Clutter-Buddies: A Volunteer Program to Assist Clients Undergoing Group Cognitive Behavioural Therapy

By

Zachary Angel

Thesis

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Masters Committee:

Melissa Norberg

Jennie Hudson

ABSTRACT

The aim of the current study was to determine the efficacy and feasibility of a volunteer-based supplementary home intervention for individuals currently attending group Cognitive behaviour therapy (GCBT) for Hoarding Disorder (HD). Current treatment outcomes are only moderate and have a high rate of dropouts. Volunteers were trained by an experienced researcher in HD; they were taught the current treatment of Cognitive Behavioral Therapy (CBT), additional Motivational Interviewing (MI), decisional balance scales and client-centered skills for eliciting behavioural changes. Self-identified participants with HD attending GCBT at a community organization opted into the study. There were six participants in each group: control and intervention. Participants were provided eight weekly two-hour sessions in their homes with two volunteers. The focus of these sessions was to help participants practice the skills learned during Group CBT sessions in their home environment. From pre-treatment to post-treatment, the intervention group showed a significant reduction in scores on the SIR ($F(1, 11) = 12.486$, $p = .006$, $\eta_p^2 = .581$), compared to the control group. Smaller changes were seen on the Home Environment Index ($F(1, 11) = 8.8$, $p = .016$, $\eta_p^2 = .494$) and changes were not statistically significant for the Clutter Image Rating ($F(1, 11) = 2.16$, $p = .175$, $\eta_p^2 = .194$). The control group did not experience statistically significant change on any of the outcome measures in this study. The effectiveness and feasibility of co-leading the intervention with the community organization are discussed alongside the feedback from participant interviews. The program shows promise for enhancing treatment outcomes for participants beyond group CBT with large effect sizes for the results, however, the small sample size and lack of specific demographic data from the sample limits the generalizability of these findings. Future studies should make gathering demographic data a requirement for participation in the program, seek to reach more participants, consider longitudinal studies and observe the durability of intervention effects.

Acknowledgments

In collaboration with my advisor, Melissa Norberg, I am responsible for the design, data collection, analysis, and authorship of the work presented in this thesis. Melissa's dedicated assistance extended to the refinement and delivery of training materials and their content. Her experience and input from her research into hoarding were beyond value, her continued support through my candidature has kept me motivated to complete my thesis. Jennie Hudson assisted as secondary supervisor, providing support and hosting meetings with Melissa and myself. Her calm approach to my flurry of stressed out questions helped in keeping me level-headed and reminded me to breathe during the most stressful parts of this process. I also would like to thank Simone Isemann for her collaborative role from the community organization to Macquarie University. Without her willingness to work with me, I could never have completed this study. The study presented in this dissertation was approved the Department of Psychology, Macquarie University, to whom I also acknowledge, as without their approval and support this project would not have been possible.

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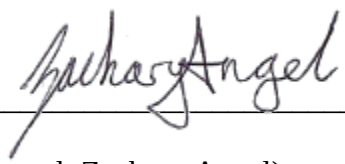
Statement of Originality

This work has not previously been submitted for a degree or diploma in any university. To the best of my knowledge and belief, the thesis contains no material previously published or written by another person except where due reference is made in the thesis itself.



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(Signed: Zachary Angel) (Date)

Clutter-Buddies: Volunteer Program to Assist Clients Currently Undergoing Group Cognitive Behavioural Therapy

1. Literature Review

1.1 Statement of The Problem

Hoarding disorder (HD) is a debilitating mental health disorder that has been classified as a stand-alone disorder in the DSM-V (American Psychiatric Association, 2013). People with hoarding disorder have been found to have increased physical and psychological disability and unemployment, general functioning, and low insight in general (Tolin, Frost, Steketee and Fitch 2008). Individuals with HD also have been noted to have lower rates of marriage and lower rates of successful interpersonal relationships than those without hoarding disorder (Nedelisky and Steele, 2009; Frost, Steketee & Williams, 2002; Frost, Steketee & Tolin, 2011; Tolin, 2011).

Hoarding disorder treatment has high rates of dropout and treatment failure, and people with HD experience more social disability and family conflict when compared to individuals who do not have hoarding disorder (Büscher, Dyson and Cowdell, 2013). There are three major criteria that are the focus of treatment. HD is defined as having a persistent *difficulty discarding* possessions that results in the accumulation of *clutter* in the living areas of the home; which leads to the intended use of the areas in the home being substantially compromised, causing clinically *significant distress or impairment* in social, occupational, or other important areas of everyday functioning (American Psychiatric Association, 2013). The type of treatment with the largest body of evidence is cognitive-behavioural therapy of HD (CBT for HD; Frost and Hartl, 1996; Mataix-Cols, 2014). This includes motivational interviewing (efforts to increase motivations to change, as well as increase adherence to treatment plans); graded exposure to non-acquiring; training in skills useful in sorting and discarding possessions; cognitive restructuring and organizational skills useful in decluttering and maintaining clear spaces in the home (Tolin et al., 2015).

Evidence for the effectiveness of CBT for HD came from small case studies and uncontrolled trials (such as Steketee, Frost, Wincze, Green and Douglass, 2000; or Muroff, Steketee, Bratiotis and Ross, 2012).

The studies that establish evidence for CBT return mixed results, often there is a positive, but limited effect on the treatment outcomes. In a controlled trial testing the effectiveness of CBT, forty-six patients with hoarding disorder were randomly assigned to receive either the CBT intervention (which involved ~twenty-five weekly, sixty-minute individual therapy sessions with home visits over a period of nine to twelve months) or to remain on a waiting list. After twelve weeks, the proportion of trial participants rated as being much or very much improved was 43% (10 of 23 participants), compared to the control group which had 0% improvement (Steketee, Frost, Tolin, Rasmussen and Brown, 2010). Specialized treatment, for example, individualized CBT for hoarding like in the previously mentioned study show promise and are useful in reducing participant scores on the Hoarding Rating Scale and SIR. When done individually though, the treatment process is lengthy, labour intensive and potentially expensive for the clients. One study that looked directly into costs of CBT for HD places the costs of therapy at around $800USD for 20 sessions in a therapy setting (Matthews, Uhm, Chan, … Yu et al., 2016). Following this, more cost-effective methods to deliver CBT-based interventions for HD (for example, group therapy, peer-led bibliotherapy, provision of self-help materials and additional home-assistance) have been tested in small, uncontrolled or wait-list–controlled trials.

