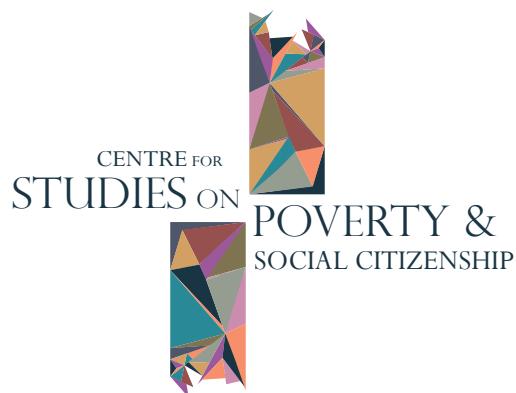


FINAL EVALUATION REPORT

Evaluating the Impact of Lanark County Mental Health's
"Buried in Treasures" Hoarding Treatment Program

March 2019

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From left: Sheri Hatherly, Tamara Derkzen, Steven Ang, Adje van de Sande, Karen McIntosh

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Introduction to the Study

With unemployment and low-income rates higher than the Ontario average (Lanark County, 2018a), Lanark County continues to face intense poverty and homelessness. While many residents face hardship for a wide range of complex issues, individuals living with mental illness represent some of Lanark's most marginalized. According to Lanark County's 2018 Homeless Count, 63% of Lanark's homeless population have mental health issues (Lanark County, 2018b).

As the lone provider of mental health services in the region, Lanark County Mental Health (LCMH) continues to serve many individuals who are housing insecure. In recent years, LCMH found that those clients specifically struggling with hoarding disorders were more likely to experience chronic episodes of homelessness. LCMH's case managers observed that clients with hoarding behaviours were often evicted from their lodging, and inevitably re-evicted over and over, constantly re-emerging as emergency service users as their underlying problems with hoarding went unaddressed. LCMH saw a clear need in the community for new services that could address hoarding, and over the past five years, they have continued to develop a Lanark-based integrated hoarding program. This initiative includes the operation of a Lanark County Hoarding Coalition, educational programming for family and friends of individuals who hoard, and a Peer Support Program.

At the centre of LCMH's integrated hoarding program is a case-focused intervention and education-based prevention model for individuals who hoard. LCMH's designated hoarding case manager provides triage and intake for clients referred into the hoarding program. After an in-depth, often multi-hour home assessment, the hoarding case worker addresses imminent risks to safety and wellbeing with clients, and continues to work closely with them to help them maintain secure housing.

To encourage long-term prevention, LCMH offers a 15-week group program called Buried in Treasures (BIT) alongside its hoarding case management program. BIT is closely based on the hoarding intervention model first developed by Steketee and Frost in 2007 (Steketee & Frost, 2007), and draws its name and a large part of its educational content from the book *Buried in Treasures: Help for compulsive acquiring, saving and hoarding* (Tolin, Frost & Steketee, 2007). Facilitated by LCMH's BIT case manager and a peer facilitator with lived hoarding experience, each session is 2 hours and includes psychoeducation focused on hoarding. This includes subjects like cognitive behavioural models, trigger exposure and the individual discarding process.

In 2017, with funding from the Ontario Trillium Foundation's (OTF) Local Poverty Reduction Fund (LPRF), LCMH invited Carleton University's Centre for Studies on Poverty and Social Citizenship (CSPSC) to conduct an evaluation of the BIT program. CSPSC's research team took a mixed-methods approach to the BIT program evaluation, including both outcome and process measures. CSPSC and LCMH decided to take a participatory approach to the evaluation study, whereby mental health peer workers would be involved in multiple phases of the research process, including participating on a Research Advisory Committee and collecting participant data.

