Coping with the enduring unpredictability of opioid addiction: An investigation of a novel family-focused peer-support organization

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abstract

Background: Opioid overdose deaths have become a major public health crisis. While efforts have focused mostly on helping opioid-addicted individuals directly, family members suffer also from the grave and enduring unpredictability associated with opioid addiction and often play a vital role in helping addicted loved ones access care. Little is known, however, about resources to help affected family members. Here we describe results from the first quantitative and qualitative investigation of a free and growing support organization for family members of addicted individuals (“Learn to Cope” [LTC]; www.learn2cope.org), organized around three key questions: 1. Who participates, how often, and in what ways? 2. What are the demographic and clinical histories of their addicted loved-ones? 3. How do participants benefit?

Method: Survey with LTC members at meetings and online (N = 509; 95% participation rate).

Results: 1. Participants were primarily middle-aged mothers (77%) of opioid-addicted adult male children, attending LTC meetings several times per month, using LTC online resources several times a week, and meeting with LTC members between meetings. 2. Their addicted loved-ones were mostly male (73%), addicted to opioids (88%), with a criminal history (70%), with just under half (41%) having suffered at least one prior overdose. Almost three-quarters (71%), however, reported their loved one was “in recovery”, with 30% having a year or more. 3. Benefits since beginning participation included gains in understanding and coping with addiction, feeling better able to help and communicate with their loved-one, and reductions in self-blame and stress. Of members trained in Narcan administration (66%), 86% had received training at LTC meetings; LTC members reported having deployed Narcan for over 44 overdose reversals.

Conclusion: The growing availability of LTC may provide a needed source of support and information for family members of opioid-addicted loved-ones and may help reduce overdose deaths through Narcan training and distribution.

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1. Introduction

Over the last two decades, opioid addiction has become a major public health crisis across the United States. Between 2000 and 2014, opioid overdose death rates have quadrupled. In 2014, approximately 25,000 Americans died from opioid overdose (prescriptions 14,000; heroin, 10,500; fentanyl 500; Centers for Disease Control and Prevention [CDC], 2016a, 2016b). The U.S. Department of Justice has declared the rise in opiate-related overdose deaths an “urgent public health crisis” and has called for a greater focus on treatment and prevention methods (U.S. Department of Justice, 2014). These strategies include increased access to treatment and training of office-based clinical providers to prescribe opioid use disorder treatment medications such as buprenorphine/naloxone (“Suboxone”), widespread distribution of the opioid antagonist naloxone to help prevent overdose death (“Narcan”), implementing prescription drug monitoring programs, and providing education programs to encourage safe prescribing guidelines and prevent diversion of prescribed controlled substances (Walley, Xuan, Hackman, Quinn, & Doe-Simkins, 2013).

While the vast majority of efforts has been focused on helping the opioid addicted individuals themselves, it has long been recognized that parents and other family members suffer greatly also from the grave and enduring unpredictability associated with having a relative with an opioid use disorder. Despite this, few specific resources exist to help this growing population of affected family members around the country. Twelve-step based family support programs such as Al-Anon, which was developed to help family members with an alcohol-addicted loved one, has many available meetings in most large commu-nities, but is focused specifically on alcohol (Al-Anon, 1995). Nar-Anon, in contrast, was developed to help family members cope with and help a drug-addicted individual in the family, but is less available and not specific to opioid drugs, focusing more broadly on all substances. In light of the nature, pervasiveness, and gravity of the current opioid overdose...
epidemic, the lack of opioid-specific family support has necessitated the rise of new organizations designed to provide face to face and online advice and peer-based social support to aid affected family members.

One such entity, emerging and growing over the past 12 years has been Learn to Cope (LTC; www.learn2cope.org). LTC is a non-profit support network that offers education, resources, and peer support for parents and family members coping with a loved one addicted to opiates or other drugs that began in Massachusetts in 2004 as a result of the growing opioid overdose epidemic. Starting as a single peer-led support group of parents, it has since expanded to include two dozen chapters throughout Massachusetts, and has additional chapters in Rhode Island, New Jersey, Idaho, and Florida and also has an online "forum" which caters to approximately 7000 additional participants nationally (as of August 15, 2016; www.learn2cope.org) using a message board/posting and information exchange format. This online forum provides peer-based social support and information to members around the clock. LTC is expanding nationally to meet the demand for parent/family support for those suffering from opioid addiction. Each face to face group meeting lasts 90 min and meets weekly to offer family members the education, resources, and support needed to help cope with their loved-one’s addiction. Members also share helpful personal experiences, such as challenges dealing with insurance payment for treatment, and the types and quality of treatment experienced in various settings. LTC is funded through a state grant, philanthropic donations, and volunteer contributions from members. The organization does not have published literature yet, but does provide some informational materials and handouts available at meetings.

