Caregiver Perception, Self-efficacy, and Knowledge of Methadone Tapers for Children With Iatrogenic Opioid Abstinence Syndrome

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Abstract

Background: There are no definitive guidelines regarding the management of iatrogenic opioid abstinence syndrome (IOAS), but methadone tapers are one common approach. Methadone tapers can be complex for caregivers to manage, and there is a paucity of data about caregiver experiences administering medication tapers postdischarge. **Objective:** The primary objective was to describe caregiver perception, self-efficacy, and knowledge of administering methadone tapers. Secondary objectives included an assessment of the change in self-efficacy and knowledge of methadone and IOAS before and after discharge as well as clinical outcomes occurring postdischarge. **Methods:** This was an exploratory, descriptive, institutional review board–approved study surveying caregivers of children receiving methadone tapers for IOAS. Caregivers were included if they had a child ≤ 12 years of age discharged to home on a methadone taper. The study consisted of 2 phases: a questionnaire and observation/counseling session predischarge and a telephone interview after taper completion. Univariate descriptive statistics were utilized for data analysis. **Results:** Phase 1 of the study was completed by 12 caregivers, and only 5 completed phase 2. The majority of caregivers were completely confident predischarge (83.3%) and postdischarge (80%) in administering methadone as prescribed. However, some caregivers were confused about the purpose of the taper and experienced difficulty in measuring oral solutions. **Conclusions:** Despite high self-efficacy, caregivers experienced difficulties in understanding taper management and during the observation session. The results of this study suggest presenting information to caregivers utilizing minimal medical jargon, conducting a counseling/observation session predischarge, and utilizing the teach-back method with caregivers to assess for understanding.

Keywords

methadone, iatrogenic opioid abstinence syndrome, children, self-efficacy, health literacy

Introduction

Children in the pediatric intensive care unit (PICU) and neonatal intensive care unit are administered opioid continuous infusions (CIs) as part of their analgesia and sedation regimen. In addition to opioid CIs, patients may also receive a benzodiazepine CI. Specifically, one study found that an average of 93% of children in the PICU received a concomitant benzodiazepine CI.¹ Iatrogenic opioid abstinence syndrome (IOAS) occurs in 35% to 57% of children when an opioid CI is tapered quickly or abruptly discontinued.^{2–4} Symptoms of IOAS include gastrointestinal dysfunction, central nervous system hyperirritability, and autonomic system dysregulation.⁵ IOAS can cause the child and caregiver distress.⁶

There are no definitive guidelines to prevent/treat IOAS.⁷ Methadone is the most commonly utilized agent, tapered over

a period of days to weeks.^{8–21} Methadone tapers can be complex for caregivers, with changing doses and dosing intervals. First, caregivers may have difficulty measuring prescribed doses of methadone solution. One study found that 41.1% of caregivers whose children were discharged from an emergency department made an error while measuring oral liquid

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medications.²² Second, caregivers with low health literacy were more likely to make medication errors when administering oral medications.²² Furthermore, patients may also receive a concomitant enteral benzodiazepine taper to prevent benzodiazepine withdrawal, which could result in additional taper complexity. Currently, there is a paucity of data about caregiver experiences administering medication tapers at home. Therefore, the purpose of this study was to describe caregiver knowledge, self-efficacy, and patient clinical outcomes with methadone tapers.

Methods

This was an institutional review board–approved, descriptive, prospective case-series of caregivers whose children received methadone for IOAS. Caregivers were included if they had a child ≤ 12 years discharged home on a methadone taper. Children were identified on a daily basis by 2 investigators using the institution's electronic medical record (EMR). Caregivers were excluded if they were not proficient in the English language or if their child received methadone for another indication (eg, neonatal abstinence syndrome). Informed consent was obtained from caregivers. Assent was obtained from children ≥ 7 years.

This study involved 2 phases. Phase 1 included a questionnaire and interview approximately 24 to 72 hours prior to discharge (Appendix A). A paper copy was provided and accompanied by a verbal reading of the questionnaire. Then, caregivers were given a copy of their child's taper. The investigator directly observed caregiver accuracy in preparing the first and last dose of the planned taper using an oral syringe and water. After observation, the investigator counseled the caregiver about the tapers, using the teach-back method to assess understanding.²³ During this session, the investigator addressed incorrect questionnaire responses. Phase 2 included a follow-up questionnaire completed at least 2 days after taper completion (Appendix B). This questionnaire was mailed 1 week prior to the expected completion date. At follow-up, 2 investigators called the caregivers to guide them through the questions and record answers. Participants were provided a prestamped envelope to return the questionnaire. Caregivers were lost to follow-up after 3 attempts.