Literature review

The American Psychiatric Association (APA) defines hoarding disorder (HD) in the Diagnostic and Statistical Manual (DSM-5) as a persistent difficulty in discarding or parting with possessions, regardless of the value others may attribute to them (APA, 2013). HD leads to significant public health/security challenges and imposes a significant burden on people with HD and their family members (Frost, Steketee & Williams, 2000; Snowdon & Halliday, 2011; Subramaniam, Abdin, Vaingankar, Picco & Chong, 2014; Tolin, Frost, Steketee & Muroff, 2015). The consequences of hoarding can be severe, including the inability to maintain basic activities of living such as personal hygiene, sanitary living conditions, and the ability to move about the home (Tolin, Frost, Steketee, Gray & Fitch, 2008). People with HD have a higher probability of being evicted from their homes, being institutionalized, and being victims of a fatal fire accident (Chapin et al., 2010; Lucini, Monk & Szlatenyi, 2009; Snowdon & Halliday, 2011). HD affects one to two percent of the population (Nordsletten et al., 2013) and is more prevalent in elderly people (Cath, Nizar, Boomsma & Mathews, 2017). It is also associated with higher social vulnerability (Frost, Steketee & Tolin, 2011). Despite the relatively high prevalence and significant health, social, and economic costs of HD, treatment remains a challenge due to limited treatment options, treatment resistance, and lack of access to resources (O'Connor et al., 2018).

There has been some success in the treatment of hoarding disorder (HD) using individual and group cognitive behaviour therapy (CBT) techniques (Frost, Ruby & Shuer, 2012). However, a drawback of CBT is that a specially trained therapist is needed to conduct the treatment. Access to this specialized form of therapy can be challenging due to the lack of resources and/or trained therapists (Frost, Ruby & Shuer, 2012). One alternative is support groups that require relatively few resources. Frost, Pekareva-Kochergina, and Maxner (2011) reported significant declines in hoarding symptoms following a non-professionally run support group – The Buried in Treasures [BIT] Workshop. The BIT Workshop is a 15-week peer and/or clinician led workshop that has been found to produce significant improvements in hoarding behaviour (National Association of State Mental Health Program Directors [NASMHPD], 2017). It is based on Tolin, Frost, and Steketee's (2007) book, *Buried in Treasures: Help for Compulsive Acquiring, Saving, and Hoarding*, which outlines a program of skill-building, learning to think about possessions in a different way, and gradual challenges to help people manage their clutter and their lives. There is significant potential for a low cost, time-limited intervention that can be used independently or in conjunction with other treatments. The BIT Workshop can be led by peer facilitators, which means that this approach can be widely disseminated.

Methodology

The participants for this research study were drawn from a growing waiting list of LCMH clients dealing with hoarding issues. Participants on the waiting list were randomly assigned to either the BIT program or a control group. Ultimately, seven participants were assigned and (retained throughout the study) for the control group; ten participants were assigned to the BIT program group. All research participants, whether in the program or control group, lived within the catchment area of Lanark County; had recently been identified by the Fire Department, Police Services, Lanark County Housing or landlords as dealing with hoarding issues; and were over 18 years old in age.

The data collection and analysis was conducted by three researchers, including the principal investigator and two research assistants, both graduate students at the Carleton University School of Social Work. LCMH's peer workers assisted with the collection of the quantitative measures.

To measure the impact of the BIT program on participants, the research team used a mixed-methods approach with both outcome and process measures. The outcome evaluation was based on a two-group experimental design, with pretests and posttests for program group and control group participants. The instruments used for these pretests and posttests were the *Hoarding Rating Scale* (HRS) and the *Activities of Daily Living in Hoarding* (ADL-H), both of which were specifically designed to measure the effectiveness of the BIT program (Frost, Steketee & Grisham, 2004).

The process evaluation included in-depth interviews with each BIT participant within days of the program ending. These interviews focused on the participants' experiences with the program and its effects on their hoarding, and their lives in general.

All the participant interviews were then transcribed and analyzed using the NVivo qualitative data analysis software program. In NVivo, each research assistant created codes based on the common themes raised within the data, and then shared and compared findings with the research team to conduct the final analysis.

The quantitative data was analyzed using SPSS, generating several independent sample t tests to compare HRS and ADL-H scores between the control group and program group. The research team also ran several paired sample t tests to compare the pretests and posttests to one another.

