve themselves, surrounding their anxiety. Training for clinicians using this approach allows adaptations to be made to make the treatment more accessible for people with both mild and moderate intellectual disability. The M CAMP-ID programme is integrative in terms of psychological models/therapeutic modalities and uses a holistic approach to the promotion of wellbeing.

The programme uses graded exposure to systematically desensitise participants to increasing aspects of the anxiety causing situation or problem. This process is completed in parallel with multiple psychological therapy sessions to support the exposure exercises by developing self-management skills during each of the sessions. A range of strategies including mindfulness exercises, acceptance and commitment therapy are used to bring about change to thinking processes. Dialectical Behaviour Therapy (DBT) sessions focus on teaching people to live in the moment and develop real life coping strategies to deal with stress and anxiety. Relaxation,

wellbeing and lifestyle sessions provide a framework for patients to work towards supporting the self-management of individuals anxiety and stress.

The inclusion of an accessible user guide connects with the clinician guide to support facilitation of the programme. All session begin with a recap of previous session to maintain continuity and identify further learning prior to progressing onto the next session. Movement through the anxiety management programme aims to maintain clinical focus and achieve the patients identified goal. All sessions begin and end with an exercise to develop breathing techniques.

Table 1 provides an overview of the session format with a brief description of the programme content.

Table 1.

Session 1: About this workbook	Overview of programme and support individual to identify therapy goal. Person centred planning and commitment to programme.
Session 2: Healthy mind and body.	Activity based session using multimedia aimed at promoting healthy lifestyle changes to promote well-being.
Session 3: What is Anxiety?	Interactive activities to support understanding and recognition of anxiety. Focus on feelings and behaviours, using body mapping exercise.
Session 4: Graded Exposure	Systematic desensitisation planning and development of individual plan.
Session 5: Talking about anxiety	Developing understanding of expressing anxious self to others using key words, pictures and body language exercise.
Session 6: Working on my anxiety skills	Practical based mindfulness session exploring ways to implement this throughout the day as part of a routine.

Session 7: learning new skills	Scenario based session - exercises using anxiety provoking scenarios of a range of commonly presented environments / situations that can cause anxiety.
Session 8: Review of my anxiety management plan.	Programme overview/recap and review of intervention goals. Plan to repeat sessions as required.

Analysis

The focus group interview notes were transcribed and coded into themes using six phase thematic analysis (Braun & Clarke, 2006). The emerging themes where identified following DA, SJ and SLJ reading and re-reading the transcript several times to familiarise themselves with the content and meaning. The second phase generated initial coding during which DA, SJ & SLJ independently identified codes from within the data from participants words and descriptions. The third phase involved searching for themes through analysis by combining related codes to identify overarching themes. Comparisons and differences in proposed codes where frequently discussed between DA, SJ and SLJ until final agreement was reached. In the fourth phase DA and SLJ examined specific quotations which were subsequently grouped into themes. The fifth phased involved naming themes and providing a narrative. In addition, DA, SJ and SLJ determined if any of the themes required a sub-theme. The final phase DA and SLJ gathered selected themes and quotes to illustrate participants feelings and experiences.

Results

Co-design of the multi-component anxiety management programme

The project allowed collaboration as a iterative process with feedback used to make adaptions and modifications to the structure and length of sessions. All participants provided feedback with general agreement on the content of the manual and user guide. The adaptation of different psychology therapies provided an opportunity for participants lived experience be captured and incorporated into the therapy sessions.

By dovetailing the user guide and clinician manual it was felt the programme would be more inclusive for people with a more severe intellectual disability. However, group members considered the adaptation process created challenges in making the programme user guide accessible. The challenges were experienced in aligning the clinician manual with the user guide and maintain uniformity within sessions. The co-design partners provided feedback to allow for several modifications be made to the user guide. A practical solution was to use different coloured shapes to code each exercise to maintain unity. It was felt this approach provided an additional opportunity to maintain engagement in each session and limit disruption to therapeutic delivery.

There was agreement from participants on the structure and content of the anxiety management manual and programme resources. Co-production partners underlined the need for continual self-management strategies to run throughout the programme to allow for clinician led instruction to integrate into the manual. Additionally, It was considered setting a therapy goal and formulating a graded exposure plan should run concurrently through sessions. The aim of this approach is to help people develop self-management skills to overcome anxiety provoking situations which impact on their lives. Encouraging the practice of anxiety management strategies between session was a key feature from participant feedback. Furthermore, it was felt different levels of support will be required for the person to achieve their goal and promote graded exposure activities. Therefore, involvement from families and carers will be important particularly in the early stages of the treatment programme.

Discussion group sessions

The discussion group sessions provided an opportunity to understand the effect anxiety has on participants lives from a live experience prospective. In addition, the group session provided insight into areas of clinical focus and using a multi-method approach for the treatment of anxiety Three key themes were identified.

Physical and psychological impact of anxiety

Three of the participants explained thinking about situations which have triggered anxiety and recognising how this is often not helpful. One participant elaborated by explaining feeling overwhelmed when using public transport. The experience of physical symptoms caused the person to vomit due to high levels of anxiety. This led to the participant worrying they would

always be sick when faced with the same situation. . Another participant identified feeling faint when in a similar situation, and emphasised how they avoided using public transport. Both participants highlighted how a lack of alternate transportation significantly affected their social networks and leisure activities.

All participants reported the physical impact anxiety had on their body. These feelings often resulting in panic and fear.. A repeated theme was the feeling of being trapped and unable to escape a situation. . One participant explained feeling suffocated when travelling by train and experiencing difficulty breathing due to a heightened state of anxiety. There was recognition from participants the physical impact of anxiety created a barrier towards accessing social and recreational activities. Consequently, often leading to increased isolation and loneliness .

