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## 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](http://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 communities, 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

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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](http://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](http://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, Laudet, & 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, & Hodgkins, 2002).

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