The results of these group therapy studies are comparable to those studies done with individual face-to-face treatment between participants and therapists (Frost, Ruby and Shuer, 2012; Giliam, Norberg, Villavicencio, Morrison, Hannan and Tolin, 2011). In one small, open trial of Group CBT (GCBT), Muroff et al. (2009) reported up to a 26% reduction in scores on the SIR as a result of sixteen group sessions and four additional home assistance sessions. Additionally, the GCBT only group had similar reductions (25%) whereas bibliotherapy only led to minimal change in hoarding symptoms (9%) (Muroff, Steketee, Bratiotis & Ross,

2009). The potential to reduce costs of treatment whilst still maintaining effectiveness may allow treatment to become more accessible as well as more likely to be offered by community organizations. However, there remain some issues with the GCBT approach to HD.

Previous research experiments tend to find that whilst cognitive-behavioural therapy has a modest, significant impact on hoarding scores pre- to post-treatment, they also report that there are significant rates of drop-out. In many studies, only a quarter of participants experience clinically significant change in their hoarding scores on measurements like the Saving Inventory Revised (SIR), which means that their scores from pre-treatment to post-treatment stayed at or above the clinical cut-offs for hoarding disorder using the SIR (Muroff et al, 2012; Frost, Ruby and Shuer, 2012). For the average patient, clutter in their homes remains three standard deviations above the normative mean after CBT treatment (Tolin et al., 2015). Follow-up data at post-treatment from longitudinal studies do not show a continued reduction in clutter in the home environment after treatment ends (Muroff, Steketee, Frost and Tolin, 2014; Tolin et al, 2015). This evidence suggests that hoarding symptoms are highly resistant (Tolin, Frost, Steketee and Fitch, 2008). Evidence for the effectiveness of CBT on reducing hoarding symptoms has not always shown positive results for each participant and treatment drop-out rates are high, and many patients express a desire for in-home care. Some researchers have looked specifically at the impact of home visits on the effectiveness of CBT on HD.

In the Muroff et al study (2012), home assistance was provided by trained non-clinician undergraduate students who delivered all but four home sessions alone after attending one home session with a clinician, totaling five sessions where a clinician was present. The coaches provided guidance based on the goals collaboratively set by the therapists and participants during the group sessions. They found that both group cognitive behavioural therapy (GCBT) and GCBT with Home Assistance (HA) were both effective in reducing hoarding symptoms. Group CBT on its own was shown to be effective for 21% of participants who

saw statistically significant change from pre-to-post-treatment measurement using formalized assessment. Whereas GCBT with HA led to 36% of participants seeing statistically significant change in their scores. It should be noted however, that whilst the changes were statistically significant at the 0.05 level, a change of 21% on the SIR does not guarantee that the average participant would score below the clinical cut-off for HD. Whilst statistically significant change is impressive, the actual clinical change was moderate, and most participants are left still with a decent hoarding problem. Both group CBT conditions in this study saw changes that were at least the same as what is reported in individual CBT sessions, which is roughly a 27% reduction in clutter (Steketee et al., 2010; Muroff et al., 2012), but the GCBT with HA group saw a 33% reduction. If there is such an increase over the GCBT approach with the addition of home assistance, despite not being statistically significant, the addition of home assistance to CBT or GCBT interventions for HD should be further explored. Additionally, in this study, a psychologist was present and contributed to at least five of the home sessions as supervision for the student-volunteers. Thus, the impact of non-clinician home-assistance, in lieu of home visits from registered or clinical psychologists, has not been adequately addressed by previous research. If it is just as effective to send trained volunteers to deliver home sessions as it is to have clinicians be paid to do so, this should serve to reduce the costs of obtaining treatment for HD.

The typical intervention for hoarding disorder today remains a costly endeavor to both the individual and society as well, and generally lasts seven to twelve months (Tolin, Frost & Steketee, 2007). Due to the costs, a fair amount of people with HD (14% in one study) tend to rely on public aid programs. These costs do not cover additional assistance that may be obtained from Catholic Healthcare in Australia, or from council-based clean-out services (usually through Fire Departments where available). In attempts to manage the gains reported in studies of individual and group CBT sessions, whilst reducing the overall cost of

long-term treatment researchers have considered the addition of non-clinician led home-sessions.

Although CBT appears to be a promising treatment approach for hoarding disorder, treatment to date has been quite labour intensive, as well as high in cost for clients. One meta-analysis found that despite the benefits of CBT seen in studies, there is a high rate of drop out, and many, if not all, patients continue to experience some level of HD symptoms and associated impairments post-treatment (Tolin, 2011; Tolin, Frost, Steketee and Muroff, 2015). Furthermore, they found that changes are only clinically significant in 25%-43% of cases, leaving anywhere from 57%-75% of patients in unchanged circumstances and potentially unliveable homes, due to lack of change in clutter or excessive acquiring (Tolin et al., 2015). This is likely because CBT for HD sees the most change on only one of hoarding disorders' main criteria – difficulty discarding (Tolin et al, 2015). This focus on difficulty discarding is perhaps unsurprising, given that most CBT-based interventions tend to focus explicitly on this feature; home visits were identified as the major predictor of reductions in difficulty discarding. Therapy sessions in-person are generally removed from the patient or client's home setting and is often done in a clear, clean, therapist's office or some otherwise uncluttered therapy room, unless using simulations. Thus, by offering home-sessions, patients are given the chance to practice sorting, discarding and decluttering in the most difficult context. Regarding clutter itself and excessive acquiring, effect sizes in all recent studies are lower (Tolin et al, 2015); as clutter is the environmental outcome of hoarding, it stands to reason that clutter would see less change in interventions that focus on cognitive aspects of hoarding. On the other hand, however, any reduction in difficulty discarding should, logically, reduce the amount of clutter in the home environment. As difficulty discarding decreases it should become easier to discard possessions and thus clutter should be reduced. One complicating feature of HD that may partially account for this inconsistent relationship between difficulty discarding and clutter may result from physical and mental comorbidities (Tolin et al., 2015). Thus, participants may, as

a result, suffer from functional impairment that could be managed by reducing excessive acquiring and the build-up or clutter in living spaces as well as the cognitions behind a participant's difficulty in discarding possessions.

