

Implementing *Living Independent From Tobacco* with dyads of people with disabilities and their caregivers: Successes and lessons learned

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Abstract

People with disabilities have more health complications and higher healthcare utilization related to tobacco use than people without disabilities. Yet, they are less likely to use tobacco cessation resources. Important to meaningful and lasting health behavior change are relationships developed in the home, workplace, and community. Some people with disabilities rely on paid and unpaid caregivers. Just like people with disabilities, paid caregivers are more likely to use tobacco, creating a unique opportunity to target smoking cessation to people with disabilities and their caregivers. *Living Independent From Tobacco* (LIFT), an evidence-based tobacco cessation intervention, was implemented with dyads of people with disabilities (n = 5) and their caregivers (n = 7). Qualitative analyses revealed that participants valued the dyadic approach and the opportunity to learn coping skills to help with smoking cessation. Lessons for offering inclusive health promotion interventions to people with disabilities and their caregivers are discussed.

Keywords: People with disabilities; caregivers; *Living Independent From Tobacco* (LIFT); tobacco cessation; tobacco intervention; qualitative health research

Implementing *Living Independent From Tobacco* with dyads of people with disabilities and their caregivers: Successes and lessons learned

Tobacco use leads to billions of dollars of medical expenses in the United States (Centers for Disease Control and Prevention, 2018). Cigarette smoking and second-hand exposure to smoke contribute to approximately 480,000 deaths annually (U.S. Department of Health and Human Services, 2014), with an estimated 60% of smokers dying from smoking-related diseases (Jha et al., 2013). Smoking rates in the general population have declined markedly over the last several decades which has been attributed, in part, to the effectiveness of current therapies and interventions (Vidrine, Cofta-Woerpel, Daza, Wright, & Wetter, 2010). Despite this success, rates of tobacco use continue to be high among vulnerable populations such as people with disabilities (PWD) (Courtney-Long, Stevens, Caraballo, Ramon, & Armour, 2014).

PWD are nearly twice as likely to use tobacco products and are more likely to have chronic health conditions related to tobacco use than people without disabilities (Courtney-Long et al., 2014). These disparate smoking rates among PWD are compounded by other health disparities including limited access to health care systems, increased engagement in health-compromising behaviors such as eating unhealthy diets and lack of physical activity, increased rates of obesity and cardiovascular disease, little to no emotional and social support, and increased rates of negative social determinants of health such as low household income, poor education, and unemployment (Krahn, Walker, & Correa-DeAraujo, 2015). There is a dire need for research investigating health promotion interventions for PWD. The lack of effective tobacco cessation programming

may contribute to tobacco-related disparities among PWD (Pomeranz et al., 2014).

Recently, Pomeranz and colleagues (2014) developed *Living Independent From Tobacco* (LIFT), an accessible tobacco cessation intervention for PWD.

LIFT is an evidence-based smoking cessation intervention that uses behavioral counseling and health education, including education on the harmful effects of tobacco and the benefits of quitting (Pomeranz et al., 2014). Participants learn the nature of nicotine and effective coping strategies to manage nicotine withdrawal (Pomeranz et al., 2014). Coupled with the LIFT intervention, participants are encouraged to use nicotine replacement therapy to support the process of quitting smoking. Previous research demonstrated that nicotine replacement therapy and behavioral counseling were most effective in tobacco cessation efforts (Carpenter, Hughes, Solomon, & Callas, 2004; Moore, Aveyard, Connock, Wang, Fry-Smith, & Barton, 2009). Taken together, early evidence demonstrated the effectiveness of LIFT in reducing tobacco use among PWD (Pomeranz et al., 2014). Moving forward, it is important to consider the unique supports available to PWD when offering health promotion programs such as LIFT.

