

Carers' Expectations and Views of Cognitive Behaviour Therapy for Adults With Intellectual Disabilities

Biza Stenfert Kroese, Andrew Jahoda, Carol Pert,
Peter Trower, Dave Dagnan and Mhairi Selkirk

Email: b.stenfert-kroese@bham.ac.uk



Background

Awareness that service users have limited control over many aspects of their lives and that :

“ subtle decisions have to be made about when it is helpful and when it may be counter-therapeutic to involve significant others in sessions.”

(Dagnan, Jahoda & Stenfert Kroese, 2007)

Perception of carers as ‘obstacles’ to be overcome:

“difficult feelings (such as envy or impatience) may be evoked in the carers during regular attendance at the therapy sessions that relate to difficulties the carer may have. A therapist needs to be aware of these, as the carer may attempt to jeopardise the process”.

(Zaman, Holt & Bouras, 2007)

FAMILY CARERS



Family carers of adults with learning disabilities endure stresses that other families do not.
(McCarron & McCallion, 2007)

A significant number of stress factors identified are related to contact with services.
(McCallion & Toseland, 1993)

Parents frequently report that the professionals they have to deal with make them feel as labelled and stigmatised as their son or daughter.
(McNett, 1980)

Families and professionals sometimes fail to understand each others' subjective experiences and expectations of service provision.
(Moxley, Raider & Cohen, 1989)

“Professional carers make up the rules whereby a short term intervention is valued more highly than a lifetime’s care. ... If repressiveness, caution, disappointment and sadness can all be located with parents, staff can maintain an image of themselves, and for themselves, which is clear-headed and rational, positive and optimistic”.
(Brown, 1992)



Paid Carers

“Researchers and practitioners have rarely considered the motivational factors that may underlie the origins and current determinants of staff behaviour.”

Hastings and Remington (1994a)

Problems with ‘implementers’:

*“Poor communication....lack of staff...disaffected staff and poor morale...
lack of knowledge...conflicting attitudes or beliefs.”*

McGuire and McEvoy (2007)

Strong association between helping behaviour and attributions (a CBT approach to staff behaviour)

Weiner(1980;1985)



Aims

What are carers' expectations of the purpose, content and outcome of CBT?

What are carers' experiences of CBT after the service user has engaged in the process?

NB Not intended as an outcome measure

Method



As part of a larger, multi-centred research study on the therapeutic process during CBT, 16 carers were interviewed before treatment commenced.
(Interview 1)

Twelve of these agreed to be interviewed again after at least 9 sessions of CBT.
(Interview 2)



PRESENTING PROBLEMS

All service users had been referred with a primary presenting problem of anger, anxiety or depression.

Method (Cont'd...)



A semi-structured interview was designed to address the research aims. Questions (content and format) were agreed upon after discussions with the research group and participating therapists.

Interviewers received one day training involving role play and feedback.

Interviews were recorded and transcribed.



Analysis

Thematic analysis (Aronson, 1994) was applied. The responses to each topic raised by the interviewers were grouped together on the basis of similarities. The concepts expressed were summarised. This resulted in a number of initial themes which were then collapsed into wider themes. It was thereby possible to identify commonalities and diversity with regard to reported expectations and views.

The findings for Interview 1 and Interview 2 will be presented separately.

Findings – Interview 1



What is the purpose of CBT?

- Talking to an outsider, talking things through about the past
- Confirming what has already been said. Try again “....*we've gone as far as we can*”
- Educational, learning new skills e.g. anger management
- Second best to tablets



Findings – Interview 1

What caused the problems?

Internal:

- He/she has always been so (weird/difficult). “*It’s something inside*”
- Physical pain
- Lack of oxygen at birth has caused brain damage

External:

- The past (abuse, trauma, loss, not grieving, a build-up)
 - The present (exploitation/pressure by/from others and having no social support)
 - Stigmatisation
-
- NB. Paid carers had a very patchy knowledge of the past (“...*blah blah* ...”)



Findings – Interview 1

What do you know about CBT?

- No idea, don't ask me (*“What's cognitive? I haven't a clue...”*)
- Only what the service user tells us (recognising importance of confidentiality)
- Being listened to
- May provide insight, awareness and coping strategies



Findings – Interview 1

What other things have been tried?

- Medication (no detailed knowledge of purpose, dosage or effects)
- Previous talking therapy (“*has been no good*”)
- Previous talking therapy gave insight
- Group anger management
- We’ve tried to talk (“....*the hours I’ve put in!*”)



Findings – Interview 1

What is your role in the CBT process?