Most studies that find reductions in functional impairment report slight improvements that still fall short of the changes seen in the other core features of HD. Functional impairment refers to the inability to use rooms in the house for their intended use, avoiding having friends and family over, physical and other mental health complications (Ayers, Ly, Howard, Mayes, Porter and Iqbal, 2013; American Psychiatric Association, 2013). Functional impairment may also reflect the ongoing issue and persistence of clutter in patient's homes – the existing clutter is an issue often left for patients to deal with alone after therapy sessions. A common expectation is that the therapy or intervention a patient receives will give them the skills needed to enact further change on their own, however the physically demanding nature of decluttering is not always something that can be addressed through GCBT, which focuses primarily on the behavioural aspects of HD. Group-CBT focuses on difficulty discarding and excessive acquiring and their related cognitions and (mostly due to the group approach) does not incorporate practicing organization skills that would be useful in enacting further change on their own in their own homes as all sessions are done on-site at the community centre. Reducing difficulty discarding, excessive acquisition, clutter and building up distress tolerance are core goals for CBT for HD. Relatedly, the functional impairment seen in HD may not be exclusively due to the symptoms, treated or otherwise, of HD itself and may be impacted by sedentary lifestyles (as a result of persistent clutter and inaccessibility to spaces in the home) or physical disabilities (either unrelated to HD, or related to the way patients cope with living in a heavily cluttered space) (Ayers et al., 2013). This means that there is a negative, feedback effect from clutter on physical health due to both pre-existing injuries or disabilities and the forced sedentary lifestyle that comes from being unable to traverse or use spaces in the home. In most cases, when physical health worsens so does clutter, and the opposite is also true. As mentioned previously, a

closer look at the clinically significant changes reported in the studies referenced suggests that whilst treatment impacts and gains are substantial in HD, most patients continue to score above or within the clinical range at post-treatment. As clinically significant change is lowest in the feature of clutter in HD at post-treatment, and most patients across studies score the highest in clutter at pre-treatment, this finding suggests that in general for patients with HD, decluttering may require far more time, and a more explicit approach to clutter and decluttering, than what is currently offered in most CBT trials.

In Australia, the current approach to HD is varied, and some take the form of GCBT with supplementary bibliotherapy and additional individual therapy-based sessions done face-to-face. However, these programs do not make use of clinician home-visits for several reasons including travel time, costs, accessibility and availability. In Australia, clients may live upwards of two hours away from the nearest medical centre, hospital, or therapist due to the size of the country and the reduced presence of psychologists and medical services in rural areas (Australian Institute of Health and Welfare, 2017). This leaves the effectiveness and the potential usefulness of supplementary home or domiciliary sessions under-researched in the Australian context. For clinicians, home visits are often seen as costly, time-consuming, labour and travel intensive (Steketee, Frost, Tolin, Rasmussen & Brown, 2010). On average, in studies looking at HD, the inclusion of home visits to the treatment program is more effective than just GCBT alone (Muroff et al., 2012; Tolin et al., 2015). It has been put forward that the inclusion and use of trained non-clinician (volunteers or "coaches") may help create a more intensive and cost-effective model, whilst simultaneously benefitting clients with a more intensive treatment program (Muroff et al., 2012). However, research into the effects of "coaching", (or trained, non-clinician volunteers) on clinical and subclinical mental health problems is still very limited in most areas, and in HD especially, few studies to date have looked at the impact of trained non-clinician home visits on HD treatment outcomes (Newnham-Kanas, Gorczynski, Morrow & Irwin, 2009). Thus, for the reasons previously

mentioned and from the results of past studies, understanding the history of HD treatment is one of the first steps necessary to take in order to develop or enhance treatments. Thus, the aims of this thesis are as follows: to pilot-test a trained non-clinician (volunteer) home-visit program to supplement the treatment of individuals currently undergoing GCBT for HD at a community organization and to determine whether this supplementary intervention can be, i) feasibly delivered by trained, non-clinician volunteers, and ii) to determine if the supplementary intervention can improve upon the moderate treatment outcomes of participants currently undergoing GCBT.

2. Methodology

2.1 Participants

Twelve adult patients attending GCBT at a community organization opted to be the participants for this study. In this study, 91.67% of participants were female (N=11) and one was male; all participants had been living with hoarding for many years and some participants (25%), had received some help from other community organizations that conduct paid clean out visits. The participants were divided into two groups. This study was an exploratory, three-factor repeated measures experiment that looked at the impact that a supplementary intervention for HD had on six individuals and their hoarding symptoms. The other six participants received GCBT only and were the control group. All participants were attending GCBT for HD at the community organization.

The exclusion criteria for this study were as follows: any Home Environment Index Scores that were 28 or higher, and any average Clutter Image Rating scores (across rooms) of 6 or higher (Frost, Steketee & Nathan, 2014). These scores would logically prevent entry into any participant's home in which there is substantial risk of physical or biological hazards. This meant if there was any exposed or unflushed human or animal pee or feces or vomit, piles of body hair, mold, odors that would be unreasonable to find in an average house, exposed glass shards or broken windows, structural insecurity and substantial risk of fire. If a home appears safe by these measurements but was later deemed unsafe upon entry either due to improper reporting or sudden preventable changes, participants were excluded from receiving any further home sessions during this study. Additionally, any participant with significant anger issues would be excluded from receiving the intervention. These exclusion criteria did not preclude participants from responding as part of the control group. Thus, participants who met exclusion criteria to not receive the home sessions were still invited to participate in follow-up measurements for comparison purposes. Allocation to

groups was done solely based on participant availabilities. Participants were required to live within 20 kilometers of MQU in order to receive home visits.

The goal of the study was to determine the effectiveness and feasibility of a supplementary intervention using trained volunteers who were studying psychology at Macquarie University to provide in-home discarding sessions for half of the participants whilst the other half had the regular GCBT sessions only. As the community organization expressed concern over participants becoming distressed or anxious over providing demographic data, participant demographics such as age, years of standard education or financial situation were not recorded. As such, methodology of recruiting participants, measurements used to assess hoarding symptom severity, the exclusion criteria used for the study and group allocation are defined below.