Because of physical, emotional, or cognitive limitations, some PWD have caregivers, such as paid staff or family members, who help with activities of daily living and community participation. Previous research found that strong social and emotional bonds are formed between PWD and these caregivers, with PWD viewing caregivers as valuable sources of practical and emotional support (De Schipper & Schuengel, 2010; Hewitt & Larson, 2007). Recent research has identified that caregivers may impact the health behaviors of the PWD they support (Kneringer & Page, 1999; Leser, Pirie,

Ferketich, Havercamp, & Wewers, 2018; Martin, McKenzie, Newman, Bowden, & Morris, 2011). This research runs parallel to work conducted by Bandura (1998) investigating health promotion through Social Cognitive Theory. This theory posits that peers role-model and reinforce behaviors in their social networks (e.g., in the home, workplace, and community). This theory also contends that peers hold one another accountable to behavior change goals, serving to reinforce and support meaningful behavior change (Bandura, 1998). Previous research highlights high rates of health-compromising behaviors among paid caregivers, such as poor nutrition, little physical activity, and tobacco use (Gallant & Connell, 1997; Leser et al., 2018; Perera & Standen, 2014), and these poor health behaviors impact the health attitudes, knowledge, and behaviors of the PWD they support (Draheim, Williams, & McCubbin, 2002; Hewitt & Larson, 2007; Kneringer & Page, 1999; Leser et al., 2018; Robertson, Emerson, Gregory, Hatton, Turner, Kessissoglou, & Hallam, 2000). These findings suggest a unique opportunity to also support caregivers who are in a position to facilitate or impede the healthy behavior choices of PWD.

Some work has investigated the usefulness of the dyadic approach in supporting tobacco cessation efforts among people without disabilities and people with severe and persistent mental illness. McDonnell and colleagues (2016) conducted a smoking cessation program for thoracic cancer surgery patients using a dyadic model, identifying that family members increased motivation, reduced their own smoking patterns, and developed important life strategies (i.e., coping skills) to support quality of life. Other work has shown promise of the dyadic approach to smoking cessation among people with

severe and persistent mental illness and their peer mentors (Dickerson et al., 2016). More specifically, Dickerson and colleagues (2016) identified that including peer mentors allowed for participants to feel supported throughout the process and the relationship itself facilitated the development and maintenance of health behaviors in and outside of the smoking cessation program. In a related vein, Barnhart and colleagues (2019) examined the usefulness of the dyadic approach to support cooking skills, healthy eating behavior, and nutrition knowledge (*Cooking Matters for Adults*) among people with developmental disabilities and their direct support professionals. Including people with developmental disabilities and their direct support professionals was acceptable and increased satisfaction across participant groups (Barnhart et al., 2019). Given both PWD and paid caregivers disproportionately engage in an array of health-compromising behaviors including smoking (Gallant & Connell, 1997; Leser et al., 2018; Perera & Standen, 2014), it is critical to better understand if these populations can be supported in inclusive health promotion interventions.

Recently, Havercamp and colleagues (2019) were the first to investigate the effectiveness of LIFT offered to dyads of PWD and their caregivers. PWD and their caregivers reduced smoking approximately 35% at post-test and these levels continued to reduce to approximately 50% at six months after LIFT as measured by carbon monoxide breath assessments (Havercamp et al., 2019). This change in carbon monoxide levels amounted to a reduction of approximately one-half pack of cigarettes per day. PWD and their caregivers reported an overall 30% increase in use of coping skills to manage nicotine withdrawal, skills that help to buffer psychological and physiological distress

associated with tobacco cessation (Brandon, Tiffany, Obremski, & Baker, 1990; Motschman, Germeroth, & Tiffany, 2012; Shiffman, Paty, Gyns, Kassel, & Hickcox, 1996). Although these quantitative data provided initial evidence for the effectiveness of the LIFT intervention for PWDs and their caregivers, questions remain about the acceptability and satisfaction when offering LIFT to dyads of PWD and their caregivers. The present study investigated the subjective experiences of dyads of PWDs and caregivers who participated in the LIFT intervention. The goal of examining these qualitative data was to better understand how the dyadic approach impacted participation in the LIFT intervention. To this end, we explored qualitatively satisfaction and if the LIFT intervention was acceptable to be implemented to dyads of PWD and their caregivers.

