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A qualitative exploration of the acceptability of a cognitive behavioural therapy self-help book for people with psychosis in Nicaragua

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ABSTRACT

Background: Cognitive Behavioural Therapy (CBT) self-help interventions have become a popular tool in High-Income Countries (HIC) to support people living with psychosis. There is limited research of this in Low- and Middle-Income Country (LMIC) contexts. We report findings of a qualitative investigation of a self-help book for psychosis in Nicaragua in Central America.

Methods: Ten service users who self-identified as having psychosis were recruited from a mental health non-governmental organisation (NGO). Participants were given a Spanish version of a popular self-help book developed in the UK. They had four weeks to familiarise themselves with the book. Following this, we asked participants about their experiences of the book via an open ended questionnaire and a focus group discussion.

Results: We conducted an inductive content analysis on the data. Evaluations of the book were positive. The book was considered easy to understand. The exercises were useful for coping with symptoms, as well as for recognising and managing relapse. Case studies were perceived useful in terms of reducing stigma and promoting self-acceptance.

Discussion: The data highlight potential acceptability of CBT self-help books in the Nicaraguan context. We make recommendations for further research and evaluation to build on this signal of acceptability.

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Psychosis; self-help; cognitive-behavioural therapy; Nicaragua; low-middle incomes countries; qualitative

Introduction

Mental health issues pose a significant, global public health challenge, especially in low- and middle-income countries (LMIC) where the vast majority of the global population reside. As well as strategies aimed at prevention and stigma reduction, one of the existing priorities is to increase the use of affordable, easily accessible evidence-based interventions (Wainberg et al., 2017). With limited financial and human resources for healthcare in LMIC, self-help interventions, especially those with minimal requirements for input from clinicians or therapists, can provide crucial support for people who suffer from mental distress (Patel et al., 2018; Tol et al., 2020). In a High-Income Country (HIC) context, self-help interventions have been tested for a range of mental health conditions, with emerging evidence to suggest that they may be useful in more serious forms of distress, such as psychosis (Scott et al., 2015). Self-help tools could be important in widening access to mental health care in LMIC, but there is a distinctive lack of research in this context (although see Naslund et al., 2017). Research has found that both facilitator-guided (Tol et al., 2020), and internet-based (Mehrotra et al., 2018) self-help can reduce

distress in LMIC (see also Bockting et al., 2016; Naslund et al., 2017), there is a clear gap in research on self-help tools in the Latin American context (Jiménez-Molina et al., 2019; see also Nickels et al., 2016). In addition, none of the reported self-help interventions target psychosis specifically. We intend to address this gap in the literature by investigating the acceptability of a self-help intervention for psychosis in a post-conflict Latin American country, Nicaragua.

Nicaragua is a lower middle-income Central American country in the midst of a mental health crisis (Sapag et al., 2013). The country lacks an official mental health policy, and less than 25% of the population (of almost 6 million people) can access mental health services if needed (World Health Organisation [WHO], 2017). The small budget for mental health care is mostly given to one psychiatric hospital, which is based in the capital city of Managua. In addition, the country has a dearth of mental health professionals (WHO, 2017). Whilst there are some initiatives developing family and community-based support networks (van der Geest, 2017), more work is needed to support psychosis sufferers and their families, harnessing them with skills that aid coping without medical interventions. Experience of mental distress is highly culturally and linguistically specific, and what works in other contexts may not be suitable in Nicaragua (e.g. Jani & Deforge, 2015). Indeed, there is growing recognition of the importance of contextualising interventions to the local culture and adopting a grass-roots/bottom-up approach to the development of forms of support (Mills & White, 2017). A good place to start this process would be to evaluate the acceptability of current self-help tools in order to discover what cultural adaptations might be necessary.

There are several approaches to self-help in psychosis, many of which rely on the principles of Cognitive Behavioural Therapy (CBT). Most self-help interventions, and clinical trials evaluating these interventions, have been developed/conducted in the UK, with a wide range of treatment targets (e.g. psychological recovery, reduction of psychotic symptoms, anxiety, depression, stigma; Greenwood et al., 2010; Morrison & Barratt, 2010). Studies on guided self-help sessions with the aid of professionals and guided manuals have shown that CBT interventions can alleviate emotional distress and the symptoms of psychosis (Hazell et al., 2018; Morrison, 2017; Scott et al., 2015) and reduce self-stigma by normalising the experiences (Kilbride et al., 2013; Morrison et al., 2016). In addition, web-based self-guided programs seem to have some utility too (Stafford et al., 2015). Self-help interventions for psychosis (e.g. Morrison et al., 2014) could make an important contribution to tackling limited treatment options in countries with a lack of mental health resources and embryonic care structures.