2.2 Recruitment

All participants were individuals who were currently attending GCBT for HD through a Compulsive Hoarding Treatment Program at the community organization. Furthermore, all GCBT attendees had access to the Buried in Treasures workbook and had attended 12 weekly sessions before the start of the home sessions.

2.2.1 Volunteer Training. Volunteers were psychology undergraduates from Macquarie University and the Master of Research Student. Volunteers read nineteen chapters from the Buried in Treasures workbook and participated in a full-day training session. The training covered: HD criteria and associated features (American Psychiatric Association, 2013), and how to engage in motivational interviewing in the context of making discarding decisions.

The role of the volunteers and the actions they were expected to take during sessions was discussed in depth; volunteers as Clutter-Buddies were to provide social support and motivation to the participants during the home sorting and discarding sessions, as well to help physically move a participants possessions to where they were being sorted to, or to the correct bin (recycling,

rubbish) if items were to be discarded. To this end, volunteers would be expected to follow sorting and discarding rules set out by the participants during the GCBT sessions held at the community organization. During the training, volunteers were also asked to bring in an item that they had been struggling to discard so that they could simulate, understand and be prepared for what might happen in the home sessions.

2.3 Measurements

2.3.1 Saving Inventory Revised. The Saving Inventory Revised is a 23-item measurement with 3 subscales; difficulty discarding (DD), clutter (CL) and excessive acquisition (EA). The measure has an established Cronbach's alpha of 0.83, and each subscale has some correlation with each other scale. items are scored from 0 (no problem) to 4 (very severe, extreme). Internal consistency in the present sample was Cronbach's α =.72 for the total scale, α = .65 for the difficulty discarding subscale, α = .87 for the clutter subscale and α = .21 for the excessive acquiring subscale. In other studies, the excessive acquiring subscale has α = .80, as such the low rating seen in this study is likely due to the responses participants had to Item 2 on the subscale "How much control do you have over your urges to acquire possessions?", in the sample it appears that this item did not load onto excessive acquiring as strongly as other items on the scale did. However, due to the historic finding of α = .80 for the subscale, no changes were made to the item inclusion for this scale. For the SIR, clinically significant change has been operationally defined as a score showing a reduction of 14 points or more from pre- to post-treatment, as well as being a post-treatment score of 42 or less, which is the point half-way between the means of the clinical and nonclinical populations (Frost, Steketee and Grisham, 2004; Gilliam et al., 2011). For all participants the SIR was delivered at pre-treatment and post-treatment, as well as at the start of each weekly session for participants in the treatment group.

2.3.2 Clutter Image Rating. The Clutter Image Rating is a visual assessment of clutter in the home that includes nine pictures. It is completed via

self-report. Possible scores range from 1 = “no clutter,” to 9 = “severe clutter” for three rooms: kitchen, living room, and bedroom (Frost, Steketee, Tolin & Renaud, 2008). It is strongly correlated with other clinical measurements of clutter and in general, the CIR completed in the clinic is strongly correlated with those completed by a therapist in the participant’s home, suggesting that the CIR completed during therapy sessions is an accurate representation of clutter in the home. For all participants the CIR was delivered at the pre-treatment and post-treatment phases.

2.3.3 Home Environment Index. This is a 15-item measurement with a focus on the sanitary state of a cluttered home. The scale of responses ranges from 0 to 3, and in most items 0 = “no risk of hazard” and 3 = “high risk of hazard”. In general, any item that scores a 2 or higher is an immediate concern and any item rated as 3 met immediate exclusion criteria for this study. The observed α in the original study was α =.89, indicating good internal consistency and it was positively correlated with other measurements of clutter (Rasmussen, Steketee, Frost, Tolin and Brown, 2014). Where the CIR provides a visual representation of clutter in the home, the HEI provides a more accurate view of the sanitary state of a home and if clutter in the home is also squalid. In this study’s sample the observed Cronbach’s α was =.86, indicating good internal consistency for this sample. For all participants the HEI was delivered at pre-treatment and post-treatment.

2.3.4 Client Satisfaction Questionnaire Revised. The CSQ-R is a revised format of the CSQ-8 (Larssen, Atkinson, Hargreaves and Nguyen, 1979; Kelly, Kyngdon, Ingram, Deane, Baker & Osborne, 2017). Both the original and revised scales have moderate to high internal consistency and load onto only one factor with a Cronbach’s α = .92 for the original 8-item scale. The revised version used in this study had a Cronbach’s α =.78. The revised scale used in this study exhibited a redirected focus of each item to better reflect the Clutter-Buddies program. The scale asks questions such as “How would you rate the quality of the service you received?”, “To what extent has our program met your needs?” and

"Have the services you received helped you to deal more effectively with your problems?" on a 5-point Likert scale with scores ranging from 0 = "Terrible" to 4 = "Excellent", with relevant terminology for each question.

2.3.5 Follow-Up Interview. Follow-up interviews with participants in the intervention group were held one to two weeks after the final home session they had with the Clutter-Buddies. In this meeting, post-treatment scores were measured, and a short thirty-minute interview was held. This interview was designed to allow participants, in their own words, to give direct feedback on the experiences they had with Clutter-Buddies and how they felt about the progress that was made. This interview simply asked three questions, "What did you like least (about the program)?", "What did you like most?" and "What would you like to change for future participants?".

2.4 Procedures

The study was reviewed and approved by the Macquarie University Human Research Ethics Committee (HREC), Reference Number: 5201701104. All twelve participants provided signed, written consent that they would participate in the study. The presence of hoarding symptoms was established by a registered psychologist working at the community organization. The SIR measurement was answered at the start of each new session, this was done to help motivate participants to continue to change as well as to provide a visual graph of the changes in their scores each week, to enhance awareness of their hoarding and how it becomes managed.

Additionally, the twelve participants that consented to participate in the study were also limited in terms of their availability. This had an impact on the group allocation process. The first home session was designed to follow a strict process, with suggestions and requirements for future sessions (Appendix 1: The First Home Session and Subsequent Sessions Outline), it included a greeting and explanation of who the volunteers were (Clutter-Buddies), where the participant met the researcher should they not remember, and the plan for the first session.