Typical of peer-support group meetings, in LTC there is sharing and communication of personal experiences among members and exchange of information (Humphreys, 2004). Unlike typical addiction recovery peer-support organizations, however, there is explicit monthly professional input by way of lectures from addiction clinicians, researchers, other addiction professionals (e.g., administrators/policy makers), members of other recovery support organizations, or persons in long-term recovery. Notably, also, weekly LTC meetings distribute intranasal naloxone (Narcan) to members and offer and provide training free of charge in how to use the medication to reverse opioid overdose. The philosophy of LTC is also different from 12-step based family support organizations, such as Al-Anon and Nar-Anon. The latter have a "detach with love" philosophy focusing on work on oneself as a means to shift the family and relationship dynamics and, thus, indirectly exert a salutary effect on the behavior of an addicted loved-one. In keeping with all 12-step organizations, Al-Anon and Nar-Anon also have a tradition of "no cross talk"; instead members are encouraged to verbalize their own experiences with a loved-one’s active addiction and their own personal/family’s “recovery”, without receiving direct feedback during meetings. In contrast, LTC takes a more direct stance often encouraging family members to provide differential reinforcement to their addicted loved-one for such things as attendance at treatment sessions, medication compliance, or for ongoing drug use, and LTC actively facilitates cross-talk and direct feedback among members during meetings.

Research on peer recovery support services has been focused almost entirely on organizations that help the addicted person directly, like Alcoholics Anonymous or Narcotics Anonymous (Kelly, 2003; Kelly & Yeterian, 2012; Humphreys, 2004). Some research has begun to emerge only recently on the largest peer-support program for family and concerned significant others affected by alcohol addiction – Al-Anon (Timko, Halvorson, Kong, & Moos, 2015; Timko, Lauder, & Moos, 2016; Young & Timko, 2015; Short, Cronkite, Moos, & Timko, 2015). Yet, despite the emergence over the past 12 years of LTC – a community-based support option specifically for opioid addiction, and it rapidly becoming a national model for peer support and prevention programming, no studies have been published investigating its characteristics and potential therapeutic value. The current study is designed to begin to help fill this gap at a time of critical need. This study is the first to characterize LTC membership and to describe potential benefits that LTC offers its participants and their addicted loved ones. Specifically, the investigation addressed three central research questions regarding the organization: 1. Who participates, how often, and in what ways? 2. What are the demographic and addiction histories of the participants’ loved ones? And, 3. How might participants benefit?

2. Method

2.1. Participants

Participants were 509 LTC meeting attendees. To be included, participants had to (1) be over the age of 18, and (2) attending LTC because of their relation to someone with an addiction. Adults were excluded from the study if, in addition to the absence of any eligibility criteria listed above, they did not attend meetings in person (i.e., for those attempting to complete the survey online through the LTC website but had never been to a LTC meeting). LTC meeting attendees had the option of completing the survey with another attendee if they were attending for the same person (i.e., parents of the same child).

Of the 591 participants that were screened at Learn to Cope meetings or using an online survey, 56 did not meet inclusion exclusion criteria leaving a total of 535. Of the remaining 535, 26 declined to participate. Consequently, of those who were approached and eligible to participate, 95% did so. The results are based on a sample of 509 participants who completed the survey; 409 of these completed the survey on paper at meetings; another 100 completed the survey electronically online through a posting on the website. For the 56 who did not meet eligibility criteria for the in-person survey the main reasons were because they did not have a relation with addiction (N = 12), or were staff members (6); of those who were ineligible from the online sample (N = 38) 37 had never attended a LTC meeting in person, and one person was younger than 18 years old.