Demographics were obtained from the child's EMR and included age, weight, in-patient methadone regimen, hospital length of stay, and discharge medications. The planned methadone taper (and benzodiazepine taper if applicable) was also collected. The investigators assessed complexity of the planned methadone taper using the Medication Taper Complexity Score–Revised (MTCS-R). Factors incorporated in this tool include methadone dose and/or interval changes, ease of measurement, number of daily doses, taper duration, and concomitant benzodiazepine taper. Scores can range from 7 to 50; the higher the score, the more complex the taper.^{8,19}

Self-reported demographic information from phase 1 included the caregiver's educational status, occupation, and response to a previously validated health literacy question.²⁴ Other information collected included caregiver's knowledge of IOAS symptoms and self-efficacy with managing methadone tapers (Appendix A). IOAS knowledge was measured using agree, disagree, and unsure responses to 9 questions related to identifying and managing IOAS symptoms. Self-efficacy related to identifying symptoms, judging when to seek medical attention, giving methadone as prescribed, preparing correct doses, and verbalizing the taper to others was measured using a 7-level Likert-type scale anchored by “*not at all confident*” and “*completely confident*” responses. Investigator comments from the caregiver direct observation session were recorded. During phase 2, the questionnaire included follow-up caregivers' self-efficacy questions regarding recognition of IOAS symptoms and management of methadone tapers. It also addressed the caregiver's experience with their child's taper and outcomes.

The primary objective was to describe caregiver perception, self-efficacy, and knowledge of administering methadone tapers. Secondary objectives included an assessment of the change in self-efficacy and knowledge of methadone and IOAS before and after discharge. Clinical outcomes occurring postdischarge (eg, IOAS symptoms) were also documented.

To ensure content validity, both questionnaires were reviewed by 2 experienced pediatric pharmacists. Additionally after receiving feedback from these pharmacists, the questionnaires were evaluated for reading grade level competency and revised to achieve an eighth grade reading level. Prior to implementation, informal feedback on experiences with methadone tapers was received by 2 end users who had children ≤ 12 years discharged home on a methadone taper. Feedback from content experts and end users was incorporated into the questionnaires. To maintain uniformity, investigators developed a script for the study. Univariate descriptive statistics were used to describe the sample, caregiver perceptions, and self-efficacy.

Results

Study Phase 1

In all, 22 caregivers were eligible for inclusion. Three declined participation; 7 were discharged before consent was obtained. Therefore, 12 caregivers were included. Table 1 contains demographics of caregivers and their children. The median age of caregivers was 28 years, and the majority were female (83.3%). One-half reported completion of some technical school/college coursework. The children of these caregivers were primarily male (58.3%), with a median age of 3.6 months. Their total hospital length of

Table 1. Baseline Demographics of Caregivers (n = 12).

Variable	Caregiver											
	1	2	3	4	5	6	7	8	9	10	11	12
Child's age at consent, months	8.3	4.0	15.3	4.9	1.2	6.9	0.9	16.2	0.9	3.2	2.3	2.7
Caregiver age, years	31	24	20	39	28	NR	26	34	42	24	31	24
Other children at home <12 years	0	2	0	1	0	2	1	0	2	1	1	2
Gender	F	F	F	M	F	M	F	F	F	F	F	F
Race	AA	C	NR	C	NA	AA	O	C	C	C	C	C
Highest education level	Some technical school/college	Some technical school/college	High school diploma	4-Year degree	Some technical school/college	2-Year degree	Missing information	Some technical school/college	Some technical school/college	High school diploma	Some tech. school/college	None of the choices listed
Health care provider	No	No	No	No	No	No	No	No	No	No	No	Yes
Relationship to patient	Mother	Mother	Mother	Father	Mother	Father	Mother	Mother	Mother	Mother	Mother	Mother
Followed a drug taper before	No	No	No	No	No	No	No	Yes	No	No	No	No
Used device before:												
Cup	No	Yes	Yes	No	No	Yes	No	Yes	Yes	Yes	Yes	No
Syringe	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Spoon	No	Yes	Yes	No	No	Yes	Yes	Yes	Yes	Yes	No	No
Dropper	Yes	No	Yes	No	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Confident filling out medical forms by yourself ^a	5	4	5	5	4	5	4	5	5	4	5	1

Abbreviations: AA, African American; C, Caucasian; M, Male; NA, Native American; NR, no response; O, Other.