In this preliminary investigation, we wanted to explore the potential acceptability of a self-help CBT approach in Nicaragua to people with a lived experience of psychosis. In order to do this, we worked with a group of service-users who evaluated a Spanish translation of a CBT-based self-help book developed in the UK (Morrison et al., 2014). We wanted to work with service-users because patient and public involvement is an important early strategy in developing a meaningful research agenda, and ensuring that interventions meet the needs of people who experience psychosis (Susanti et al., 2020). Our aim was to guide future research on self-help tools for psychosis by creating some initial data on how this type of intervention is perceived in a Latin American LMIC context.

Methods

We employed a qualitative research design, collecting data via an open-ended questionnaire, as well as focus group responses to structured questions. Data were collected in Matagalpa, the fourth largest city in Nicaragua with an estimated population of 200,000.

Ethical approval

We obtained ethical approval from the Health and Life Sciences Research Ethics Committee (Psychology, Health and Society) at the University of Liverpool (Ref: 4699).

Participants and recruitment

People were eligible to participate in the research if they were service users with a lived experience of psychosis. Participants were invited to take part through a mental health Non-Governmental Organization *Cuenta Conmigo*, established to support service users and carers with lived experience of psychosis. Those who were interested in participating were advised to contact RB, one of the psychologists of the group, to discuss involvement and to ask any questions about the study prior to participation. All participants gave informed written consent prior to their participation in the research.

In total, ten service users participated in the research (six men, four women). They were a subsample from a group of 28 (mean age = 41.80 years, mean time since diagnosis = 11.90 years) who took part in focus groups around lived experience of psychosis in Nicaragua (reported in Lyons et al., 2020). Participants from the focus group study were invited to take part in the current study, and the recruitment stopped when ten people had expressed their interest. The sample size of ten was based on the availability of the Spanish version of the book for our research purposes. The research had two components: 1) written pen and paper evaluation using an open-ended questionnaire, and 2) focus group discussion, exploring in more depth the acceptability of the intervention for people with psychosis in Nicaragua.

Ten participants initially consented to participate in the study. Seven of these participants gave a written evaluation answering the open-ended questionnaire, and nine participants attended the focus group discussion.

Materials and procedure

(i) *The Self-Help Resource*

We gave ten participants the Spanish version of Morrison et al. (2014) *Think you're crazy? Think again: a resource book for cognitive therapy for psychosis (Crees que estás loco? Piénsalo dos veces. Recursos para la terapia cognitiva de la psicosis)*. We chose this book for three reasons: 1) the authors of the book are world-leading researchers on psychosis and CBT interventions; 2) the book is written in a lay language with exercises that are easy to follow; and 3) there were commercially available Spanish translations of the book. This self-help book, that was developed in the United Kingdom, provides a simple step-by-step guide that aims to give the readers the tools to understand and manage their distress. The book includes exercises based on CBT techniques (e.g. analytically challenging obtrusive thoughts and voices; self-formulation of the causes of psychotic experiences) and has two case studies embedded throughout the book.

(1) *Written evaluation of the Self-Help Resource*

Participants were given four weeks to familiarise themselves with the book and the exercises. Following this, seven of the ten participants completed and returned an open-ended pen and paper questionnaire which included five open ended questions which generated qualitative responses- "How did you find the book and the exercises?"; "Was the book useful for you?"; "What was good about the book? Give specific examples"; "How could the book be improved? Give specific examples"; and "Do you think something like that would be useful for the people that hear voices in Nicaragua? Why?".

(2) *Focus group discussion*

In the focus group sessions, participants had an opportunity to expand their opinions about the book, allowing the researchers to explore in more depth the issues raised in the questionnaire

responses. The discussions topics were similar to the questions asked in the questionnaire and focused around (i) participants' personal views about the book, (ii) how it could be improved, and (iii) opinions about the usefulness of the book in the Nicaraguan context. Upon arrival, the facilitators agreed on ground rules with the participants at the outset of the focus group, including agreements not to talk over each other, to ensure all views were valued, and to not disclose any information discussed outside the group setting.