2.2. Design and procedure

From February 2015 through August 2015, study staff made one visit to each LTC meeting location in Massachusetts and Rhode Island in the eastern United States. Study staff visited 16 LTC meeting locations in Massachusetts to offer members the opportunity to participate. All LTC members were given the option to complete the survey online if they preferred to do so or were not in attendance during the study visit (a link to the survey was posted on the LTC website). There was one additional meeting location in Rhode Island that study staff did not visit, and these members were only given the opportunity to participate online. The dates were scheduled in advance by contacting the facilitator and requesting the opportunity to visit that location. Upon arrival, participants were presented with information about the research and given the opportunity to decline participation. After addressing any questions, LTC attendees were given the survey to complete. Participants were given a $10 gift card for completing the survey. The study and all study related measures and documents were approved by the Partners Healthcare Institutional Review Board (IRB).

2.3. Measures

2.3.1. Demographics

The survey asked participants for information about age, gender, race, ethnicity, marital status, primary religious background and current religious practice, education, and household income to establish baseline characteristics of the sample. Demographic questions were selected from the Texas Christian University Comprehensive Intake (TCU CI; Institute of Behavioral Research, 2002), and the Global Appraisal of Individual Needs (GAIN; Dennis, Titus, White, Unsicker, & Hodkins, 2002).
2.3.2. Family history
Participants were asked to specify any history of alcohol use problems, drug use problems, or other addictions in their families, excluding their addicted loved one(s) for whom they attend LTC meetings, in order to assess family history of addiction (TCU CI; Institute of Behavioral Research, 2002).

2.3.3. LTC meeting participation
Study staff developed questions to assess members’ participation in LTC in consultation with LTC members and meeting coordinators. Participants were asked to indicate at which location they attend meetings, what prompted them to begin attending LTC, whether or not they had facilitated a meeting, and if their loved-one knew of and supported their involvement in LTC. Participants were also asked to provide up to 5 qualitative responses each regarding what they found most helpful and least helpful about LTC meetings. Lifetime as well as past six months’ rates of participation were assessed (i.e. attendance, leadership, engagement, and volunteering).

2.3.4. LTC subjective scales
Study staff developed items using a Likert Scale (1 = strongly disagree to 7 = strongly agree), for participants to rate their degree of agreement with statements regarding the perceived benefits of joining LTC their understanding of the nature of addiction, their helpfulness to and ability to communicate with their loved one, improving their coping skills and reducing stress and self-blame. Participants were asked an additional question regarding how helpful their participation in LTC has been in terms of their loved ones’ access to and engagement in treatment and recovery support services (0 = has not helped at all to 4 = has made all the difference).

2.3.5. LTC online forum participation
Study staff developed study-specific questions to assess LTC online participation and engagement. These were assessed by asking participants if and when they registered on the LTC Online Forum, and how often they used it over the past six months. Participants used a Likert Scale (1 = not at all helpful to 7 = extremely helpful) to rate how beneficial the online forum has been in helping them to understand, cope and obtain greater knowledge about addictions.

2.3.6. Narcan opioid overdose prevention training
Study staff developed questions assessing Narcan training. Participants were asked to indicate if they had been trained to administer Narcan, and, if so, whether they had received their training at LTC or at another location. Additional questions assessed whether participants currently had a Narcan rescue kit at home and whether they had ever administered Narcan to reverse an overdose. Those who had received NARCAN training answered four additional items rating how helpful and informative their training had been at LTC using a Likert Scale (1 = strongly disagree to 7 = strongly agree).

2.3.7. Loved one’s background
Participants were asked to provide demographic and other background information about up to three loved ones for whom they were attending LTC. Questions assessed loved ones’ gender, date of birth, education, living arrangement, employment, major source of income, criminal history, substance use history, lifetime and past year treatment history (TCU CI; Institute of Behavioral Research, 2002; GAIN; Dennis et al., 2002), and recovery status.

2.3.7.1. Qualitative questions. Participants were asked to list up to five things they found most helpful and up to five things they found least helpful about LTC.

2.3.7.2. Analysis plan. Quantitative analyses: Measures of prevalence/frequency (e.g., percentages), central tendency and data distributions and spread were computed using SPSS v.21.
Qualitative analyses: Data were collected and organized using an inductive, grounded theory, approach (e.g., Glaser and Strauss, 1967) whereby open-ended answers to the questions were collected from respondents and then analyzed and categorized according to emergent themes. Two coders (first and second author, JFK and NFS) reviewed the responses and made preliminary categorizations. Responses and categories were then discussed, formal categories created, and final coding conducted. Coding agreement statistics were calculated on a random subsample of responses (N = 30) using the Kappa statistic (which corrects for chance agreement). Kappa for the current study was high (K = 0.81).