Findings and Analysis

Outcome Analysis

As mentioned above, the quantitative design of the study called for a two-group experimental design comparing pretest and posttest scores on the *Hoarding Rating Scale* (HRS) and *Activities of Daily Living in Hoarding Scale* (ADL). In comparing the pretest to the posttest scores of the participants in the program group, as revealed in Tables 1 and 2 below, the results indicate that participants showed significant improvement on both the HRS and ADL, based on a t test for paired samples.

Upon analysing the means of the ADL scores for the program group, the mean score of the pretest, 2.33, considered moderate (2.1-3.0) in the ADL scoring guide, drops to a mean of 1.67, considered mild (1.5-2.0), in the posttest. Notably, scoring 2.1 or higher on the ADL indicates that clutter has caused substantial difficulties in an individual's ability to function in their home (Tolin, Frost & Steketee, 2007); BIT participants were able to minimize their hoarding habits to the point where they could cross this functionality threshold.

Table 1: Comparing the Pretest to the Posttest Scores for the Program Group on the HRS

Mean of the Pretest	31.88
Mean of the Posttest	21.00
$t = 3.7$, df. = 7, p = < .05. Therefore, there is a significant improvement.	

Table 2: Comparing the Pretest to the Post Test Scores for the Program Group on the ADL

Mean of the Pretest	2.33
Mean of the Posttest	1.67
$t = 2.8$, df. = 7, p = < .05. Therefore, there is a significant improvement.	

That being said, in order to establish a cause and effect relationship between the program and the outcome results, and confirm that it was the treatment program that caused the improvement in the participants in the program group, the program group would have to be compared to an equivalent control group. However, as shown in tables 3 and 4 below, in comparing the pretest scores of the participants in the program group to the pretest scores of the participants in the control group on both the HRS and ADL, the results indicate that the two groups were not equivalent, based on a t test for independent samples. This means that, even if the results shown in tables 1 and 2 revealed a significant improvement on the part of the program group participants, it was not possible to determine conclusively that the treatment program caused the improvement.

The fact that the two groups were not equivalent could be explained by the difference between the control group and program group intake process. With limited resources, the case manager was restricted in the amount of time she could spend with control group participants, and so, they were not subject to the same rigorous intake process as program group participants. Because these assessments meetings were shorter, control group participants might also have been less accurate in their self-reflections when completing the surveys, potentially underestimating the severity of their hoarding habits.

Nevertheless, as discussed in the section below, focusing on the qualitative part of the study, we are confident in concluding that the BIT program is effective.

Table 3: Comparing the Pretest Scores of Program Group vs. the Control Group on the HRS

Mean of the Program Group	31.88
Mean of the Control Group	18.29
t = 6.03, df. = 13, p = < .05. Therefore, there is a significant difference.	
Note: This means that the two groups were not equivalent	

Table 4: Comparing the Pretest Scores of the Program Group vs. the Control Group on the on the ADL

Mean of the Program Group	2.33
Mean of the Control Group	1.55
t = 2.59, df. = 13, p = < .05. Therefore, there is a significant difference.	
Note: This means that the two groups were not equivalent	

Process Analysis

Qualitative research findings and themes are presented under the stages of client participation within the BIT program:

1. Joining the BIT Program

There were different ways the participants learned about the Buried in Treasures (BIT) program. Many were existing clients or had family members who were clients of Lanark County Mental Health (LCMH). Others found out through community advertisements. Some clients reported not being particularly aware that they were hoarding until they interacted with the program advertisements:

“I didn’t even know I had an issue. It was just...yeah. But reading the pamphlet, it was like, you know, ‘Are you collecting things?’ Yeah. I’ve got piles and piles of stuff all over. But I wasn’t dealing with anything and I didn’t know how to deal with it, so I was just avoiding it”.