Management of anxiety in social situations

All participants identified close family members as supportive and an essential part of their daily lives. Participants emphasised their reliance on family members to feel confident to engage in social situations . There was a general feeling that members of the public were not always sympathetic to their difficulties. One participant reported people often stare and make derogatory comments or offer limited support .

Three of the participants identified crowded areas being a specific problem and created difficulties within a variety of activities such as shopping, or attending the gym. A participant detailed a situation when attending a sporting event and experienced an episode of heightened anxiety due to crowd noises. This resulted in the participant having an 'extreme panic attack' and requiring support from a family member. This situation resulted in the participant feeling increasingly reliant on family members to provide support to attend subsequent sporting events, thus impacting on their level of independence.

All participants considered their social anxiety weighed heavily on their families and carers. They described feeling the 'eyes of others' watching them in social situations. Participants discussed creating solutions which could be personalised. These included methods of alerting members of the public to increasing levels of anxiety by creating a simple step by step instruction card which could guide people in providing support.

Participants described hospital environments as being 'scary places' and reflected on healthcare situations that were anxiety provoking. There was consensus between participants the most provoking situations surrounded medical interventions or attending GP surgery.

In contrast, participants highlighted the level of anxiety and stress experienced when visiting loved ones in hospital. Participants talked about their families and medical professionals not always providing them with information about a family members condition. Participants considered that this paternalistic outlook focused on providing reassurance, rather than information about the family members medical condition. There was a general consensus between participants that being provided with information would be beneficial in alleviating their worry and better understanding a prognosis.

Coping strategies

In discussing individual coping strategies used to manage anxiety symptoms participants highlighted a range of self-management strategies. Key strategies included using digital media to access resources to practice anxiety management techniques. However, some participants reported they often needed direction to access and effectively use relaxation resources.. All participants described physical exercise as an effective method for relieving stress and providing some level of independence.

Distraction techniques were frequently used by all participants. Participants reported listening to music effective in self-control of symptoms and particularly helpful when approaching crowded areas or traveling on public transport. Furthermore, participants considered tasks and hobbies beneficial in reducing anxiety on a general level.

The participants underlined the need for continued development of their individual self-management skills.. All participant reported the co-production group had provided the opportunity to examine and gain a greater insight into their own specific needs.

Discussion

This is the first study in the UK which has used a quantitative approach to understand the lived experience of people with intellectual disability and involved these people in developing an intervention for the treatment of anxiety in clinical practice. There are several findings identified through this study.

The themes which emerged from the discussion groups provided a greater understanding of how anxiety impacts people's lives. This understanding illustrates the daily challenges faced by people with intellectual disability and the strategies used to overcome anxiety provoking situations. The participants detailed their daily struggles in managing their psychological distress and the interconnected relationship with physical symptoms of anxiety.

The social peer support between participant members within the group allowed for the exchange and sharing of experiences. The emotional support participants demonstrated towards each other during the group session enabled identification with others. In addition, provided opportunities for peer support when participants were self-critical in reporting a difficult anxiety provoking experience. The shared learning from the discussion groups was incorporated into recommended strategies to promote and develop self-management skills. A key strategy identified in the discussion groups was the value of physical activity and digital resources to enhance the development of self-management skills.

This information provided a key contribution to making further developments to the anxiety management programme. The feedback provided by co-production partner's generated ideas and allowed changes to the session manuals.. In addition this process enabled improved alignment of the manual guides and additional resource development. Feedback group sessions underlined the importance of using a range of interactive strategies to engage people with varying abilities to maintain motivation and interest.

The inclusion of an accessible user guide aims to support participant engagement in the programme and provide clear guidance throughout the sessions. The inclusion of practice exercises and graded exposure within sessions further promotes the development of self-management strategies. Although, involvement from families and carers to support exposure exercises between sessions will be important in the initial stages of the programme.

A potential benefit of the anxiety management programme is an increased exposure to life events and the potential to reduce paternalistic outlook. This could lead to increased autonomy, improved self-esteem and quality of life in people with intellectual disability.

These findings highlight the potential clinical implications. Although, caution is needed as the anxiety management programme need to be tested in clinical practice with people who have an intellectual disability and anxiety.

Strengths and limitations

A strength of this study was the inclusion of people with intellectual disability as co-production partners in the development of a treatment programme. Furthermore, provides a greater understanding from a lived experience prospective and the effect anxiety has on people's lives.

However, a limitation of this study is the small number of people with lived experience who agreed to participate in the discussion groups. In addition, feedback was provided by people with mild intellectual disability and might not represent those people with more severe intellectual disability.

Next Steps

It is important to test the manual in clinical practice. A future study will provide an opportunity to examine the multi component programme and manuals in a clinical environment. A key objective will be obtain further understanding from people with intellectual disabilities and make recommended changes or adaptations. A clinical trial will aim to evaluate the comparative differences of a multi model approach as a psychological treatment of anxiety for people with intellectual disability. Examination of any improvements in mood, behaviour and quality of life will help evaluate the effectiveness of the programme.

A potential challenge could be the commitment of practicing and completing steps of exposure between sessions. People with more severe intellectual disability will require additional support during and between sessions. . The manual is designed to be modified to individual needs and form the basis for a person's anxiety management plan. Therefore, involvement within the anxiety management programme from families and carers will be vital.

Ethical Information

The study was approved through the Trust's research ethics approval process. Data was extracted and anonymised from the standard electronic patient record system used in routine clinical care. According to the Health Research Authority algorithm (see http://www.hra-decisiontools.org.uk/research/) this study was not defined as research

and therefore did not require submission to the Integrated Research Application System (a single system for applying for the permissions and approvals for health and social care / community care research in the UK).

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