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Please cite this publication as follows:

Holtum, S. (2015) Coping with cognitive behaviour therapy for psychosis, adapting it for another culture, and community inclusion. *Mental Health and Social Inclusion*, 19 (3). pp. 107-113. ISSN 2042-8308.

Link to official URL (if available):

<http://www.emeraldinsight.com/doi/10.1108/MHSI-05-2015-0018>

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Coping with cognitive behaviour therapy for psychosis, adapting it for another culture, and community inclusion

Cognitive behaviour therapy has been adapted for psychosis (CBTp) and is gradually becoming more available to people diagnosed with psychotic disorders in the UK, with several studies suggesting it is helpful. However, it is often possible to understand more about how a therapy helps – and when it does not - by interviewing people about their experience of it. Wood, Burke and Morrison (2015) summarised the results of several studies involving interviews with service users who have received CBTp. A second issue with CBTp is its suitability for people belonging to non-Western cultures, discussed by Habib, Dawood, Kingdon and Naeem (2014). Finally, it has been acknowledged that a key part of people's recovery in relation to severe mental distress is connecting or re-connecting with communities important to them. Wong, Stanton and Sands (2014) discuss how people achieve this.

What works in cognitive behaviour therapy for psychosis (CBTp)?

Wood et al. (2015) note that UK national guidelines recommend CBT for psychosis, delivered one-to-one (National Institute of Health and Clinical Excellence, 2009). However, CBT comprises a number of different approaches that are tailored to the individual client, and it is difficult to know whether there are certain key things that are more important than others. Also, there can be aspects of therapy that people find difficult that are never formally recorded unless we ask people about their experiences and report them. So Wood et al. (2015) searched for studies that had done this, specifically looking at studies of people who had been in one-to-one rather than group CBTp.

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Wood et al. (2015) found six studies published between 2002 and 2013. They tended to have small samples (between 5 and 13 people), and in two studies the samples included therapists. Wood et al. (2015) analysed the Results section of each paper, using thematic synthesis (Thomas and Harden, 2008). This enabled them to summarise the themes in relation to service users' experiences as reported in the papers.

The themes reported by Wood et al. (2015) fell into three main areas:

1. The relationship between service user and therapist,
2. Change and recovery,
3. Difficulties with CBTp.

In CBTp a respectful therapist and an equal relationship are crucial

Service users emphasized how valuable it was that they felt the therapist related to them in a collaborative way and treated them as an equal human being. One service user was quoted as commenting that it was more usual to be "looked down on" by professionals but with the CBTp therapist the feeling was, "I'm someone on her level" (p. 290). This in itself has the potential to raise people's self-esteem, suggest Wood et al. (2015).

Also important was the therapist's ability to talk to service users respectfully, show genuine interest in them and to react with understanding rather than shock at what the service user said. This made one service user "feel normal" (p. 290).

Change and recovery

Service users seemed to appreciate being given a clear explanation of the aims of CBTp. They also reported that being given an explanation of their difficulties was helpful in understanding them and made them seem more normal. One therapist also reported this formulation process to be helpful in terms of raising the therapist's own hopefulness that

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therapy had something to offer. Service users found some of the homework of CBTp useful – such as taking small steps towards doing things that they valued but found difficult. This led to some service users feeling more able to go out to “school, college or work-places” (p. 292). Having an explanation for when they felt bad also helped people to cope with difficult times.

Difficulties with CBTp

Not all service users found CBTp easy, and one study suggested that a common belief in society is that the professional does things to the service user to make them better rather than it being more a joint effort (Kilbride et al., 2013). Thus, it might be difficult for most service users to get used to being asked to do “homework” in between sessions. Also there was evidence that some therapists might not have coped well when service users did not do their homework, as sometimes service users did not seem to understand why it was important. This suggests some form of breakdown in communication or at least understanding.

One difficulty service users mentioned was how distressing it could be to talk about events from their past, which is usually necessary for producing a full explanation of people’s current difficulties. Service users often recognised this, but it could be a significant hurdle. It was important that service users were able to take an active role in the therapy, for which they might not be ready, or the idea of taking such an active stance may be unexpected, as alluded to already. I suggest another factor might be that some service users may not have ever been expected to take much control in their treatment previously. For some, to move into a more emancipated role may require confidence-building.

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Can CBT for psychosis be adapted for a different culture?

Habib, Dawood, Kingdon and Naeem (2015) point to the lack of research on CBT for psychosis outside of Western countries. In Pakistan, write Habib et al. (2015), it is difficult for people to have regular outpatient therapy because they tend not to live near a clinic, so inpatient treatment is more practical. Habib et al. (2015) report a small pilot study of CBTp in an inpatient unit in Pakistan, after they adapted CBTp to have a better fit with the culture in that country. They compared up to 16 sessions of CBTp with 'treatment as usual', which was antipsychotic medication and nursing care. Those receiving CBTp also received usual care. At the end of the study, the 'treatment as usual' group was also offered CBTp.

What does culturally adapted CBTp look like?