Method

Participants

This study was part of a larger project on smoking cessation for PWD and their caregivers, and half (50%) of the data collected from the present study's sample of participants were previously published (Havercamp et al., 2019). These data addressed separate questions related to the LIFT intervention regarding its effectiveness to reduce smoking and impact knowledge about tobacco use and coping skills (see Havercamp et al. (2019) for more details). This study was approved by the university's institutional review board and written informed consent was obtained from all participants.

Participants were recruited online and through statewide disability networks. Eligible participants either provided care to a PWD at least 3 times a week (caregivers) or were a PWD who had a caregiver; were at least 18 years of age; were able to understand and

speak English; and were able to breathe into a carbon monoxide monitor. For the present study, disability was defined as a state of impairment(s), activity limitation(s), and/or participation restriction(s), consisting of limitations that impacted physical, mental, and/or behavioral health (World Health Organization, 2019). Participants were currently using tobacco on a daily basis and agreed to limit their involvement in tobacco cessation programs to LIFT for the duration of the study.

Seven dyads (PWD and caregiver) were recruited; however, two PWD dropped out of the study for non-program related reasons resulting in a total of twelve participants who completed the LIFT curriculum and evaluation protocol. See Table 1 for participant demographics. All caregivers in the present study were paid staff who had provided care to a PWD who served as their dyad partner. Dyad partners reported knowing one another for an average of 10.8 years (range 6 months to 40 years).

Semi-Structured Interviews

Following the eight-session LIFT program, semi-structured interviews were conducted with each participant regarding their experience of the LIFT program. Interviewers followed a semi-structured interview guide, which allowed for modifications to the wording of questions to reflect the participant's language and understanding of the question and to the order of the questions to follow the participants' lead. Participants were asked about changes in tobacco use attributed to the program, *"Have you quit smoking as a result of your participation in the program? If no, have you reduced your tobacco intake? What aspects of the program were most helpful to you in quitting? What aspects of the program may be most influential in helping you quit in the future?"* The

Interview Guide provided additional questions that could be asked to probe for more information. For example, after the question, “*What do you think about the written materials (i.e., the book)?*”, the following probes could be asked: “*Was it easy to understand? Appropriate pictures? Addressed your questions about tobacco? Captured your own personal experiences with tobacco (e.g., reasons for smoking)?*” The semi-structured interview topics included overall program experience and satisfaction, helpfulness of overall program and specific program components and materials, and recommendations to improve the program.

Data Analysis

Participant interviews were recorded, transcribed, and entered into ATLAS.ti 8 for analysis. Data were analyzed based on a grounded theory approach (Glaser & Strauss, 1967; Glaser, 1992). Specifically, transcriptions were read multiple times and notes of initial impressions were recorded. Codes were generated and assigned to data after an iterative, constant comparison process between interview responses. Next, codes were analyzed and compared. Similar codes were organized into categories that described the code groups. Categories were then analyzed for relationships and were combined into overall themes that emerged and explained the results of the semi-structured interviews. Finally, the codes, categories, and themes were evaluated by two other research staff and discussed until consensus was reached. All three researchers involved in the coding and qualitative analyses have disability expertise and experience with health promotion and behavior change.

Results

A total of 43 codes emerged from the data. These codes were then consolidated into 12 categories, which summarize the codes. Finally, five overall themes that explained the data emerged from the 12 categories. These themes, in order of importance, were: course content, group dynamic, areas for improvement, outcomes of the class, and importance of qualified instructors. Table 2 illustrates the frequency of discussion for the themes and categories that define each theme.

Course Content.