For all participants, the first hour of the first session involved determining the room in which sessions would focus on decluttering, the participant's rules for sorting and discarding that the buddies should follow, the participant's goals and a discussion of how attainable the goals would be, as well as a discussion of ground rules and how the first session may not be as productive as desired due to the newness of the Clutter-buddy to participant relationship. Finally, the first session explained how the buddies were meant to help, that is; the buddies are there to guide and assist in the decluttering and sorting process – they are not there to do all the work, and they are not there to force the participant to change, but rather to provide social support, feedback, and problem solving ideas to the participants as needed. This alongside physical assistance in moving larger objects would make up the core of home sessions.

3. Results

3.1 Baseline Characteristics

All data were analyzed using IBM SPSS Statistic version 23. There were no significant differences between groups at time one on the SIR, CIR or HEI. See Table 1 for means and standard deviations.

No participants had failed to complete the measurements at pre-treatment, nor at any other time during the program. Of thirteen possible participants already attending CBGT at the community organization, one person chose to not participate in the study. Of the remaining twelve, one person had to be excluded from being part of the intervention group due to having an inaccessible home with an HEI score above the threshold. This participant was still invited to respond to the post-treatment assessment.

There were no sessions identified, where participants did not clearly understand the role of the Clutter-Buddies, or needed further explanation, nor were any participants unhappy with the roles of the Clutter-Buddies. All Clutter-Buddy volunteers met for weekly supervision with Melissa Norberg to discuss

how sessions were unfolding, seek advice, manage any potential stress or issues that presented, and to help problem solve what worked or did not work for each participant.

3.2 Intervention Effects On Main Outcome Variables

Two participants in the control group did not respond to the researcher's attempts to contact them for the post-treatment assessment. As such, their pre-treatment scores were carried forward before conducting hypothesis testing. In the intervention group, one participant did not complete the satisfaction questionnaire. Results were analyzed in SPSS using univariate ANOVA's holding scores on each measurement at pre-treatment constant and comparing them to scores at post-treatment. When holding the pre-treatment scores constant, the intervention group had significantly lower scores on the SIR and HEI at post-treatment. CIR scores did not significantly differ across groups.

For the CSQR frequencies were analyzed. These results are summarized visually in Table 2. There were no significant changes on the averaged CIR scores from pre- to post-treatment found in the analyses, however, it is unclear if there was an equal non-effect on the clutter subscale of the SIR; analyses of the effects on the intervention on each subscale were not completed.

Table 1

Means (standard deviations), analyses and effect sizes for group cognitive behaviour therapy with supplementary home intervention and non-intervention control groups

Measure	Group	Pre-test mean (SD)	Post-test mean (SD)	Between-groups analysis	*p*-value	Partial eta squared (η^2)	Observed Power	% Reduction
SIR-T	Control	68.67 (8.16)	63.33 (7.81)	F(1,11) = 12.486	0.006	0.581	0.881	7.77
	Intervention	64.17 (7.02)	43.33 (8.95)					32.47
CIR-Av	Control	4.66 (1.93)	4.50 (1.85)	F(1,11) = 2.165	0.175	0.194	0.261	3.43
	Intervention	3.33 (1.28)	2.89 (0.62)					13.21
HEI-T	Control	15 (8.41)	14.17 (7.62)	F(1,11) = 8.800	0.016	0.494	0.752	5.53
	Intervention	13.50 (5.39)	9.33 (4.45)					30.89

Table 2

CSQR Item Means and Standard Deviations	Mean	SD
How would you rate the quality of the service you received?	3.800	0.447
Did you get the kind of service that you wanted?	3.400	0.548
To what extent has our program met your need?	3.200	0.837
If a friend needed similar help, would you recommend our program to them?	4.000	0.000
How satisfied are you with the amount of help you received?	3.600	0.548
Have the services you received helped you to deal more effectively with your problems?	3.600	0.548
In an overall, general sense, how satisfied are you with the service you have received?	3.600	0.548
If you were to seek help again and our program was available, would you come back to our program?	4.000	0.000
Total (N=5)	3.650	0.434

3.3 Qualitative Feedback

Feedback from the interviews followed a largely positive and similar pattern for most, if not all, participants. Quotes are from the conducted interviews. One participant rated the best aspect of the program as the practical skill building that the buddies helped build up with them and the procedures and strategies for decluttering offered by the buddies. The main responses from the participants rated the physical act of Clutter-Buddies coming to their home as necessary for their personal improvement; the pre-allocated time slot (two hours each week on the same day each week) helped motivate them to be present and willing to work as they knew when they would start and when they would end and the repeated motivation and words of encouragement, along with the weekly measurements and comments from the volunteers on progress made helped participants clearly identify changes made in their home. One participant responded that "Two hours was enough for me to go through [the more difficult items] that needed emotional discussions. It gave me enough momentum to remove things on my own, (after the intervention)".

Additionally, half of the intervention participants reflected on how useful the volunteers were in reducing their stress and talking them through a situation where they otherwise would have become very frustrated, or very distressed; these participants openly reported that the Clutter-Buddies program was more useful than other assistance they had received in the past.

Feedback for what participants liked the least about the program was less definitive and overlaps somewhat with what they would like to see changed for future participants. One participant said there was nothing about the program that she did not like. Half of the participants wanted more and longer sessions.

One participant commented that Clutter-Buddies "Felt like a taste of something you wanted or needed more of but could not have." Another participant responded that the Clutter-Buddy volunteers were "Too nice", and that she would have preferred to be pushed more to discard some of her possessions. This was despite having asked Clutter-Buddy volunteers to not push her to make

decisions on baby toys and clothes. Others expressed a strong desire for psychoeducation regarding the effect comorbid disorders may have on hoarding.

One participant requested that in the future, the plan for the first session should be made available to participants a week before their first session so that they know what to expect, because this participant had so much anxiety before her first session that she was "nauseous for three days".

Related to this, 33% (N=2) of participants reported a desire to – in the future, based on how positively they felt about the Clutter-Buddies – be challenged and pushed by the volunteers to discard not only more items, but more difficult items (for example, those items that held no physical use or worth, but were highly sentimental or otherwise desired but not necessary for participants to have in order to lead a healthy life).