The participants found their discovery of the BIT program to be very timely and their reasons for joining varied. Some of them, including their family members, were getting frustrated with having too many things in their homes. Others felt that it was time to address their hoarding issue and believed the program would help them achieve this, they did not know where to begin on their own. The desire for more support was a key theme. For one participant, this decision was bolstered by physical limitations due to a disability:

“We were both becoming extremely frustrated with what we have. Our place is clean and sanitary, but we have stuff everywhere. With my disability and my wife’s health problems, we were kind of stuck. Things got set there for now and stays there with other things for now so it added up. We knew that physically pounding at it was not going to be enough. We needed knowledgeable help. We could work hard but we also needed to work smart.”

Apart from physical limitations, the lack of space within the home also influenced some of the participants' decisions to join the BIT program. As another participant mentioned:

"I had an invasive surgery a few years ago and I realized then that I couldn't keep up and I was still living in a world where I was acquiring things and not getting rid of them... And a relative moved in...and I have a small house. Yeah, it was a series of things. They moved back home and yeah, there just was way too much stuff and I realized that I needed some help in moving it out."

Many reported that moving homes or wanting to move homes was a significant event that drew the issue to their attention and prompted them to reach out for help.

The lack of space in their homes resulting from hoarding affected the participants' relationships with family and friends. Most of them did not want people over because of the state of their homes; some were even hesitant to open their front door. They were embarrassed because of the mess and clutter. Many reported friends and family were making comments about the state of their home. One participant even had arguments with her parents about it:

"I guess it was more when my parents would come over. They would complain about the mess and you know, their assumptions are that you just need to clean it and get rid of stuff and deal with it. It was such a simple thing for them, but they didn't understand how difficult it is for me."

Some people also spoke of the role their marital relationship played in the problem of hoarding in their life.

"In my relationship that I was in, it was kind of like I was doing [the program] more for him than for me, thinking he had more of a problem than I did. But then through the course of the course I realised I actually do have more of an issue."

A few participants stated that the lack of socialization due to hoarding made them feel isolated and depressed.

"If you just leave your home because you can't be there and your friends won't come over and your family won't come over, eventually something within us says we need human interaction. I must do something."

In terms of how long the participants have been dealing with hoarding, the reported range was between 2 to 50 years, with the issue usually progressively worsening within the lives of participants.



2. Experiences during the BIT Program

All the participants reported that the BIT program was positive and helpful. Most of them felt a sense of relief knowing that there were others who were dealing with hoarding. Many described it as an eye-opener, since it provided them with answers and helped them recognize the seriousness of the issue. It also provided them with a sense of purpose and direction. One of the participants described her experience:

"It was a lot of things, a lot of emotion brought up to deal with that I didn't realize. Well, I knew that I was attached to items that maybe other people weren't but not to the degree and not for the reasons. So that was a bit of an eye-opener and the emotional end of it. The good thing about it as well was that I realized that I wasn't the only person. I used to think I was, and trusted in [the program facilitator] and myself, believing I have the ability to change, you know."

Many participants reported that the program provided them with a better understanding of hoarding behaviours. They delved into their relationship with their things and came away with new understanding of some of their struggles.

"It was great. I was extremely excited. I really wanted to get some advice on how to go through stuff. My main thing was to try to answer more questions as to why it was happening, which was really great. The book that they have is an easy read. It explains a lot of things. It was great. And [the facilitator] was excellent."

Some participants also noted that they learned more about the connection between their hoarding behaviours and other mental health difficulties they face. Many noted that their hoarding started during a period of depression and one noted that she now understood her hoarding behaviour to be a continuation of addictive behaviours. These new understandings were noted as very helpful.

There were other ways by which the program influenced the participants. One of them reported to be more optimistic:

"The program helped me to become more tuned in to the optimistic side. I was pretty depressed and pretty much at my wits end when I first joined up... I realized that there are other people and I realized that it isn't really my fault. I was just never given the skills during my lifetime on how to make decisions and how to deal with certain things. I knew how to make decisions but for all the wrong reasons. Never for me, and this is the first time in my life that I haven't had a child or a relative to look after."