Participants most frequently discussed items related to LIFT course content in the interviews. The theme of course content emerged from four categories of participant discussion which included 1) class design, 2) course materials, 3) knowledge, and 4) smoking reduction strategies. Specifically, participants discussed the following topics within the theme of course content:

- Setting a quit date on the first day of the class was beneficial (class design)
- The nicotine replacement therapy offered and reading materials as part of the class were useful (course materials)
- Learning about financial cost of smoking was a helpful incentive to stop smoking (knowledge)
- Learning about the health effects of smoking on every system in the body was helpful (knowledge)
- Learned various new strategies to reduce smoking such as exercise and talking to family/friends (smoking reduction strategies)

To illustrate the value of the knowledge learned from the course content, one participant with a disability described their increased understanding of the negative health consequences of tobacco this way:

“...it was cool you see the disability in the book and see someone with a disability or whatever and I thought it was cool and a little bit scary to see what [happens to people with my condition] when you are smoking.”

Another participant (caregiver) added:

“Everybody pretty much knows it’s harmful but I didn’t realize how harmful it would be to almost every system in your body. Ya know I thought for lungs and breathing but it affects everything so that’s good that they pointed it out.”

Group Dynamic.

Next, participants most frequently discussed topics related to the group dynamic of the LIFT course. The theme of group dynamic emerged from four categories of participant discussion which included 1) group discussion, 2) group support, 3) accountability, and 4) class structure. Specifically, participants most frequently discussed the following topics within the theme of group dynamic:

- Valued the group discussion to learn from others’ experiences with smoking and their perspectives (group discussion)
- Valued working together in a group setting and being with other people in the same situation working towards the same goal to provide accountability to each other (class structure, group support, accountability)

- Thought the dyadic approach was a valuable component to the class, particularly for accountability (class structure, accountability)
- Thought having support from the group throughout the process was an important aspect of class (group support)

One participant (caregiver) noted the importance of the dyadic approach: *“And I think [the program is] just really well designed...you know the way it was set up with a person with a disability and a caregiver. I think it was really helpful to both people. I don’t know it just worked perfectly.”*

Another participant (caregiver) discussed the value of social support from the class: *“I think now I’m gonna be able to [quit smoking], when I think of [wanting a cigarette], I’m going to be able to envision our group conversation that we had in class and be a little more real than just like words on a page. I think I’ll think of the people that were here [in the class], what was said, and how we applied it in real life you know, and to our real feelings and stuff.”*

Finally, another participant referenced how important the group dynamic, group support, and accountability were for a person with a disability:

“A lot of the motivation came from [the instructor]. A couple of days [the person with a disability] didn’t smoke at all because [the class] set a stop smoking date on the 10th. And on the 10th and 11th [the person with a disability] didn’t smoke at all. That’s because I don’t think [the person with a disability] wanted to disappoint [the instructor]. So [the person with a disability] actually stopped smoking for those two days.”

Areas for Improvement.

Participants also discussed areas for improvement for the LIFT course. The theme of areas for improvement emerged from two categories of participant discussion which included 1) class improvement suggestions and 2) negative aspects of the class. Specifically, participants most frequently discussed the following topics within the theme of areas for improvement:

- Suggestion to focus the class on smoking reduction rather than quitting because advertising it as a quit class could turn some people off and they would miss out on valuable information in their smoking reduction journeys (class improvement suggestions)
- Suggestion to use Facetime as a participation option for when a person with a disability is sick or unable to attend (class improvement suggestions)
- Suggestion that the classes could be condensed to reduce redundancy and shorten the duration of the program (class improvement suggestions)
- Suggestion to allow non-smoking caregivers in the class so that whoever provides the most support for that person with a disability is able to learn and better support the quit effort even if they don't smoke (class improvement suggestions) (note: as result of this feedback, enrollment was expanded to non-smoking caregivers)
- Some parts of the book were hard to read for people with disabilities (negative aspects of the class)
- Complaints about dates/times and location of the classes (negative aspects of the class)

Two participants (person with disability and caregiver) illustrate how the reading materials for the program were received by people with disabilities:

“There were hard parts to read in the book and easy parts to read in the book.”

“Um, yeah. I think some of the written material might have been a little bit hard to understand for our class. But there again, I think you have a good teacher they can reword it or help with that.”

Outcomes of the Class.