^aConfidence was measured using the following scale: 1 = not at all; 2 = a little bit; 3 = somewhat; 4 = quite a bit; 5 = extremely.

Table 2. Study Phase I Questionnaire Responses (n = 12).

Category	Caregiver											
	1	2	3	4	5	6	7	8	9	10	11	12
Knowledge												
Sweating	U	A	A	U	A	U	A	A	A	A	A	A
Constipation	U	A	A	U	D	U	U	D	U	A	U	A
Being fussy	U	A	A	A	A	A	A	A	A	A	A	A
Being tired	U	A	U	A	A	A	U	D	A	D	U	A
Increase the methadone dose	U	D	D	D	A	D	D	D	D	U	D	D
Skip a dose	U	D	D	D	D	A	D	D	D	U	D	D
Give an extra dose	U	D	U	D	D	D	D	D	D	U	D	D
Call the PCP	A	A	A	A	A	A	A	A	A	A	A	A
Continue methadone as prescribed	A	A	A	A	A	D	A	A	A	A	A	A
Self-efficacy^a												
Recognize symptoms of IOAS	N/A	4	5	7	7	5	7	7	6	6	5	7
Take child to PCP	7	7	5	6	7	7	7	7	7	6	7	7
Give methadone as prescribed	7	7	5	7	7	7	7	7	7	2	7	7
Prepare correct dose of methadone	7	7	5	7	7	7	7	7	7	7	7	7
Explain to other caregivers about methadone	7	6	7	7	4	7	7	7	7	5	N/A	7
Observations												
Measured doses correctly	Yes	Yes	Yes	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes
Air bubbles in syringe	No	No	No	No	Yes	No	Yes	No	No	Yes	No	No
Able to repeat information during teach-back	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Expressed understanding during teach-back	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes

Abbreviations: A, agree; D, disagree; IOAS, iatrogenic opioid abstinence syndrome; PCP, primary care physician; U, unsure/don't know.

^aSelf-efficacy was measured using the following scale: 1 = not at all confident to 7 = completely confident.

stay ranged from 12 to 121 days. One caregiver (8.3%) reported that she was a certified nurse assistant. Additionally, 1 caregiver (8.3%) reported that she had administered a methadone taper previously. Also, 11 (91.7%) caregivers rated themselves as extremely confident or quite a bit confident in completing health forms, indicating that the majority had adequate health literacy.

Confidence With and Knowledge of Methadone Taper. Table 2 describes caregiver responses and investigator observations regarding self-efficacy and knowledge. The majority (83.3%) were completely confident in giving methadone as prescribed and judging when to take their child to the primary care physician (PCP; 75%). However, only 5 (41.7%) were completely confident in identifying IOAS symptoms. Only 1 caregiver (8.3%) got all 4 of the symptom knowledge-based questions correct, and this caregiver had previously administered a methadone taper. Three caregivers (25%) answered 3 or more symptom knowledge-based questions incorrectly. The most commonly missed IOAS symptom questions were related to constipation and being tired. In regard to taper management, 9 (75%) caregivers said that they would not skip a dose of methadone if their child had IOAS symptoms.

Purpose of and Experience With Methadone Taper. Three caregivers expressed confusion about the purpose of the taper. Of those, 2 expressed good understanding after

counseling. One caregiver expressed confusion about the term *taper* but was able to recognize the term *wean*. After the initial counseling session, she could not verbalize the purpose and directions of the taper; thus, additional counseling was provided. Furthermore, 2 caregivers seemed concerned about managing the taper at home and managing withdrawal.

Measuring and Administering a Methadone Taper. All children were prescribed oral methadone solution. One caregiver expressed concerns about differentiating between milligrams versus milliliters and twice-daily versus 12-hour dosing. Although 1 caregiver had previously followed a methadone taper, she expressed concerns about administering a concomitant benzodiazepine taper and interpreting oral syringe markings. Another caregiver was confused about dosing versus dosing interval.