The focus group was led by RB (male clinical psychologist) and SC (female research assistant in psychology) and was undertaken in Spanish at *Cuenta Conmigo*, Nicaragua, in October 2019. The focus group was digitally audio-recorded using an encrypted Dictaphone and lasted approximately 45 minutes. Audio-recordings were translated verbatim into English for the analysis by JC, native Spanish speaker with high proficiency in English. All identifiable information was removed during transcription. Participants were provided with a 15 USD payment to reimburse travel costs and to compensate for the time spent at the focus group and participation in the book evaluation. This was deemed as a reasonable payment to off-set the number of hours participant spent reviewing the book, travelling to the focus groups, and participating in the focus group. In Nicaragua, average hourly pay is 3, USD and the number of hours participants were required for the research amounted approximately to this.

Analysis

We used content analysis, a technique that allows large amounts of text to be managed and organised in response to pre-defined research questions (Schreier, 2012). This approach is appropriate for short and similar responses, which characterised both the focus group discussion and the open-ended evaluation questionnaire. We utilised an inductive approach, whereby codes and resultant categories were derived directly from the raw data (Moretti et al., 2011). The resulting categories were a reflection of the visible, obvious content in the data.

The data were read and re-read by the authors (ML and JC) to ensure thorough familiarisation with the data. ML and JC then independently assigned initial codes to the data before sharing with the wider study team. After initial reading and re-reading the questionnaire and focus group responses, we decided to combine the data from the two studies due to high similarity in the questions and the responses (e.g. Creswell & Creswell, 2017). Due to the anonymity of the answers, we could not match the participants from the questionnaire study to the focus group interview. We discussed the codes during meetings, and given the similarities in identified codes between data sources, codes across both types of data were organised into overarching categories with related and similar codes combined, and redundant codes removed. The authors agreed the final category configuration as a comprehensive reflection of the data.

Results

We identified four categories: (i) Generic opinion about the book, (ii) The value of case studies, (iii) Additional benefits of the self-help book (iv) Suggestions for how to improve the book.

(i) Generic opinions about the book

Participants had overwhelmingly positive opinions about the book. The book was described eight of the participants with words such as "*beautiful*", "*useful*", "*informative*", "*instructive*", "*important*", "*interesting*", "*great tool*", "*nice*", "*excellent*", "*easy to understand*", "*practical*", "*great utility*". Some of the values attributed to the book by participants related to accessibility, the potential to reduce societal stigma, and providing alternative options to medication.

Overall, participants felt that the book and similar resources would be acceptable and beneficial to people in Nicaragua. The consensus was that the book should be made accessible more widely.

It should be known by more people that want to know what options they have to get out of this darkness. **Questionnaire study participant 4.**

I think that the reproduction of this book is important because it would be accessible to more people who need the information in the book. **Focus group participant 5.**

It would be great if it could be reproduced in a massive way because it is a very interesting book that gives us many guidelines. It has a lot of information on how to try to lead our lives in a normal and healthy way. **Focus group participant 1.**

More specifically, participants thought that the book would be useful not just to people who live with psychosis, but also to others in society. They viewed the book as promising for reducing stigma, and increasing empathy towards people who live with psychosis in Nicaragua.

As all my friends here, I think that this book has to be reproduced here, because there are many people who are without information. We live in a discriminating culture. They see you in the streets and discriminate against you. The book educates you, it teaches you to understand the situation of many families. The information that this book contains . . . we as human beings know what we go through but there are many people out there that need more information. **Focus group participant 7.**

(ii) The value of case studies

Participants highlighted the importance of the two case studies outlined in the book in both the questionnaire responses and the focus group data. The case studies seemed to benefit the participants in several ways. For example, they appeared to identify with people depicted in the case studies, initiating a process of comparative reflection and reducing feelings of isolation.

Yes, it was useful because when I read it, I realised that I am not the only one living this. There are people that are going through a worse situation than mine. **Questionnaire study participant 6**

[I] loved the book because it talks about the voices and because you learn a lot how to control the problem of the voices. I liked what it tells about Calvin. I also identify myself with Casi, because I have something similar to hers. It helped me reflect and to start feeling better. **Focus group participant 5.**

As well as allowing identification with the case studies, they appeared to give participants hope for recovery in the future.