- Support (eg. “...*to get there and back...*”)
- Like to be included but...confidentiality
- It’s separate
- Happy to take on a role if there was a need
- Nothing to do with me (eg. “...*my role is quite different...*”)



Findings – Interview 1


What is your ideal outcome?

For the service user:

- Better quality of life
- Happiness
- Confidence
- Insight
- “*Putting things behind*”, acceptance, peace of mind, calmer
- “*Deep rooted stuff needs to come to the fore*”

For others:

- To have some sense talked into them
- To get/keep a job
- To stop lying
- Not to commit suicide
- To accept responsibility
- To get on better with others

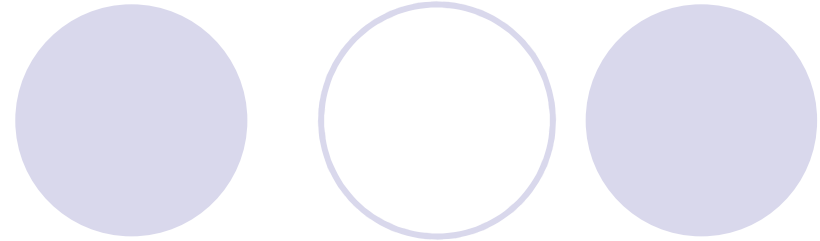


Findings – Interview 1

What are your expectations of CBT

- No change in the long-term
- Can/cannot make service user worse
- Nothing works, can't see how this can
- Too many people already involved, CBT will result in duplication and/or manipulation by the service user
- Hope for a step in the right direction, “*not going to sort it out all in one*”

Findings – Interview 2



What do you think of it so far?

Positive outcomes:

- Better than last time
- Improved mental health (interested again, enjoying going out, eating better, looking forward to things again, improved relationships, more sociable/relaxed, less seizures, more eye contact, confidence/assertiveness/self esteem)
- Improved cognitive skills such as better insight (e.g. not blaming self anymore, “*his analysing not too bad*”), better problem solving, organising, more initiative
- Prepared to listen, easier to talk to
- Able to ask for help
- Not so angry/ anger “*has stopped*”
- Managed to break away from partner (abusive relationship)
- Less demands on me (e.g. “*less phone calls flying at me....makes my job easier*”)



Findings – Interview 2

What do you think of it so far? (Cont'd...)

Negative/neutral outcomes

- No changes or marginal/short-lived
- Doesn't put strategies into practice
- “kinda stuck”

Findings – Interview 2

Why do you think these changes (if any) have happened?

- Therapist has liaised with us
- Therapist has ‘worked through’ problem
- Therapist has given coping strategies
- Therapist has given emotional support (not reprimanded)
- Therapist has ‘normalised’ problem
- The benefit of distance and ‘new blood’
- Therapist has more time to go into depth
- Fear that [his behaviour] will be reported
- Environmental/medication changes (i.e. not CBT)



Findings – Interview 2

What expectations and hopes do you have for the future?

- ‘Top up’ will be needed (“...*maybe just a coffee and a chat...*”)
- After therapy more anxious again/will start blaming
- Doubt whether the positive outcome will be long-term
- Ongoing cycle will continue
- “*We still have a long way to go...*”

Findings – Interview 2

What is your view of CBT?

- Generally a good thing
- Can relate to what was talked about
- Wonderful, brilliant, lovely style (“[Therapist] *is a saint*”)
- Don’t really know too much about it
- Gender of therapist is important
- Not helpful, challenging behaviours reinforced when people are allowed to off-load (“*I’m not a psychologist but...*”)
- Too many people involved, duplication



Findings – Interview 2

What does the Service User think of CBT?

- Didn't understand at first, now ok
- Nervous at first, now ok/confident/T. not seen as a threat
- Values opportunity to express feelings
- Enjoys, looks forward to sessions
- Values continuity, will miss these sessions/happy to go on for ever
- No negatives mentioned therefore “...*it must have had a positive something...*”
- Don't know but I'll be asking
- Very focused on idea of confidentiality



Findings – Interview 2

What is your role in CBT now?

- None
- No, not invited
- Staying in the session if the service user isn't confident
- Link person
- Outside support, give an opportunity to talk
- Generalisation (“*expanding it outside T's office*”)



Discussion

- Carers have limited knowledge of process and aims of CBT
- Carers have limited sense of involvement in therapy process yet some had good psychological insight
- Ideal outcomes rarely described in psychological terms yet reported outcomes described as improvements in psychological well-being
- Recognition of benefits but short-term only
- Demand for long-term input