Research in Developmental Disabilities 47 (2015) 385–392

Contents lists available at ScienceDirect

Research in Developmental Disabilities

Effectiveness of cognitive-behaviour therapy for hoarding disorder in people with mild intellectual disabilities

Stephen Kellett [a,b,*], Heather Matuozzo [c], Chandanee Kotecha [d]

[a] Centre for Psychological Services Research, University of Sheffield, UK
[b] Sheffield Health and Social Care NHS Foundation Trust, UK
[c] Clouds End, Birmingham, UK
[d] University of Sheffield, UK

ARTICLE INFO

Article history:
Received 15 May 2015
Received in revised form 22 September 2015
Accepted 23 September 2015
Available online 23 October 2015

Keywords:
Hoarding, Intellectual disabilities
CBT

ABSTRACT

Evaluations of cognitive behavioural interventions for hoarding for those with intellectual disabilities (ID) have not been previously attempted. This investigation therefore examined the acceptability and effectiveness of cognitive-behavioural therapy (CBT) in a sample of $N = 14$ adults with mild ID. All participants had hoarding as their primary problem and received twelve individual CBT sessions, all conducted via domiciliary visits. The primary outcome measure was an environmental measure (Clutter Image Rating Scale), which was scored at baseline, end of treatment and at six-month follow-up. Acceptability of CBT was measured via the treatment refusal and dropout rate. Secondary self-report outcomes included measures of hoarding, depression and anxiety. Results demonstrate that hoarding significantly reduced following treatment on both self-report and environmental assessment. No participants refused or dropped out of treatment and that there was no evidence of relapse over the follow-up period. No adverse treatment incidences were reported. This open trial suggests that CBT may be a safe and effective intervention for hoarding difficulties in people with ID, but that the evidence base in this population needs urgent and detailed attention.

1. Introduction

Hoarding disorder (HD) was a recent new addition to DSM-5 (APA, 2013) and was characterised as a well-defined and distinct disorder, rather than a sub-variant of obsessive-compulsive disorder as has traditionally been the case (Mataix-Cols et al., 2010). HD is typified by the acquisition and failure to discard of a large number of possessions that have little objective value or use. Hoarding behaviour over time creates (and then maintains) sufficient clutter in homes, so that the activities for which the living spaces were originally intended become difficult/impossible and the person experiences significant associated distress or impairment (Frost & Hartl, 1996). The frequently huge amounts of clutter generated tend to significantly impede the basic activities of home living, such as cooking, cleaning, eating and sleeping (Grisham, Frost, Steketee, Kim, & Hood, 2006). Chaotic home environments can also create on-going and significant health and safety problems, such as risk of infestation or crush injuries (Frost, Steketee, & Williams, 2000). Hoarding tends to emerge around early adolescence, with the clinical course being chronic and progressive without intervention (Grisham et al., 2006).

* Corresponding author at: Dr. Stephen Kellett, Consultant Clinical Psychologist and Psychotherapist, Clinical Psychology Unit, University of Sheffield, S10 5FY, UK.
E-mail address: s.kellett@sheffield.ac.uk (S. Kellett).

http://dx.doi.org/10.1016/j.ridd.2015.09.021
0891-4222/

The occurrence of mental health problems in people with ID indicates that over 40% of adults develop diagnosable mental health problems such as psychotic or affective disorders (Cooper, Smiley, Morrison, Williamson, & Allen, 2010). Whilst the prevalence figures for anxiety disorders in people with ID vary according to methodology, occurrence rates range between 10 and 39% (Gustafsson et al., 2009). Moss, Prosser, Ibbotson, and Goldberg (1996) stated that in ID populations significant proportions of psychiatric disorder goes undetected/untreated and accordingly Williams, Clarke, Fashola, and Holt (1998) commented on the profound lack of knowledge concerning hoarding and ID. Whilst there is no extant evidence of the prevalence rate for HD in adults with ID, it is estimated that about 16% of children with ID engage in hoarding that is not linked to either their OCD and/or autism (Testa, Pantelis, & Fontenelle, 2011). People who hoard do not display more autistic tendencies than psychiatric controls (Pertusa et al., 2012). When people met diagnostic criteria for Autistic Spectrum Disorder then Klin, Danovitch, Merz, and Volkmar (2007) argued that this leaves them vulnerable to pursuing behaviours related to overly and highly circumscribed interests creating associated social isolation.