Participants also discussed how the LIFT course affected them. The theme of outcomes of the class emerged from three categories of participant discussion which included 1) smoking reduction, 2) easier to quit smoking after class, and 3) recommend the program to others. Specifically, participants most frequently discussed the following topics within the theme of outcomes of the class:

- Acknowledged that the program led to a reduction in the number of cigarettes smoked per day (smoking reduction)
- Comments that after attending the program it is easier to quit than previously believed (easier to quit smoking after class)
- Comments that they would recommend the program to other people with disabilities (recommend the program to others)

One participant with a disability explained the new coping strategies learned from the program in order to reduce his/her smoking:

“I’m taking more long walks, riding my bike. trying to get a lot of exercise.”

Additionally, three participants with disabilities described increased confidence in their ability to quit smoking:

“It was a lot easier than I thought it would be. Uh I thought it was going to be a lot harder. Well I mean... me being trying to quit smoking; I thought it was going to be more difficult.”

“I’m hoping I quit. As much as I’ve cut down, I think it’s going to be a lot easier to quit now than without this class.”

“It’s a lot easier like this than to quit on your own. It’s the activities we did, things like that... it really help me.”

Importance of Qualified Instructors.

Finally, participants discussed the importance of qualified instructors within the LIFT course. The theme of importance of qualified instructors emerged from the category of good instruction. Specifically, participants most frequently discussed the following topics within the theme of importance of qualified instructors:

- Liked the class instructor (good instruction)
- Thought the instructors were an important aspect of the course, especially to help participants with disabilities understand difficult parts of the book (good instruction)

To illustrate the value of good instruction in this program, one participant (caregiver) stated:

“I mean [the instructor] did a really good job of keeping it flowing. And I guess real. Like it’s not like [the instructor] was up there preaching or anything so it was really nice. [The instructor] was understanding and genuine I guess.”

Discussion

To our knowledge, this is the first study to evaluate the subjective experiences of PWD and their caregivers participating together in a LIFT intervention for smoking cessation. By investigating these subjective experiences, the present study attempted to use qualitative inquiry methods to examine whether including PWD and their caregivers as dyads in the LIFT intervention was beneficial. Answering this question is critical given relationships between PWD and caregivers influence health behavior and health-related attitudes (De Schipper & Schuengel, 2010; Hewitt & Larson, 2007; Kneringer & Pager, 1999; Leser et al., 2018; Martin et al., 2011).

We interviewed the same group of participants as reported in Havercamp and colleagues (2019) and found five overall themes related to their subjective experiences in the LIFT intervention: Course Content, Group Dynamic, Areas for Improvement, Outcomes of the Class, and Importance of Qualified Instructors. Participants valued the knowledge gained in the LIFT intervention in terms of knowledge and coping skills for smoking cessation (Course Content). Participants also described significant value in the group, and especially the support provided by the dyadic approach to smoking cessation (Group Dynamic). Importantly, participants also described that their self-efficacy to quit smoking increased as a result of the intervention and many participants reported that they

had successfully reduced their smoking. These data complement other studies that highlight the value of including a dyadic approach in health promotion efforts.

Like McDonnell and colleagues (2016), our qualitative data revealed that the dyadic approach increased motivation to adhere to the smoking cessation intervention. More specifically, data gleaned from the Group Dynamic comments highlighted that the dyadic approach resulted in increased group support and increased accountability as it related to behavior change (i.e., smoking reduction). These findings are consistent with those of Dickerson and colleagues (2016) who found that the inclusion of peer mentors with people with severe mental illness in a smoking cessation intervention resulted in participants feeling more supported to achieve meaningful behavior change (i.e., smoking cessation). Given that LIFT was originally developed for people with disabilities, there were concerns that the inclusion of caregivers would render the intervention unacceptable for both populations. In contrast, not only was LIFT acceptable for both PWD and their caregivers, the dyadic approach was given high levels of satisfaction across both participant groups. These qualitative data take on new meaning when considered with effectiveness data from Havercamp and colleagues (2019) underlying notable smoking reduction and increased coping skills among both PWD and their caregivers participating together in LIFT. Taken together, our qualitative analysis revealed that the Group Dynamic, the dyadic approach, strengthened the class structure of the intervention and accountability across and between participant dyads, supporting meaningful and lasting smoking reduction and increased coping skills to manage nicotine withdrawal (Havercamp et al., 2019). Future research should continue to explore inclusive health

promotion efforts as a novel way to target healthy behavior change among PWD and their caregivers.