. . . the persons and the cases that appeared are similar to my case and it was useful for me to realise that you can get out of this situation. **Questionnaire study participant 7.**

(iii) Additional benefits of the self-help book

As well as the case studies, participants mentioned several other reasons for liking the book. The specific useful features that the participants discussed were exercises, useful information, and ease of understanding.

The exercises. The explanations of their disease and how it was the first time they made them take medicines. The cognitive therapies, the talks with the general practitioners. **Questionnaire study participant 1.**

The exercises were evaluated especially positively, for their clarity, ease of understanding and for making therapeutic sense.

For me it was of great utility because I could understand the exercises. The persons that worked on this book have a great focus on how to help the reader to have a better life quality. The exercises are useful as a therapy. **Questionnaire study participant 3.**

In addition, participants described how the book provided useful practical strategies for coping that could be implemented into everyday lives in terms of recognising, preventing, and dealing with psychosis. There was a particular focus on the utility of relapse prevention strategies included in the self-help book.

It was useful because it talks about how to prevent: being warned about the relapse symptoms of the disease
Questionnaire study participant 1.

... it teaches us how to identify the situations that make us have a relapse and how to avoid them in the future. It gives us techniques to improve our way of thinking and acting. **Focus group participant 4.**

The self-help resource was also thought to encourage self-reflection which was considered to promote self-acceptance and could reduce self-stigma.

We make mistakes, we are human beings, at the end of the road there is always a light ... we are here because we have hope and we agree with the book. **Focus group participant 7.**

(iv) Suggestions for how to improve the book

Most participants suggested that as an improvement for the book, there should be more case studies which incorporated a wider range of experiences which more adequately reflected cultural diversity.

it occurred to me that everything would be more interesting if there were more testimonies from other patients ... it would enrich the book more. **Focus group participant 1.**

According to focus group participant 2, " ... *there should be more testimonies because not all of us have the same symptoms, especially the psychotic ones*". **Focus group participant 2**

In addition, participants mentioned the usefulness of additional information about medication for psychosis, especially as a tool for family members to be mindful of side effects.

... one of the most useful tools would be to name the antipsychotic medications and give at least a summary of the more serious effects, so that at least family members know of symptoms. so that they know what it will be like and they are conscious about it **Focus group participant 7.**

Another suggestion for improvement was the inclusion of more short exercises that could be completed with ease, in a short period of time.

Include more detailed information and more exercises of self-help completed in a short period of time ...
Questionnaire study participant 3.

Give the perceived value of the self-help resource, participants also talked about the utility of having a resource like this available through the internet, which would increase accessibility for people in Nicaragua.

I would like them to open a page on the internet and we could have access to this material. But we do not have it, we just keep the idea **Focus group participant 4.**

Discussion

To our knowledge, this is the first study to explore service user perspectives on the acceptability of a self-help CBT tool for psychosis in the Latin American context. Our Nicaraguan participants had an overwhelmingly positive experience with the Morrison et al. (2014) exercise-based self-help book. The responses of the participants in both studies (focus group and open-ended questionnaire) indicated that the book concurred with the recommended elements of CBT for psychosis (Morrison & Barratt, 2010). More specifically, participants discussed how the book gave them strategies for recognising, preventing, and dealing with a relapse, as well as tools for coping, promoting a hope for a better future. These are some of the important factors that underpin the structures and principles of CBT in psychosis (Morrison & Barratt, 2010), and suggests that this approach may also be relevant and acceptable in the context of Nicaragua.

A global shift towards enhancing the accessibility and efficiency of mental health services has led to the development of low intensity or self-help versions of psychological interventions such as cognitive-behavioural therapy with proven effectiveness in high (Scott et al., 2015) and low-

income settings (Bockting et al., 2016; Naslund et al., 2017) for a range of mental health conditions. In the current study, participants highlighted the value of the case studies, the provision of practical strategies for self-management, and the short exercises included within the book. In particular, the two case studies detailed in the book were described as the most useful feature of the book and participants expressed desire for more case study examples along with a stated preference for additional short exercises. This supports extant evidence in other contexts which demonstrate that case studies can be effective in normalising experiences (Best et al., 2018), and that sharing lived experiences of psychosis can instil hope and promote personal recovery (Repper & Carter, 2011). Our data extends this to Central American contexts and points to the potential value of personal stories, self-management strategies and short exercises in supporting recovery cross-culturally in both high- and middle-income settings. Stories of lived experiences have the potential to be used successfully in interventions (Peck et al., 2020) and our data suggest that self-help interventions in Nicaragua would benefit from a wide range of personal stories which reflect the cultural diversity in Nicaragua that a wider range of service-users could relate to.