In terms of the BIT program structure, the participants all agreed that the Peer Group (which meets bi-weekly after completion of the program) is very helpful in that it keeps participants accountable. One of the participants stated:

"That's what's great about the peer group - because you know you set goals and you kind of hope to get those goals met by the next meeting."

The Peer Group also gives them assurance of ongoing support that they are not “cast off” once the program is done. This allows them to check-in with each other regarding their own progress. One of the participants explains:

“...the peer support works both ways you know. You can help each other, and we always leave here feeling better than when we come in. And when you keep hearing of all the stuff you didn’t do, you go home thinking ... it’s another day. Now you go home and okay, I’m going out to the garage to take a look at the stuff that’s everywhere... and take a look [with] fresh eyes.”

Many of the participants also acknowledged the importance of the facilitator, being happy with how she led the group, and happy with the support they received. One of them described this succinctly:

“I’m really impressed with what [the case manager] has pulled together and the people that she has with us. It’s really - well I look at it and it blows me away that she’d been able to pull all of that together. There are no spots in it where you kind of - you know, you put it on and you think okay we’ll think of something else for the next two hours because I’m not interested in this. She’s really done a good job of keeping it interesting. It’s not just brow beating. You guys are all here because you have a problem. We know we’ve got the problem. We don’t need somebody embarrassing us. Instead, it remains very positive and when it’s positive in there, you leave the room feeling positive. You feel like, yeah, I can do something when I get home or I can go home and I can think about what we did and said today and tomorrow, it’s a new day and we’re going to pull that stuff again and see if I really need it. Do I really want it, or is it just sitting there.”

And on a separate occasion:

“[The case manager]... she’s been very knowledgeable with what’s going on, very knowledgeable of our problems and physical limitations and very inventive of how she can help us out either physically or with suggestions to put that stuff near the door. [She’ll say] ‘When I come next, I’ll take all that stuff and if it needs to go to the dump, I’ll come when its open and we’ll load your car and my car and we’ll both go to the dump and get rid of twice as much stuff, whether it goes to the recycle or it’s garbage.’ ... It’s been easier to reach that decision and then with that support worker coming out saying, ‘Fine, it’s got to go, your decision not my decision’ and I’ll say ‘Yeah, it’s got to go now.’ ‘Fine, it’s gone. It’s in my car and the doors are closed. You can’t go in my car.’ Okay fine, I’ve let go of it. And so that part of the program, having those people, that personnel in the field have been incredibly important. It’s like having the program come home with us.”

Many took away a sense of having to plan their days and be more mindful about their choices in general:

"But I'm finding the program is helping with some of those things that we don't think about, questions we don't ask. I don't' mindlessly go through my day anymore. I think about it. I actually make plans, because [the case manager] is big on plans. So, you know, I actually say, okay, if I want a coffee all week, I need to put aside money for that".

Finally, some of the participants admitted that the BIT program, including the homework and the reading, was challenging, but it kept them on track, nonetheless. One participant noted the ambivalence many felt about the both wanting to do the work of the program and wanting to avoid it:

"And while we want to do the program we don't really want to do the program. It's a lot of work, and overwhelming, do you know what I mean?"

3. Post-Program: Moving Forward

In terms of client recommendations, there were suggestions to add more staff so there could be more one-on-one support. Participants suggested more home visits to help keep the participants accountable and felt that more offerings of the BIT program could help with early intervention for a lot of people with hoarding issues. Finally, one participant thought an app with daily reminders and interaction could help keep some participants on track.

Although most of the participants believed that their hoarding behaviours had not completely resolved, the BIT program has helped them improve. Some noted that they had stopped acquiring more items, and many noted that they had gone through much of their stuff and gotten rid of things. They understood their behaviours in a new light and understood the habits they were creating (such as 'only handle it once' and planning enough time to get through a box or container) to be something that they would continue using into the future. One of the participants shared that it has helped him establish a filtering process:

"...it can make me stop at that point and think. I haven't picked up that thing yet but what? Do I need it? Do I want it? What am I gonna do with it? Where am I gonna put it? Those thoughts have all been kind of wedged in that train of thought and those thoughts now stay with me and I find even I've taken apart the displays and put all insignia in boxes that are all lined up under glass and look at it and say okay, I've got duplicates in here. Do I need duplicates? They are not going to wear out. They are not gonna fall apart. What am I going to do with them?"