Complexity of Methadone Taper. In all, 11 children were discharged on methadone. Table 3 includes a description of the methadone tapers and taper complexity. Caregiver 5's child was not discharged home on methadone. The median MTCS-R was 22, and the majority (91%) were classified as medium or difficult complexity. The median duration of the home taper was 7 days (range = 5-23 days). There was heterogeneity in the number of dosage changes (range = 1-5); 7 patients (63.6%) were discharged on a concomitant benzodiazepine taper.

Table 3. Methadone Taper and Complexity Scores (n = 11).

Variable	Patient										
	1	2	3	4	6	7	8	9	10	11	12
Initial dose (mg/kg)	0.14	0.09	0.08	0.1	0.31	0.07	0.1	0.14	0.09	0.08	0.1
Ending dose (mg/kg)	0.03	0.02	0.02	0.05	0.01	0.02	0.03	0.05	0.05	0.04	0.04
Duration of methadone (days)											
Inpatient	6	22	6	7	8	2	12	7	12	5	8
Outpatient	5	23	9	6	9	7	6	5	7	8	8
Dose changes											
Inpatient	1	3	3	5	1	0	1	2	1	0	1
Outpatient	1	5	3	4	3	1	2	1	1	1	2
Interval changes											
Inpatient	2	0	2	1	2	0	2	2	3	1	2
Outpatient	1	2	1	1	1	2	1	1	2	2	1
Concomitant benzodiazepine taper	Yes	Yes	Yes	No	Yes	No	Yes	No	Yes	No	Yes
MTCS-R total score	17	35	25	16	25	14	22	11	23	16	25
MTCS-R classification	Medium	Difficult	Difficult	Medium	Difficult	Medium	Medium	Easy	Difficult	Medium	Difficult

Abbreviation: aMTCS-R, Medication Taper Complexity Score-Revised.

Study Phase 2

Of the 11 caregivers eligible for phase 2, 5 were lost to follow-up after 3 unsuccessful contact attempts. One caregiver's child expired as a result of heart failure before taper completion. Of the 5 caregivers included in phase 2, 4 (80%) caregivers had a child with a medium taper complexity and 1 (20%) with an easy complexity based on the MTCS-R. Table 4 describes caregiver responses from phase 2. The majority (80%) were completely confident that they gave methadone as prescribed, could determine when to take their child to the PCP (100%), and identify IOAS symptoms (60%). Only 1 caregiver reported that his child experienced withdrawal symptoms (ie, diarrhea, agitation) 1 day after taper completion. This patient had a cardiology appointment and was initiated on a new taper.

Measuring and Administering the Methadone Taper. One caregiver said that she found it hard to remember the methadone dosing schedule and had difficulty managing the timing of methadone and benzodiazepine tapers. Of note, this caregiver had followed a methadone taper before. Another caregiver said that she initially felt overwhelmed with the methadone taper. This caregiver missed all 4 IOAS symptom knowledge questions in phase 1. Four caregivers reported that they were given an oral syringe from their pharmacy; 2 of these reported that their pharmacy had prefilled the syringes according to the taper. Another caregiver reported that her pharmacy marked unfilled syringes with the appropriate doses.

Discussion

This is the first study to evaluate caregiver knowledge and self-efficacy of methadone tapers for children with IOAS.

This study evaluated caregivers' ability to interpret methadone tapers, skill in preparing doses, and postdischarge outcomes. These findings are significant given that in 1 prior study, 41% of children with IOAS were discharged home on a methadone taper.⁷

A previous descriptive, exploratory study assessed caregiver knowledge and self-efficacy with hydrocortisone in 60 caregivers of children with congenital adrenal hyperplasia.²⁵ The investigators assessed knowledge and self-efficacy using a 32-item questionnaire. Knowledge was tested using a series of true/false questions, and self-efficacy was measured using Likert-type questions. Most caregivers demonstrated a high self-efficacy to manage stress dosing and steroid injections.²⁵ It is difficult to compare these findings with our own. First, hydrocortisone is a maintenance medication for children with congenital adrenal hyperplasia. In contrast, IOAS is an acute diagnosis that resolves over time. In addition, these children were receiving hydrocortisone fixed doses versus a tapering regimen. Despite these differences, both studies demonstrated that caregivers expressed high self-efficacy.²⁵

Overall, caregivers in this study expressed confidence in their abilities to manage tapers and determine when to consult the PCP. However, based on caregiver responses and the observation sessions, it appears that the caregivers were overconfident. Only 1 caregiver was able to identify symptoms or how to manage a taper. The majority of caregivers misidentified being tired as a symptom of IOAS, which is concerning, given that this could indicate overeducation. The caregivers' baseline IOAS knowledge could be a result of prescribers' variable approach to patient and caregiver education.