4. Discussion

This study is the first study to assess the results of an intervention using volunteers trained to provide home assistance to participants with Hoarding Disorder without the direct input from a clinical or registered psychologist *during* sessions. That is, no experienced psychologist was present within the home sessions at any point.

The main findings of this research indicate that the additional home-sessions using Clutter-Buddies was effective for participants currently undergoing group Cognitive Behavioral Therapy for HD. The results of the intervention on the main outcome variables showed that for two of the three outcome variables, the supplementary intervention using Clutter-Buddies had a significant positive effect compared to the control group which involved only attending the community organization's GCBT sessions. Additionally, participant feedback using both the CSQR and CBSQ showed a majority positive outlook and high levels of satisfaction with the Clutter-Buddies program. Due to the small sample size (N=12) for this study, the feedback from the intervention group provides useful information when considering if and how to implement this program as co-led between Macquarie University and the community organization.

The benefits of the intervention at minimum mirrored the benefits seen in previous trials of GCBT with home-assistance (Muroff et al., 2014; Steketee et al., 2010). However, for both the SIR and HEI observed power is high and they exhibited large effect sizes. Breaking down the results for scores on the SIR shows that the Clutter-Buddies intervention was only effective for one third (N=2) of the intervention group, leaving two thirds of the group without clinically significant change beyond the impact of GCBT sessions.

Additionally, the use of the HEI in this study was largely to account for and assess the state of squalor in the homes of the participants. Therefore, that the intervention had a significant effect on these scores is interesting and could be due to a similar effect seen with scores on the CIR in this sample of 12 individuals. For two of the six treatment group participants, scores on the CIR were recorded as higher in the self-report than they were upon observing the participant's homes. For one participant, who rated her HEI scores a full mark higher than they were in reality for most of the items and only after discussing their thought process was it clear why. This participant understood "please respond honestly" as being overly general about her responses, such as to item 5 "Human/animal waste/vomit" she responded higher because she has a family cat and occasionally the litter box is used, and because it is on the first floor, it sometimes goes uncleaned for a day, or item 14, "Do the dishes" the response was higher because her son and husband would sometimes leave dishes in the sink and they would stay there for weeks sometimes. The higher rating of these items may also have influenced the reductions seen on the HEI.

Clutter-Buddies therefore, may represent a more approachable, or comfortable form of mental health social support and, due to their training and goal-setting, the buddies may also provide participants with the type of social support they desire, while still effectively helping them with their hoarding problem (for example, Perry and Pescosolido, 2015).

4.1 Satisfaction Frequencies And Interviews. The Client Satisfaction Questionnaire-Revised, the Clutter-Buddies Satisfaction Questionnaire and the

follow-up interviews provided useful feedback and responses regarding the personal effectiveness of the Clutter-Buddies program. No participants had any negative feedback regarding the way the volunteers trained in this study interacted with them, nor were there any complaints of theft, over-stepping boundaries or causing severe discomfort. In fact, all participants in the intervention group praised the volunteer's abilities to increase their motivation and reduce their stress during times when they would otherwise have "had a meltdown" – Participant 8.

Responses to the CSQR highlight that all participants would return to Clutter-Buddies in the future and that they would recommend the program to friends who were seeking help for HD; the CSQR also found that despite the desire for a longer program run time, 60% of respondents in the treatment group were "Very satisfied" with the services they received during the Clutter-Buddies program and all respondents rated themselves as "Somewhat" or "Significantly" better able to deal with their problems, this further suggests that participants shared a strong, positive reaction to the volunteers and services offered both during the sessions and upon reflection, suggesting that the impacts of the program were both positive and salient to participants.

In a similar vein of thought, the interviews were designed to elicit more free-flow interactions and less rigid feedback responses from participants, as well as to guide future iterations of the Clutter-Buddy program, provided it was successful in further improving the effects of GCBT on HD. There are five main takeaway points resulting from the interview process. One is that the first session plan and what participants should expect from the program and the volunteers should be made available to participants up to one week in advance of their first session with the Clutter-Buddies.

This would ensure that participants who may have additional anxiety issues could better prepare themselves for what the first, and subsequent, sessions will be like. Interestingly, no participants were concerned over the identity of their would-be volunteers; all participants had met the researcher at the community organization prior to the commencement of home-visits with both the researcher

and another Clutter-Buddy. In the future this may also be a relevant piece of information to make available to participants before the first session.

A second outcome is that participants desire a longer treatment run time; whether it is longer session times (for example, two and a half to three hour long sessions) or a longer active period (24 to 48 weeks rather than 8 weeks) that is more strongly desired is unclear, additionally, it remains unclear, both in this study and from previous studies (Muroff et al., 2012) on exactly how many home-sessions are the golden amount of home-sessions, so to speak.

Thirdly, from the interviews we can see that participants in this sample had a strong desire for or to receive social support, from *someone*. As no demographic data bar age and sex were collected, it is not possible to generalize these findings to any larger population from which the sample in this study was drawn.

Fourth, in this sample, it was clear that psychoeducation, for both HD and other disorders, was lacking, despite the first session with participants being focused largely on psychoeducation. This should be noted alongside the observation that around only one third of the participants from week to week could recall or reflect positively on the content of that week's GCBT session. As the sessions at the community organization were designed around both GCBT and bibliotherapy in the form of "*Buried in Treasures*", it is concerning that so many participants could not recall the information discussed.

This effect may be somewhat explained by the expectation and historic prevalence of information processing deficits in hoarding disorder.

Finally, as the volunteer-participant relationship developed, and especially towards the end of sessions, it became clear that whilst starting slow and gentle with pressure for a participant to discard items was beneficial for the working relationship of the Clutter-Buddies and participants, it was not as beneficial for the continued progress of participants. One third of participants provided feedback that they wanted to be challenged more as their working relationship

with the volunteers developed. This information is beneficial in planning for future iterations of the program.

4.3 Study Limitations. The current study had several key limitations. First and foremost is the small sample size and lack of demographic data. In addition to this, two participants in the control group could not be followed up with. While their scores from pre- to post-treatment were carried through, there remains the chance that those two participants experienced significant changes, either positively or negatively, in their home clutter situation.

In such a small sample size, the lack of true data for these participants could have had a noticeable impact on the analyzed outcomes of the study.