3. Results

3.1. Who participates, how often, and in what ways?

3.1.1. Member demographics
LTC members completing the survey ranged in age from 23 to 85 years (M = 55.33, SD = 8.59). Members were predominantly female (77.0%), White (97.8%) and non-Hispanic (98.6%).

Members reporting religious affiliations were mostly Catholic (33.3%), non-denominational or not specified Christian (10.5%), and other Protestant (8.5%), while 15.7% of members reported that they do not consider themselves a member of a religious group. Over two-thirds of LTC members reported that they currently practice their religion, whether regularly (27.8%) or not regularly (40.5%) attending services. Nearly two-thirds of members are currently married (64.8%). About half (49.0%) hold a Bachelor’s, Master’s, or Doctorate-level degree, and the median average household income was $100,000 (IQR = $65,000 to $150,000).

3.1.2. Family history of addiction
Excluding their addicted loved one(s) for whom they became involved in the LTC organization, the majority of participants (76.2%) reported a family history of alcohol use problems, while 52.8% and 18.5% of members reported drug use problems and other addictions, respectively, in their families.

3.1.3. Involvement in the LTC organization
Eighty-eight percent of meeting attendees identified themselves as members of the LTC organization. Approximately half of participants (53%) had been attending for a one year or less (see Fig. 1).

Members estimated an average attendance of 11.5 meetings (SD = 9.9) over the previous 6 months and 48.6 meetings on average in their lifetimes (median = 15.0) but there was considerable variability around this average (SD = 119.8). Over half of LTC members (54.1%) continue to engage with other members outside of meetings at least once and up to 10 times or more per month. Seventeen percent of members had as meeting facilitators at the present time and/or previously.

Over half of members (51.8%) did not attend their first LTC meeting until at least a year (32.2%; at least 5 years: 19.6%) after learning about their loved one’s addiction. Participants cited a variety of sources from which they first learned about LTC meetings. Nearly half of members (45.9%) first found out about LTC from a friend or family member, followed by other referral sources (14.7%) including local police departments, other family support groups (e.g., Al-Anon), coworkers, or school and community events. See Fig. 2 below for a breakdown of referral sources.

Eighty-five percent of meeting attendees reported that their loved one for whom they attend LTC meetings is aware of their involvement in the LTC program. Overall, their loved ones are supportive (Median = 5; range 1 to 7) of their involvement in the LTC organization, with over one-third (35.2%) of members stating that their loved ones are very
supportive of their involvement. Members reported that in terms of their loved ones' access to and engagement in treatment and recovery support services, their participation in LTC had helped moderately (M = 2.6, SD = 1.2).

3.1.4. LTC online forum use

More than half of meeting attendees (58.6%) are also members of the LTC online forum. Most online forum members (76.7%) were not using the online component prior to attending their first in-person meeting. Users of the online component reported visiting the online forum on an average of 2.8 days per week (SD = 2.5) during the prior 6 months. Online forum users reported substantial benefits of the LTC online forum in helping them cope with (M = 5.4, SD = 1.4), understand (M = 5.5, SD = 1.4), and obtain a greater knowledge about how to deal with their loved one's addiction (M = 5.7, SD = 1.4).

3.2. Demographic and clinical characteristics of addicted loved-ones

3.2.1. Characteristics of participants' addicted loved ones

In total, 500 members reported a total of 554 addicted loved ones for whom they attend to LTC meetings. The majority of members (90.8%; N = 454) were involved in the organization because of their relation to only one person with an addiction (M = 1.11, SD = 0.38), though
there were also a number of members who were involved because of two (8.2%; \( N = 41 \)) or three or more addicted loved ones (1.0%; \( N = 5 \)). Members \( (N = 469) \) provided additional background information for up to three people about whom they are concerned, indicating that of 515 addicted loved ones, 88.7% \( (N = 457) \) were their children, 8.5% \( (N = 44) \) were other relatives (e.g., spouses, siblings, aunts/uncles, cousins) or friends, and 1.4% \( (N = 7) \) each were their stepchildren and grandchildren.