The cultural adaptations were made in line with the results of 92 interviews with service users, their carers and mental health professionals in Lahore, Pakistan. Service users and carers in Pakistan, write Habib et al. (2015) "use a bio-psycho-spiritual-social model of illness" (p. 204). People often seek help from faith healers as well as formal medicine. Because families tend to be closely involved with the care of service users in Pakistan, Habib et al. (2015) involved them from the start. One key carer was identified for the therapist to work with alongside the service user, and that person attended therapy and helped with any 'homework'. Cultural beliefs stemming from consulting with faith healers were built into the formulation process. These could include explanations from traditional Indian, Greek and Chinese medicines.

Was culturally adapted CBTp helpful?

Habib et al. (2015) reported that 21 people were randomly assigned to receive CBTp on top of their usual care, and 21 to receive only usual care. Psychotic symptoms were

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assessed using standardised procedures. Level of insight was also assessed, although the authors admit this can be controversial: It includes adherence to treatment, recognising that one is ill, and recognising that a symptom is part of psychosis. This does not allow for spiritual interpretations of benign hallucinations or refusal of treatment that has unpleasant 'side' effects. However, it was one of the measures used in the study.

All 21 service users attended at least 10 out of the 16 allocated sessions. By the end of therapy there were highly statistically significant differences between the two groups on psychotic symptoms and insight. This was after controlling for pre-therapy symptom levels, although they appeared very similar across the two groups at the start.

One limitation of this study is the lack of a follow-up assessment after people left the mental health unit. Another, which the authors also acknowledge, is the choice of measures, which are based on Western illness concepts. Finally, there was no information about the nature of the inpatient unit, and the degree to which service users were able to leave the unit in carrying out homework assignments. However, the authors went to great lengths to adapt CBTp for a local population, potentially making it more accessible to that population. In addition family members were included and perhaps might continue supporting people after they leave the unit. It was unfortunate that the lack of access to centres offering such therapy means that people had to receive it in an inpatient setting miles from their home community, leaving open the question of how well service users and their carers would adapt once back in their local community. Potentially, because therapy was adapted to their cultural beliefs, however, the prospects for this may be good.

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How do people re-join communities after severe mental distress?

As Wong, Stanton and Sands (2014) point out, social inclusion is a key part of recovery in relation to mental distress. They write from a USA standpoint, being based in Pennsylvania. However they point out that integration into the community can appear very different depending on people's individual circumstances. They interviewed 20 people from diverse backgrounds and with different mental health diagnoses about their social inclusion.

Wong et al. (2014) suggest that the view of social inclusion for people in mental health recovery has been rather narrow, focusing on supported housing and involvement in the local community. However, they report an earlier study as suggesting that only 30% of people in supported housing were involved in their immediate neighbourhood community (Wong, Nath and Solomon, 2007). Other aspects of group belonging were important, and this is what Wong et al. (2014) explored.

Wong et al. (2014) used an existing theory of social inclusion to make sense of their qualitative findings from the 20 interviews: the 'capabilities approach' drawn from the social model of disabilities (Burchardt, 2004). This approach emphasizes the importance of individual choice and self-determination, and enabling people to build their capacity for involvement in communities of value to them and connecting with others.

Participants from widely different backgrounds in a large US town were interviewed. They ranged in age from 32 to 65 years, with 11 men and 9 women, 11 being African American, 3 Asian American and 6 White, 8 having only school education, 9 were in supported housing, 6 belonged to sexual minorities (Lesbian, Gay, Bisexual and Transgender) and diagnoses were varied, with 12 having a diagnosis of schizophrenia, schizoaffective disorder or bipolar disorder.

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The study explored the extent to which participants had built relationships and taken on responsibilities in communities they valued, and what had helped them to do this.

Although Wong et al. (2014) describe the study as using a grounded theory approach, unusually for grounded theory, they appear to have analysed the data for its fit to the existing capabilities theory. This may be a reasonable approach, as long as they were careful not to ignore data that did not fit it. Indeed there were examples of cases that seemed not to fit, as for example a participant who did not express commitment or a wish to take on responsibilities, but was appreciative of feeling safe after being homeless for some years.

Wong et al. (2014) noted that participants belonged to four different types of community, with 15 of the 20 belonging to a mental health group and most belonging to more than one type of group:

1. Mental health groups
2. LGBT groups
3. Religious groups
4. Wider groups – e.g. neighbourhood, work-related, education, training or volunteering

Connectedness and citizenship

Participants felt connected with others in various groups, and many had taken on responsibilities, such as serving as advocates, as board members of mental health service user organisations, or volunteering. Connectedness refers to relationships of interdependence, where people both gain and give support, such as in therapy groups or rehabilitation services. This could also be true of the LGBT community, although one woman found it difficult to be in that community after a relationship breakup. Several people had

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part-time jobs, and one a full time position. One participant felt less comfortable at work than at the community health centre because at the latter she could say things that seemed less acceptable or understood at work.

Some people felt they had taken on citizenship roles, for example where they had joined advocacy and campaigning groups, or a member of the board of a mental health consumer organisation. Participants felt a sense of pride in being able to contribute to these groups and make a difference for others. This was possible even for those who had difficulty interacting with others, for example in the case of a man who planted trees, which enhanced the locality.