The availability of the participants and Clutter-Buddy volunteers determined who received allocation to either the control or intervention groups. There were limited days and time slots available that the current group of volunteers could deliver home sessions. Though similar to the distribution of sexes seen in other studies and a reflection of the tendency for more women with HD to seek help for HD (Tolin et al., 2015), this study consisted of 11 women and 1 man as the participants. Comorbidity was not addressed in this study, yet participants desired help with the other issues impacting them.

As this study was designed specifically to address clutter and assist with sorting and discarding attempts made by participants in their homes, psychoeducation for other disorders was not taken into account during training, and as a result, the volunteers had to remind participants to seek psychologist help for problems that were not part of their training several times over the course of the program. Lastly, the follow-up interviews were between one and two weeks post-last session with the Clutter-Buddies. Due to this, and the lack of a more delayed follow-up session, the durability of the effects seen in this study cannot be spoken for following the termination of both the Clutter-Buddies home sessions and the support from the GCBT sessions with the community organization.

4.4 Directions For Future Research. Overall, there are several key areas to take this research in both future short-term and longitudinal studies. Whilst these findings are interesting and show some promise for the effectiveness and potential value of the Clutter-Buddies program, the first goal of future research should be to replicate these findings in a much larger sample size. Analysis of the effects of the Clutter-Buddies intervention on each subscale; clutter, difficulty discarding, and excessive acquisition would also be useful to check in future studies. This would help to identify which aspects of hoarding disorder are most impacted by the intervention and in what ways the program could be further improved. Relatedly, this study focused on the impacts of the intervention on the overall, or total, scores on each measurement. Due to the nature of the intervention focusing on only one room for the duration of the program, it may be more accurate to only perform analyses on the CIR for the specified room, rather than averaged CIR scores. The same could be said for the subscales of the SIR. Additionally, the program itself needs to be reformatted to better reflect the feedback, desires and needs of participants; whether this means Clutter-Buddies offers more sessions in total, or longer sessions for a similar amount of time would also need to be addressed.

A longitudinal study looking at differences between a 16 and 24-week program could assist in this. Future comparisons regarding home-assistance should also consider having more substantial differences in the in-home sessions; for example, this study explicitly trained volunteers to avoid making participants feel forced or unfairly pressured in the discarding process and from follow-up interviews, it became clear that over time participants needed to be challenged more strongly to discard difficult items to continue progressing and reducing their scores after a certain point.

Finding this point, as well as managing the development of a working relationship between volunteers and participants, and the ways volunteers challenge and motivate participants to discard items should also be a key focus for future research.

5. Conclusion

This study builds upon previous trials of supplementary home-assistance for individuals attending group Cognitive-Behavioral Therapy for Hoarding Disorder. The study did so by exploring the effectiveness and feasibility of a volunteer-based home-visit program with no presence of clinical or registered psychologists during the sessions. This allowed the study to determine the effectiveness of non-clinician home-assistance in the course of treating HD with GCBT. These findings reveal evidence of the positive additional impact of non-clinician home-assistance beyond that of GCBT on its own (33% reduction in the intervention group compared to 23-27% reductions seen in open trials of GCBT). Non-clinician, or volunteer-based home-assistance has the added benefit of providing additional support to individuals struggling with HD without increasing the cost of treatment.

The additional costs that clinician home visits entail is one of the main reasons why more therapists and community organizations do not offer them. However, by adding eight home-sessions to the GCBT treatment plan offered by the community organization, we saw statistically significant change on two of the three outcome variables for this study. Hoarding symptoms as measured on the SIR and home squalor and clutter measured on the HEI saw significant improvement beyond the improvements seen in both group and individual CBT for HD. This study provides initial positive evidence for the usefulness of volunteer-led home-assistance programs as a supplement to GCBT.

Future research into non-clinician home-assistance for HD should consider both the length of the sessions and duration of the treatment, as well as the ways in which the working relationship of the volunteers and participants can be used to further improve the results seen from treatment.

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Appendices

Appendix 1. The First Home Session and Subsequent Sessions Outline

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The First Home Session and Subsequent Sessions

First Session Plan/Script

What does the first session look like? What do subsequent sessions with participants look like? The first session will be focused more on making sure all information and rules are correct than other sessions.

Home sessions will follow a set outline:

1. At first session only, introduce yourselves and explain that you're from Clutter-Buddies and we've met at the community organization (if applicable) or that you're one of the buddies working in the program and mention you being part of these sessions and greet the participant as you would any other person you've just met.
    - You're new to them, make sure it's all right if you enter their home if they haven't invited you in.
    - Mention the need to check safety using the ECCS to make sure their home is within the safety requirements set by the researcher and Macquarie University and this will take 2-3 minutes and can be done whilst you have this chat.
2. Ask a casual question to lead into making sure they have everything ready: "Why don't we just have a chat first before we start?"
    - In the chat, mention that part of the clutter-buddy program is the repeat measurement of their progress on the Saving Inventory Revised (SIR) and how repeated measuring can increase outcomes threefold because it makes progress more readily visible for participants.
    - One of our goals is to substantially increase the amount of discarding you do without group sessions and eventually, without buddies.
    - "So, you've done the SIR a few times now at Lifeline and the scores for today are what we'll consider your baseline, so we'll refer to these scores each new

session to see how much you've changed. If there isn't change, we can discuss ways for us to help you out better during our sessions."

- This is where you are now on the SIR scales, at the end of our 8 sessions, where would you like to be on these scales? Buddies are to keep the SIRs in the participant's folder.

3. After the SIR explain to them that they may find us as annoying or more annoying than other people who have come to their homes in the past, like from Catholic Health Care. As we're here to help them discard substantial amounts of items, we need to ask them "If this is ready for the tip?" many times – so are there any phrases that get used that annoy you? Is it ok to say, "Can we toss this?" And if in the future "Can we toss this?" (or whatever phrase) starts to annoy you, please let us know and we can find out another way to ask you.
4. Check if they have the four containers ready for the sessions.
    - Items to Keep, Items to Discard, Items for Friends/Gifting, Items to Recycle/Donate
    - None of this should be news to them, refer to the "Home Session Requirements" hand-out and have a spare just in case they lost theirs. If these are not ready, we can chat to them for a bit, but we're unlikely to do the whole session for fear of ending up just churning their piles and possessions rather than making decisions to discard items.
5. Before you start the session properly, ask them to walk you through their rules for Sorting, Discarding and Letting Go. Ask them to show you to the room you'll be helping them with. Start the session when everyone understands what items they can handle, and which rules they must follow.
    - Don't be afraid to question ambiguous items, referring to the participants' sorting and discarding rules.
    - If you give advice, make sure they've consented to hearing it, and be creative in how you help them problem solve.
    - The room shouldn't change from week to week unless significant progress is made. If they want to chop and change, remind them that we're more likely to see clear signs of change if we focus on one room than if we try to do every room.