The addicted loved ones to whom members attribute their participation in LTC were primarily male (72.8%). Heroin and other opioids were reported as their primary substances (87.5%); other drugs reported were alcohol = 61.1%; cannabis = 34.4%; cocaine/crack = 17% benzos 0.74%; not sure = 0.54%). Members reported that over two hundred of their loved ones had overdosed at least once (40.8%). Most of the addicted loved ones (70.4%) had been arrested at least once in their lifetime, and half (49.7%) had stayed in jail overnight or longer. According to member reports, 71.2% of loved ones \( (N = 223) \) were in recovery at the time of data collection, over one-third of whom were in early recovery (up to 3 months in recovery =36.8%) and just under one third (29.6%) had achieved longer recovery with a year or more of sobriety.

3.3. How might participants benefit?

3.3.1. Changes in understanding, coping, self-blame, stress, and communication

All members reported that since joining LTC, they have gained a substantially greater understanding of the nature of addiction \( (M = 6.3, SD = 1.2; \text{range}= 1–7) \), feel more helpful to their loved ones \( (M = 5.8, SD = 1.4; \text{range}= 1–7) \), blame themselves less for their loved ones’ addiction \( (M = 4.9, SD = 1.5; \text{range}= 1–7) \), feel less bothered or stressed \( (M = 5.5, SD = 1.7; \text{range}= 1–7) \), are better able to cope \( (M = 5.7, SD = 1.3; \text{range}= 1–7) \) with their loved ones’ addiction, and are able to communicate with their loved ones’ more effectively \( (M = 5.6, SD = 1.4; \text{see Fig. 3}) \).

3.3.2. Narcan training

Nearly two-thirds of LTC members \( (N = 329; 64.6\%) \) reported having received training to administer Narcan to reverse an opioid overdose. Of those who had been trained, 85.7% were trained during an LTC meeting \( (N = 282) \). An additional 76 members reported that they were intending to participate in the Narcan training at a future LTC meeting. Over two-thirds (68.3%) of LTC members reported currently having a Narcan rescue kit at home. Six percent of LTC members had used Narcan to reverse an overdose in a loved one, reporting a total of 44 overdose reversals and 73% of these individuals received training at LTC.

Members who had participated in the Narcan training provided by the LTC organization reported positive benefits (see Fig. 4) in how to recognize \( (M = 6.46, SD = 0.96; \text{range}= 1–7) \) and respond to \( (M = 6.68, SD = 0.71; \text{range}= 1–7) \) an opioid overdose. Members found the training very helpful and informative \( (M = 6.74, SD = 0.65; \text{range}= 1–7) \) and felt very confident in their ability to administer Narcan if necessary \( (M = 6.36, SD = 0.94; \text{range}= 1–7) \).

3.3.3. Qualitative responses about what LTC participants liked best and least about involvement in meetings

Participants were asked to list up to five things each that they liked and disliked about attending LTC meetings. For things participants’ liked, of the 509 study respondents, 481 (94.5%) reported at least one thing they liked, generating a total of 1774 unique written responses. The majority of these responses fell into categories that corresponded well with Yalom’s theoretical curative factors involved in professional group therapy (e.g., universality, instillation of hope, catharsis, cohesion, imparting of information, altruism, interpersonal learning, existential factors; Yalom, 1995; see Table 1 for definitions). Responses are ranked ordered and presented in Table 1. Categorizing and summing across the total number of responses (i.e., across all five of the things participants reported liking about LTC), the most common aspect that participants reported liking fell into Yalom’s category of “imparting of information”, this was followed by “cohesion”, “universality”, and “instillation of hope”. Despite “imparting of information” being the most frequently reported therapeutic factor across all responses, the most frequently reported aspect that participants reported in their first of the five responses that respondents listed fell into Yalom’s category of “universality”, representing a sense of belonging and shared suffering and common purpose (Yalom, 1995). The kinds of information obtained from meetings and which were coded under the “Imparting Information” category pertained to information about Narcan, the disease of addiction, the course of recovery, types of treatment and opioid use disorder medications, and insurance coverage for treatment.