Some participants stated that the program helped bring their hoarding issue to the forefront of their lives. This has allowed them to now to organize their things better and to downsize by disposing or donating items they no longer need. They also mentioned that they have gained better control in terms of acquiring things. One of the participants stated:

"I try to stay away from the store unless I need something in particular. That was something I learned in the program. If I look at the flyer and there is something I want to buy, I go to the store, walk to the section where the particular item is and get back out."

All of the participants acknowledged that the peer group will be helpful moving forward. They also reported that the program book will be useful in terms of looking back at what they have learned. Some anticipated needing to participate in the program again. Finally, they felt that having continuous access to trained case workers would help with their progress.

Recommendations

Offering More BIT Groups

As one of the participants suggested, more sessions of the BIT program could increase LCHM's capacity for early intervention. Also, many BIT participants expressed an interest or need in rejoining the BIT program. Increasing the number of BIT sessions offered would create room for new clients to start engaging with this psychoeducational model while also accommodating clients that have participated in the program before who want to participate again. As described above, the BIT program incited participants to develop a deep self-awareness, to relate to others, to cultivate a sense of optimism and empowerment and to develop real skills to deal with their hoarding behaviours. Offering more BIT sessions will allow for current clients to continue to build on this progress while also proliferating these positive changes to a wider client-base.

Expanding Hoarding Program Staff

Many of the BIT participants emphasized having one-to-one hoarding support from the hoarding case manager helped them stay motivated to work on their hoarding habits and enhanced their progress in decluttering and cleaning their home. At the moment, LCMH only has one designated case manager for the hoarding program. Increasing the hoarding program staff would greatly increase the capacity for LCHM to take in more hoarding clients, and provide more adequate and timely interventions to current clients. Increasing program staff will also help LCHM offer more BIT sessions, as recommended above.

Volunteer Program

Several BIT participants identified with having a physical disability or impairment, which appears to impact their ability to address their hoarding and physically deal with clutter. Inviting volunteers to work with these clients would increase BIT participants capacity to change the internal state of their home and remove some of the physical barriers they face to working on their hoarding habits. As many of the BIT participants have testified, the process of facing one's hoarding habits and building de-cluttering skills can be quite challenging and emotional. For this reason, volunteers should likely be vetted and trained so that their volunteer work will help support client needs instead of creating unnecessary psychological harm. Inviting volunteers to work with BIT participants would also help reduce the social isolation that many of them seem to experience.

Hoarding App

One BIT participant suggested a hoarding app, with prompts to help individuals maintain progress in their decluttering work. An app could not only provide timed reminders for decluttering and reflection activities but could also track individual progress, which could be rewarding for clients to review. Many participants enjoyed and highly regarded the BIT program book, and the idea of having

a reference to go back to was comforting to them. An app could potentially work as a quick hoarding reference, with brief and easily digestible content that could help clients remember and take in some of the central BIT concepts.

Further Research

While many of the qualitative and quantitative measures used for this evaluation, indicate that the BIT made a strong and positive impact with participants, a clear cause and effect relationship between the program and the outcome results could not be established. Further research studies could provide different results and potentially help make an even clearer connection between the BIT program and the significant progress made by BIT participants in addressing their hoarding habits.

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About the Centre for Studies on Poverty and Social Citizenship

The Centre for Studies on Poverty and Social Citizenship (CSPSC) is focused on generating critical and innovative knowledge about poverty and social citizenship that can inform social work practice.

CSPSC is a research centre based at the Carleton School of Social Work and aligns with the school's commitment to research on social welfare in Canada. CSPSC collaborates with community-based organizations to support and research innovation happening at the community level.

About Lanark County Mental Health

Lanark County Mental Health (LCMH) is a community based mental health service responding to Lanark County adults and transitional aged youth (17 years and over) who experience mental health concerns.

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