6. Monitor participant distress levels intermittently, NOT continuously. Make use of motivational interviewing strategies and remind them that we are not mind-readers. As much as we would love to only do work for the remainder of the session, if you need to take a break and we haven't noticed, please let us know.
7. Take breaks as necessary, end session after two hours, offer support and check distress, remind participants of the resources available to them, offer to take the items to be discarded to the tip and fill out an Authorization slip if they agree and say farewell.

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Subsequent Sessions Plan/Script

1. Greet the participant. Ask how they've been, if they've found anything out on their own that they think would be useful in our sessions and would like to share with us. Have a chat about things Ask to be let in if they haven't invited you. As a guiding principle, try to be as human as possible, whilst still focusing on the work; make your interactions feel comfortable and not forced, but don't let participants travel off-topic.
2. Bring out a new SIR to be filled in. Talk with them about their progress of lack of progress. "So, from last week to this week you have reduced your score/not reduced your scores, that's great/let's talk about what's been going on, and if there is anything, we can do differently in this session that will help you better"
    - Be supportive of their attempts on their own, and the progress they make during sessions.
    - Remind participants that it's ok to be unsure of things and if they want our opinions or help with an item's category, that we can give them. We're meant to be buddies, so helping them out is part of what we do.
3. Check that they have the 4 containers ready still for this session. Ask if they have made any changes to their rules and if they want us to be aware of them. If everything is ready, move to the room as group and start the session.

4. Something unexpected happens! The participant is crying over an old bone China bowl. You must pause the session and note the event and address the problem. First you should ask what's wrong and note the details of the problem.
    - "I can't throw this out, it was a gift from my late grandmother!"
    - You should remind them that not every item needs to be discarded – we're trying to declutter their home and increase the amount of discarding they do, yes, but we're by no means aiming to change people into minimalists. They can keep items.
    - If the participant clams down after a talking it through for 10 minutes, suggest starting up the session again.
    - If they do not calm down, end the session, suggest they organize a one-on-one session with Simone at Lifeline and offer a 5-minute phone-call to check-in tomorrow if they'd like it.
5. Check-in with the participant roughly 2-3 times a session, don't make it common enough to justify their belief that they should be distressed by discarding items, but don't neglect to ask them, especially if you can visibly see signs of distress.
6. Take breaks as necessary and monitor yourselves too – if you need to take a break, or the session is too emotionally charged for you, talk it out with your other buddy and the participant and organize a break.
7. End the session after two hours is up, or if a behaviour experiment took place, end it after the experiment has been set. Discuss the procs and cons of what buddies did and noticed during the session – where did things go wrong, where did they go better than expected?

Appendix 2. Ethics Approval

Office of the Deputy Vice(Research) -Chancellor

Research Services
Research Hub, Building C5C East

MaNSW 2109 Australiacquarie University

T: +61 (2) 9850 4459 http://www.researcABN 90 952 801 237h.m g.edu.au/

15 December 2017

Dear Associate Professor Norberg

Reference No: 5201701104

Title: *Clutter-Buddies, Volunteer Program to Assist Clients Undergoing Cognitive-Behavioural Therapy*

Thank you for submitting the above application for ethical and scientific review. Your application was considered by the Macquarie University Human Research Ethics Committee (HREC (Human Sciences & Humanities)).

I am pleased to advise that ethical and scientific approval has been granted for this project to be conducted by:

- Macquarie University

This research meets the requirements set out in the *National Statement on Ethical Conduct in Human Research* (2007 – Updated May 2015) (the *National Statement*).

Standard Conditions of Approval:

1. Continuing compliance with the requirements of the *National Statement,* which is available at the following website:

http://www.nhmrc.gov.au/book/national-statement-ethical-conduct-human-research

2. This approval is valid for five (5) years, subject to the submission of annual reports. Please submit your reports on the anniversary of the approval for this protocol.

3. All adverse events, including events which might affect the continued ethical and scientific acceptability of the project, must be reported to the HREC within 72 hours.

4. Proposed changes to the protocol and associated documents must be submitted to the Committee for approval before implementation.

It is the responsibility of the Chief investigator to retain a copy of all documentation related to this project and to forward a copy of this approval letter to all personnel listed on the project.

Should you have any queries regarding your project, please contact the Ethics Secretariat on

9850 4194 or by email ethics.secretariat@mq.edu.au

The HREC (Human Sciences and Humanities) Terms of Reference and Standard Operating

Procedures are available from the Research Office website at:

http://www.research.mq.edu.au/for/researchers/how_to_obtain_ethics_approval/human

_research_ethics

The HREC (Human Sciences and Humanities) wishes you every success in your research.

Yours sincerely

Dr Karolyn White

Director, Research Ethics & Integrity,

Chair, Human Research Ethics Committee (Human Sciences and Humanities)

This HREC is constituted and operates in accordance with the National Health and Medical Research Council's (NHMRC) *National Statement on Ethical Conduct in Human Research (2007) and the CPMP/ICH Note for Guidance on Good Clinical Practice*.

Details of this approval are as follows:

Approval Date: 15 December 2017

The following documentation has been reviewed and approved by the HREC (Human Sciences & Humanities):

Documents reviewed	Version no.	Date
Macquarie University Ethics Application Form	2	Revised application received 13/12/2017
Response addressing the issues raised by the HREC		Received 13/12/2017
Participant Information Sheet/Consent Form	2	13/12/2017
Withdrawal Form	2	13/12/2017
Debriefing Statement	2	13/12/2017
Questionnaires & photographs	2	13/12/2017
Protocols	2	13/12/2017

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