Fig. 3. Subjective benefits of participation in Learn to Cope.
Regarding aspects LTC members found last helpful about LTC, there were comparatively very few. Of the 509 respondents, only 161 (31.6%) reported at least one thing they did not find helpful and the sub-sample as whole generated a total of 242 written responses. Within the sub-sample of respondents who reported aspects of LTC they did not find helpful, the majority reported only one thing (N = 110; 68%), followed by 31 (19%) reporting 2, 13 (8%) reporting 3, and 4 (2%) and 5 (2%) people reporting 4 or 5 things they didn’t find helpful. Most responses fell into three main domains: meeting content, meeting process, and logistics of attending. Forty-three responses (18%) pertained to meeting content and discussion bringing about feelings of discouragement or sadness. In terms of process, 40 responses (17%) alluded to problems with other members routinely dominating the meeting. Regarding logistics of attendance, 30 responses (12%) expressed a need for meetings to become available in more locations and offered more frequently, noting long commute times and scheduling conflicts.

Table 1

<table>
<thead>
<tr>
<th>Therapeutic factor</th>
<th>Definition</th>
<th>#</th>
<th>Examples</th>
</tr>
</thead>
<tbody>
<tr>
<td>Imparting Information</td>
<td>Members are educated and empowered through the exchange of information in a dynamic interactive group as well as formal instructions or psychoeducation (Yalom, 1995).</td>
<td>901</td>
<td>- “Advice and information members share about treatment programs”</td>
</tr>
<tr>
<td>Cohesiveness</td>
<td>Members feel a sense of unconditional acceptance, belonging, security, and validation in the group; cohesion is a precondition from which other therapeutic factors will flow (Yalom, 1995).</td>
<td>475</td>
<td>- “There is a great deal of compassion, non-judgment, and camaraderie among members. We’re all in a club we don’t want to be in.”</td>
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<tr>
<td>Universality</td>
<td>Recognition of shared experiences and feelings with other group members (“We’re all in the same boat”) removes a member’s sense of isolation, validates experiences, and raises self-esteem (Yalom, 1995).</td>
<td>415</td>
<td>- “That everyone there looked no different from me thought I had walked into a PTA meeting the first night all looked like someone I would meet at a school or church function.”</td>
</tr>
<tr>
<td>Instillation of Hope</td>
<td>Members are inspired or encouraged by observing improvement of others at different stages who have overcome problems similar to their own (Yalom, 1995).</td>
<td>162</td>
<td>- “The fact that some people have children who are in long-term recovery— that has given me tremendous hope”</td>
</tr>
<tr>
<td>Catharsis</td>
<td>Members experience relief from emotional distress by telling their story to a supportive group (Yalom, 1995).</td>
<td>92</td>
<td>- “Speakers— hearing stories of hope in recovery. It makes you feel your loved one has a chance. Some of the speakers have had horrific stories that would seem impossible to overcome”</td>
</tr>
<tr>
<td>Altruism</td>
<td>Members in a group can help each other, which in turn can lift their own self-esteem by gaining a sense of value and significance (Yalom, 1995).</td>
<td>56</td>
<td>- “Being able to get everything out in the open to others so that I can process my feelings”</td>
</tr>
<tr>
<td>Other (not categorized)*</td>
<td>Other responses not falling specifically into any therapeutic factor and not pertaining to meeting operations (Yalom, 1995).</td>
<td>43</td>
<td>- “Sharing experiences helps to provide an outlet for our anxiety and daily worries concerning our family member.”</td>
</tr>
<tr>
<td>Organizational aspects relating to meeting structure, availability, facilitators, and/or online forum.</td>
<td>24</td>
<td>- “Achieving some goodness ad self-worth; knowing that I can help others”</td>
<td></td>
</tr>
<tr>
<td>Existential factors</td>
<td>Members accept that life continues on, with pain, death, sadness, regret, and joy, and learn to ultimately live with and through these conditions.</td>
<td>6</td>
<td>- “Being able to help someone else with going through it makes the hell you have experienced be of value”</td>
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<tr>
<td>Development of socializing techniques</td>
<td>The group serves as a safe and supportive environment for members to develop social skills, tolerance, empathy, and other interpersonal behavior (Yalom, 1995).</td>
<td>5</td>
<td>- “Making politicians aware of opioid problem”</td>
</tr>
<tr>
<td>Interpersonal learning</td>
<td>Members learn how to develop supportive interpersonal relationships through interacting with other group members (Yalom, 1995).</td>
<td>3</td>
<td>- “People here are raw and in need”</td>
</tr>
</tbody>
</table>