Building competencies

Wong et al. (2014) describe commitment to recovery as a form of emotional-cognitive competency. They refer to a participant who was moving away from identifying with his diagnosis: "I'm moving toward being a person again and not Mr. Bipolar". Coping with hearing voices or aggressive thoughts or strong emotions could be difficult but participants talked about making use of available treatment or professional support. Participants talked about developing their empathy for others, for example people worse off than themselves or who were minorities within their communities. They used their own past experience or learned from others to take on responsibilities. Wong et al. (2014) describe the ability to feel satisfaction from helping others as a competency. I wonder if this is stretching the concept a bit. It may be a universal human ability that only needs the right conditions to emerge.

Wong et al. (2014) describe "moral competencies" (p. 690). One of these was described as being honest about one's mental health condition when in the community, and

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it leading to increased closeness. Participants spoke of working together or mutual responsibility for each other in a supported house. Another competency described was gradually building trust when new to a community, such as a local church, and another was a sense of obligation when serving on a mental health board or as a volunteer. There was a strong commitment to help others.

A third type of competency Wong et al. (2014) describe was social competencies. People became more able to pick up social signals from others, to cope with disagreements, and to draw on skills they had before they were ill. One participant gradually came to realise that others in a training class were laughing with him rather than at him, "because I have a humorous side" (p. 691). Some participants engaged in political or charitable activities learned about "the political machine" (p. 691) or about fund raising.

Wong et al. (2014) highlight the important point that involvement in certain types of group, such as LGBT, service user groups and advocacy groups do not need the "active assent of people who are unaffected by mental illness or who do not share the other "marginalised" statuses of our participants" (p. 691). However, they also point out that those with a higher level of education "tended to be more socially connected than those who did not" (p. 692), perhaps because they had already gained some skills they could use again following disruption of their life by mental distress. Having existing links with organisations and support from family also helped.

In relation to lessons for services, Wong et al. (2014) suggest that social skills training could be helpful for some people as part of their recovery, to help them with "community re-integration, friendship-building and interpersonal problem-solving" (p. 693). Also, people's existing competencies need to be drawn upon, in the way that they suggest social

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work does. There is criticism of the tendency to assume that social inclusion must always be about integration into the wider community, where that community must actively consent to it. People may find a sense of belonging by being part of minority groups important to them, and taking on responsible roles there. Wong et al. (2014) cite Mandiberg (2010) in emphasising this point. People can be supported to be part of subgroups that they personally value and this will help in their recovery.

Conclusions

It should be no surprise that being treated like an equal by a CBTp therapist is helpful to service users (Wood et al., 2015), but it is unfortunate that many service users do not feel they are given that level of respect often enough in mental health services. Service users who had received CBTp also valued it for helping them make sense of their psychotic experiences. In order to reach this understanding they had to revisit pasts that could be very distressing, although many accepted it as necessary to arrive at the explanation they needed, as childhood adversity leaves its mark. This is consistent with the British Psychological Society's report on psychosis (Cooke, 2014), which emphasises the importance of formulation: a detailed explanation of people's difficulties, arrived at collaboratively over a number of sessions.

Practical therapeutic work in CBTp helped many people to get back into places they valued, such as college and work, but others felt that explanations of the homework to build up confidence were not forthcoming. Perhaps therapists may become discouraged if people have too much difficulty with homework, and it may be important to ensure that therapists fully understand the barriers in people's current circumstances. Therapists may also need to

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understand the need to become involved in service users' emancipation, since they may not be used to taking an active role in their therapy, and may have been given negative messages about their recovery prospects.

Habib et al. (2015) have adapted CBTp for a non-Western culture and have involved a family member in therapy sessions alongside the service user, with what appear to be very positive results. It seems worth looking into whether these results can be repeated elsewhere. The necessity of delivering the adapted CBTp in an inpatient unit may be a disadvantage if the gains do not continue after service users and family members return home. However, the overlay of a bio-psycho-spiritual-social model onto CBTp seemed an important step forward. Given that Westerners also have cultures and subcultures, including religious and spiritual ones, perhaps there are lessons for the West here.

Wong et al. (2014) illustrated how people in recovery may view mental health communities as a key part of that recovery. This suggests that it may be a mistake to assume that people should only be supported in joining or re-joining wider society, especially when those wider groups may express prejudice or discrimination. Nor does re-integration always have to involve high levels of social interaction, where someone can make a contribution in other ways, as in the example of planting trees. However, the research illustrates well how people gradually built or rebuilt their social competencies after the major life disruption of severe mental distress, diagnosis and treatment. Some people may benefit from social skills training if there was a lack of varied social experiences in their earlier lives. However, it is important also to start with people's existing strengths and capacities and to build on these. Haslam (2014) has discussed the importance of belonging to social groups that are of personal value to each individual. Such belonging not only enables people to feel

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comfortable and make a contribution: it helps them rebuild a positive identity and gradually move away from identities such as 'Mr Bipolar'.

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