Overall, the CBT self-help book seemed to help in normalising experiences related to psychosis, which can be a useful tool for reducing self and societal stigma (Morrison & Barratt, 2010). Mental health-related stigma is universal, and especially pertinent to those who have a diagnosis of schizophrenia (Thornicroft et al., 2019). Our participants talked about the book giving hope for a better future by increasing acceptance of not just oneself, but also acceptance from other people. Studies in the HIC context have found that addressing internalised stigma has a positive influence on recovery (Morrison et al., 2016), and in our Nicaraguan participants, identification with the case studies offered a hope for recovery. Indeed, normalising experiences do not only reduce internalised stigma, but can also be used to combat stigma from others (French et al., 2011). This could have particular relevance to participants in the current study who highlighted the high levels of societal stigma within Nicaragua (see also Lyons et al., 2020). Studies on service user experiences of stigma, especially in the LMIC context, are conspicuous in their absence (Thornicroft et al., 2016), and it is unclear what approach (e.g. normalcy vs solidarity; White et al., 2017) would be most efficient in Nicaragua. Important next steps would be to explore further the associations with CBT self-help, stigma, and recovery in a LMIC context.

Although self-help interventions for psychosis do provide a promising future avenue for improving the lives of individuals with lived experiences of psychosis in Nicaragua and elsewhere in Latin America, the impact that these interventions have on important outcomes (e.g. better quality of life; functional outcomes) require further research. It may be that in order to maximise the effectiveness of self-help, there needs to be some adaptations to consider the cultural contexts. CBT has largely been developed and evaluated in the West, embracing Western values and sensibilities, which may not be as effective in more collectivist, religious cultures. It may be useful to factor in families (e.g. Habib et al., 2015; Ma et al., 2020; Nickels et al., 2016) and religion (Heffernan et al., 2016; Turner & Hodge, 2020) when designing psychosis self-help tools in the Nicaraguan and Latin American context. Future research could develop different versions of CBT-based self-help, and make a comparison of the effectiveness of these tools.

Our results are somewhat limited by the small sample size consisting of participants with good literacy skills. The level of illiteracy in Nicaragua is still relatively high, especially among the older population (UNESCO, 2015), and the exercises in the book would not be appropriate for people who cannot read or write. In addition, the self-help book would be unlikely to benefit the most vulnerable (e.g. people with intersecting vulnerabilities, Vázquez et al., 2021). Future self-help interventions will require development and research in more diverse sections of the population.

In conclusion, our study points to the potential acceptability of a CBT-based self-help book for people with psychosis in Nicaragua. The Morrison et al. (2014) book was praised for being practical, useful, and easy to understand. Our Nicaraguan service users found the exercises and case studies of high utility, and talked about the value of the book in identifying, preventing, and dealing with a relapse of psychotic symptoms. The therapeutic importance (e.g. normalising experiences,

diminishing stigma) of case study examples in warrants more investigations in the Latin American context. Future studies could build on this initial signal of acceptability and explore the use of such interventions more widely within the Nicaraguan population and across other Central- and South-American contexts, as well as undertaking definitive evaluations of the effectiveness of these interventions in helping to reduce distress and/or enhance wellbeing. Heim and Kohrt (2019) recent call to explore the relevance of i) cultural concepts of distress; ii) treatment components; and iii) treatment delivery when adapting scalable interventions, can help to inform research efforts aimed at evaluating the effectiveness of self-help materials for psychosis in these regions.

Disclosure statement

No potential conflict of interest was reported by the author(s).

Ethical statement

Ethical approval was obtained from the Health and Life Sciences Research Ethics Committee (Psychology, Health and Society) at the University of Liverpool (Ref: 4699). Participants gave written consent for their data to be used in the research.

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