| | | |  |
| # Examples | | |  |

*Not a part of Yalom’s therapeutic factor framework.
4. Discussion

This study investigated a novel and expanding mutual support organization for family members of opioid addicted loved ones known as Learn to Cope (LTC). Centered around three fundamental research questions, results indicated that typical LTC participants regularly attend face to face meetings and frequently utilize online LTC resources. The addiction histories of their addicted loved ones for whom they are participating, suggest a pattern of severe, addiction-related pathology including a high proportion of opioid overdoses. A sizeable proportion of participants also reported their loved ones are currently in recovery from opioid and other drug use disorders. Personal, and broader public health, benefits from participation include technical aspects to do with informational and tangible social support, such as gaining access to Narcan and learning how to use it confidently, as well as the more typical aspects of mutual-support organization participation, such as gains in emotional and companionship support (e.g., universality, cohesion, instillation of hope, catharsis; Yalom, 1995). These latter social support benefits, in particular, may help alleviate participants’ mental health burdens related to chronic worry and distress. In sum, LTC may provide a helpful, easily accessible, and timely resource for parents and other family members suffering from substantial stress, worry, and frustration, due to a loved-ones’ opioid addiction.

Somewhat surprising in the current study was the extraordinarily high participation rate, which reached 95% of those approached. This may reflect the degree of commitment and desperation parents and family members feel in response to the worry of opioid addiction in a family member. Consequently, there may have been a strong desire to want to do anything that they perceive could help in the current opioid crisis from which they themselves are suffering so greatly, including communicating their experiences through participating in research. In addition, was the value and positive benefits that members reported, particularly the concrete information obtained at meetings, with very little reported negatives down sides.

In terms of the first research question regarding who participates how often and in what ways, findings suggested that participants are primarily mothers of opioid addicted adult male children, and who attend LTC meetings several times per month, use the LTC online resources several times per week, and also meet with LTC members between meetings. A significant minority also become involved in serving the organization through helping to lead/facilitate meetings. The greater female participation (mothers) could potentially reflect the documented greater emotional attachment felt by mothers (compared to fathers) toward their children (Alger & Cox, 2013), but it is unclear exactly why this might be the case. Attendees also overall appear to be of White race, quite well educated with about half with a bachelor’s degree or above, and with average household incomes at roughly twice the national average. These participating factors reflecting high SES could be indicative of the observed demographic shift in the current opioid addiction crisis away from impoverished minority inner city neighborhoods typical of past opioid epidemics, to predominantly White middle-class suburban areas in the current crisis (Cicero, Ellis, Surratt, & Kurtz, 2014). That said, it is also worth noting that the higher SES demography of this LTC sample are similar to a sample of Al-Anon members, who were also predominantly female (86%), white (94%), and, on average, had 15 years of education and personal income of $52,000 (Timko et al., 2013). Given their similarity to Al-Anon members, they may also reflect characteristics typical of support seeking family members of individuals with alcohol and other drug problems. If minority individuals are less likely to attend groups like LTC and Al-Anon, research may be needed to understand why this is the case, and to address the needs of these family members of addicted individuals. Finally, it is also noteworthy that the online resources were used so frequently by members. This online participation may provide an added layer of convenience to obtain and exchange information and support.

The addicted loved-ones for whom LTC members were participating, were mostly White males, addicted to opioids, with a criminal history, and just under half had overdosed on opioids at least once. Almost three-quarters of participants, however, reported that their addicted loved-one was in recovery, with just under one third having a year or more of recovery. The high proportion of reported overdose again is indicative of a high degree of addiction-related pathology and perhaps highlights the rationale for the explicit technical and tangible support that exists in LTC providing Narcan availability and Narcan overdose reversal administration training at meetings. As noted, two-thirds reported training in Narcan administration with 86% receiving that training at LTC meetings. In addition, family members’ continued participation in LTC despite a fairly high degree of reported early stage recovery among their opioid addicted loved ones may reflect the reality of a continued risk of relapse in the early years of recovery despite achieving full sustained remission (i.e., 12 months or more without symptoms; White, 2012; Hser, Evans, Grella, Ling, & Anglin, 2015), and thus, the need for continued support. It may also reflect a desire to help other members who are new or continue to struggle emotionally, which is associated with its own psychological benefits and emotional rewards (Riessman, 1965).