In addition to the successes of the present study, several lessons were learned from the qualitative analysis (Areas for Improvement): a) adjust expectations from tobacco cessation to tobacco reduction, for some participants, reduction might be a necessary first step (e.g., consider Stages of Behavior Change); b) use technology to facilitate class participation for those whose limitations interfere with class participation; c) modify class structure to minimize redundancy without sacrificing the opportunity to practice and master new skills; and d) improve the cognitive accessibility of the LIFT participant materials. Future research is needed to evaluate the impact of these recommended changes on the effectiveness, acceptability, and satisfaction with LIFT among PWD and their caregivers.

There were limitations to the present study and therefore results should be interpreted with caution. First, though the protocol for conducting and analyzing the interviews was as rigorous as possible, qualitative analyses are still subjective in nature. This limitation was reduced through achieving consensus of the ratings among three researchers who independently reviewed the transcripts. A second limitation is that while our sample was comprised of people with a wide range of disability types and functioning levels, it lacked racial and ethnic diversity. More research is needed to understand the degree to which person-level characteristics such as race, ethnicity, and the nature of the disability impact the effectiveness and response to the LIFT program.

The present study builds on research on the relationships between PWD and their caregivers (De Schipper & Schuengel, 2010; Hewitt & Larson, 2007), highlighting that when participating together in health promotion activities, meaningful gains in satisfaction among participant groups can be achieved. Given that some PWD rely on caregivers to support independent, self-determined living, more needs to be done to better understand how these relationships can be leveraged to support gains in health in both populations. Here, we present an innovative approach of offering LIFT to PWD and their caregivers, resulting in high levels of satisfaction in both groups, gains in knowledge of coping skills used to support smoking cessation, and increased self-efficacy to reduce smoking. These data are particularly novel given PWD are largely absent from health research, particularly qualitative health research (Banas, Magasi, The, & Victorson, 2019). Importantly, our qualitative analysis revealed a significant component underlying success with LIFT was the dyadic approach. Inclusive health promotion interventions, such as the LIFT dyadic approach, may be an effective way to improve the health of both PWD and their caregivers.

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Table 1: Participant Demographics

Dyad	People with Disabilities					Caregivers			
	Disability Type	Age	Sex	Race	Education	Age	Sex	Race	Education
1	Intellectual	57	Male	White	Some high school	62	Male	White	College graduate
2	Cerebral Palsy	25	Female	White	High school graduate	58	Female	Black	College graduate
3	Seizures	38	Male	White	College/technical school	58	Male	White	High school graduate
4	Intellectual, speech, seizures, other	48	Male	White	High school graduate	78	Male	White	College graduate
5	Hearing, seizures	64	Male	White	High school graduate	39	Female	White	College graduate
6	Intellectual, cerebral palsy	57*	Male	Black	High school graduate	59	Male	White	College graduate
7	Intellectual	33*	Male	White	High school graduate	23	Male	White	College/technical school

*Individual did not complete the intervention

Table 2: Qualitative Themes, Categories, and Frequencies

Theme	Categories	Total Discussion Frequency
Course Content	Class design, course materials, knowledge, smoking reduction strategies	54
Group Dynamic	Group discussion, dyad approach, accountability and group support, class structure	35
Areas for Improvement	Class improvement suggestions, negative aspects of the class	19
Outcomes of the Class	Smoking reduction, easier to quit smoking after class, recommend the program to others	18
Importance of Qualified Instructors	Good instruction	10