It is worth noting that hoarding has been identified to be an aspect of the behavioural phenotype of one specific ID syndrome; Prader–Willi syndrome (Cassidy & Schwartz, 2009). Hoarding is therefore particularly common in PWS with an occurrence rate of 60% and particularly centres on the compulsion to hoard food (Storch et al., 2011). Hoarding in PWS is ego-dystonic and thus a significant cause of distress (Dykens, Leckman, & Cassidy, 1996). In residential settings, people who hoard can also take possessions from other residents and then hide such possessions in their personal living space (Van Houten & Rolider, 1988). Hoarding for people with ID who live in communal residential settings can significantly interfere with staff/peer relationships and often threatens the viability of the community placement itself (Lane, Wesolowski, & Burke, 1989). Staff asked to intervene, often experience the delivery of help as stressful as hoarding clients have poor insight/understanding, with a high frequency of intervention–interfering behaviours and reduced adherence to therapeutic tasks (Tolin, Frost, & Steketee, 2012).

Hoarding has been conceptualised from a number of different theoretical models (Gordon, Salkovskis, & Oldfield, 2013), with the cognitive-behavioural model receiving the greatest empirical attention. Skirrow, Jackson, Perry, and Hare's (2014) cognitive-emotional formulation of hoarding in ID suggests that clutter occurs when those with ID are unable to use emotional cues to differentiate between memories/objects that do and do not need to be remembered/retained. The CBT model characterises hoarding as a product of the interaction of three factors, (a) deficits in information processing, (b) beliefs about and attachments to possessions and (c) avoidance behaviour (Frost & Hartl, 1996). Allied assessment scales being developed and evaluated (e.g. the Saving Cognitions Inventory; Steketee, Frost, & Kyrios, 2003) and studies have employed a variety of primary outcome measures including visual ratings of clutter (e.g. Hartl & Frost, 1999), the Yale-Brown Obsessive scale (e.g. Frost, Steketee, & Greene, 2003) and the Saving Inventory-Revised (e.g. Muroff et al., 2009). Therapy based upon the CBT model has been manualised (Steketee & Frost, 2007). Uncontrolled (Tolin, Frost, & Steketee, 2007) and controlled (Steketee, Frost, Tolin, Rasmussen, & Brown, 2010) outcome studies do evidence empirical support for the model. However, when the CBT model has been tested in more varied clinical samples (such as in a geriatric hoarding), evidence indicates attenuated outcomes (Ayers, Wetherell, Golshan, & Saxena, 2011), without necessary population specific alterations (Ayers et al., 2014). A recent meta-analysis of the CBT treatment model (Tolin, Frost, Steketee, & Muroff, 2015) found large effect sizes for symptom reductions, but with lower rates of clinically meaningful change for individual participants.

In terms of ID specific outcome evidence, then the evidence base for hoarding treatment consists of three single case studies and one $N = 3$ study. Each study was based on the application of behaviour therapy. Allyon (1963) used satiation to reduce towel hoarding in a female with ID during a psychotic episode. Van Houten and Rolider (1988) showed reduced hoarding due to movement-suppression timeout and Lane et al. (1989) taught appropriate discard through use of timeout. Berry and Schnell (2006) used a multiple baseline design with $N = 3$ ID hoarders and showed reduced hoarding for each participant when item return procedures were instigated.

In summary, the previous attempts to treat hoarding in ID contexts have been purely behavioural and there have been no prior attempts to test the generalizability and utility of CBT model. There is a growing body of evidence that indicates that CBT can be effectively adapted to treat emotional disorders including anxiety and depression in people with ID (Taylor, Lindsay, & Willner, 2008) and the current study chose to test the effectiveness of CBT based on this evidence. The current study was novel and innovative in attempting to index the safety, effectiveness and durability of CBT for hoarding for the first time in an ID context. Study hypotheses were as follows; home environments will be significantly less cluttered following CBT and will show no evidence of clutter relapse during follow-up; hoarding will reduce following CBT with no relapse over follow-up and finally mental health (anxiety and depression) will improve during CBT and not relapse over the follow-up period.

2. Methods

2.1. Participants

The sample consisted of $N = 14$ adults with ID with hoarding difficulties. To be a potential participant then participants needed to be on the social services case register for people with established intellectual disabilities. Three of the participants lived in a communal house, but had their own rooms; the remaining participants lived independently (alone or with their partners). Inclusion criteria for the study required participants to be 18 years or older and staff to report a primary presenting problem of excessive acquisition of objects, a significantly cluttered home environment and difficulties with discarding