Benefits reported since starting to participate in LTC include gains in understanding and coping with addiction, feeling better able to help and communicate with their addicted loved one and experiencing reductions in self-blame and stress. These psychological and emotional benefits are perhaps what might be expected from mutual-support organization participation and could accrue fairly quickly among LTC members. Also, most members reported becoming trained in how to administer the overdose reversal medication, Narcan, at LTC meetings with high satisfaction and reported very high confidence in their ability to use it. Furthermore, 44 members reported using Narcan to reverse a potentially fatal overdose in their addicted loved one. Together these critically important powerful positive and negative reinforcing aspects of LTC participation may be key in its perceived value and its ability to engage and retain members.

Noteworthy in our findings was that the systematic analyses of qualitative data revealed that, unlike most mutual-support organizations studied to date, which have “universality,” “instillation of hope,” and “cohesion” as the best liked/most helpful aspects of participation (e.g., Kelly, Myers, & Rodolico, 2008; Labbe, Slaymaker, & Kelly, 2014), the most common aspect of LTC participation overall that members liked the most fell into the “imparting information” category, reflecting perhaps the fact that LTC members were able to obtain useful factual information about such things as experience with effective treatment programs and insurance coverage for their addicted loved one as well as how to obtain and administer Narcan. The once a month professional in-service at LTC meetings and ability for members to ask these treatment/research/policy professionals questions at meetings reflects a potentially highly valued component of LTC and, may help explain this therapeutic factor’s top rating. It should be noted, however, that the most common first response that members wrote down in response to this question, did fall into the “universality” and “cohesion” categories, but overall the most common response across all five possible responses fell into the “imparting information” category. So, the sense of belonging, shared suffering and common purpose, and feeling of emotional support, was still strong in LTC as has been shown in the other studies (Kelly et al., 2008; Labbe et al., 2014).

There were comparatively very few things reported that members did not like about LTC with the majority related to the content and process of meetings, and logistics of attending meetings. The fact that many found content discouraging may relate to the nature of addiction with frequent relapses, as well as fatal overdose deaths which are reported with some regularity at meetings. The domination of some meetings by some members, perhaps may indicate that facilitators may need to intervene more frequently to allow greater equity of talk time for these wanting to speak during a meeting. Finally, logistics of attending
meeting was mostly related to travel time to meetings. As meetings grow in number, this should become less of a concern.

4.1. Limitations

Results from the current investigation should be considered in light of important limitations. This is a preliminary look at this organization and, while it is expanding rapidly, it is still relatively small. Also, results reflect one region of the United States and there is large regional variation in opioid addiction and overdose prevalence which could affect the likelihood that similar results would be obtained across the entire country. Also, it should be remembered that the sample is self-selected and we do not know how many people may attend LTC and drop out or how quickly. Thus, these individuals are likely underrepresented in the current results. The cross-sectional nature of the current study cannot speak to the causal utility of participation. This should be investigated in prospective studies to determine how well LTC is able to engage people and confer unique benefits and in what ways family participation might also benefit the addicted loved-ones. Furthermore, given the mostly White, well-educated, and relatively high SES membership of LTC (and Al-Anon) more research is needed to understand potential barriers to participation for minorities or those of lower SES. Finally, several of the measures assessing various constructs (e.g., Narcan training) were developed specifically for the study, and while possessing inherent face validity, other kinds of validity and reliability of these measures is currently unknown.

4.2. Summary and conclusion

LTC consists of highly concerned and motivated mothers of opioid addicted male adult children who attend regular face to face meetings but also make frequent use of convenient online resources as well. Most report gaining explicit training in how to use Narcan to reverse overdose at LTC meetings and report that this training is effective and helpful. Moreover, members reported a total of 44 overdose reversals that they had themselves carried out using Narcan. Participation also appears to help members gain substantially in their understanding of addiction, how to communicate more effectively with their addicted loved ones, and to cope better, blame themselves less, and to feel less stressed. Members, in particular, appear to value the important specific technical information available through meetings which could be reflective of Narcan availability and administration training, but also professional in-services that allow for question and answer sessions with addiction experts, and the vast experience among members in dealing with treatment facilities and insurance coverage for treatment. In sum, the free and growing availability of LTC may provide a valuable and helpful source of in-person and online community support for family members of opioid-addicted loved-ones and may help reduce overdose deaths through providing Narcan training and distribution in the midst of the current opioid crisis.

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