Table 4. Study Phase 2 Questionnaire Responses (n = 5).

Category	Caregiver				
	1	4	7	8	9
Self-efficacy^a					
Recognized symptoms of IOAS	3	7	7	7	6
Judged when to take child to PCP	7	7	7	7	7
Gave methadone as prescribed	7	7	7	4	7
Prepared correct dose of methadone	7	7	N/A	7	N/A
Explained methadone to other caregivers	7	7	7	7	7
Perceptions					
Felt overwhelmed	A	D	D	D	D
Found easy to measure each day	A	A	A	A	A
Administered methadone accurately every time	A	A	A	A	A
Was hard to remember methadone dosing schedule	D	D	D	A	D
Wasted a lot of methadone	D	D	D	D	D
Would feel comfortable administering methadone again	A	A	A	A	A
Found regimen difficult to follow	D	D	D	D	D
Clinical outcomes					
Unscheduled PCP/ED visits related to methadone	No	No	No	No	No
Child had withdrawal symptoms	No	Yes	No	No	No
New taper written	No	Yes	No	No	No

Abbreviations: A, Agree; D, Disagree; ED, Emergency Department; IOAS, Iatrogenic Opioid Abstinence Syndrome; PCP, Primary Care Physician.

^aSelf-efficacy was measured using the following scale: 1 = *not at all confident* to 7 = *completely confident*.

A direct observation session was performed in phase 1 to assess ability to prepare doses. Caregivers expressed confidence in preparing doses, but 5 (45.5%) experienced difficulties preparing doses. Of note, all caregivers were able to repeat the information during the teach-back method, though one caregiver required remediation. This suggests that caregivers should demonstrate measurement with oral syringes prior to discharge. The results from the knowledge questions and the direct observation session in phase 1 were concerning. With both assessments, the caregivers verbally expressed understanding, but they exhibited difficulty when required to answer knowledge questions or measure the dose using an oral syringe. Based on these findings, clinicians should use the teach-back method to determine topics needing remediation.²³ This method would be especially helpful in assessing the knowledge and skills of caregivers who have a high self-efficacy.

Some caregivers demonstrated difficulty understanding medical terminology despite the majority demonstrating

adequate health literacy using a validated health literacy question.²⁴ Health care providers assume that caregivers will understand medical terms, but it is important to utilize lay language when counseling. The validated health literacy question used focused on the caregiver's confidence in completing medical forms.²⁴ Thus, the adequacy of health literacy may overestimate the true literacy level of the caregivers. It is possible that results may have differed using another assessment tool.

This study evaluated the complexity of the planned tapers using the MTCS-R.^{8,19} It builds on the investigators' previous work by including the caregiver's perception of complexity. Based on the MTCS-R, 10 methadone tapers were considered to be of either medium or difficult complexity. Of the 5 caregivers included in phase 2, 4 (80%) had a child with a medium taper complexity and 1 (20%) with an easy complexity, based on the MTCS-R. These caregivers noted that the tapers were not difficult. It is unclear if we would have found different results if we were able to follow-up with the remaining caregivers administering difficult tapers.

Postdischarge outcomes were also assessed. One caregiver expressed difficulty and frustration with the taper because she found it hard to remember the methadone dosing schedule, and another caregiver said that she was overwhelmed initially. The majority reported that they received oral syringes when getting the prescription; some were pre-filled or had doses marked. This may have eased caregiver burden and minimized errors. Although pharmacies may charge a small service fee, the cost may be offset by the reduction in caregiver burden and error minimization. Only 1 child in phase 2 experienced withdrawal symptoms, and none presented with oversedation. To date, there has been little data about postdischarge clinical outcomes.

There are a number of limitations. Generalizability is limited given the sample size. Only half of the eligible participants were available for follow-up. In the absence of relevant survey instruments, the questionnaires used were developed de novo. However, the items were developed by pediatric pharmacists and tested in a subset of end users for feedback/acceptability. Formal assessments of construct validity were not possible. Because IOAS may be treated with other opiates and/or adjunct agents, some may argue that our results lack ecological validity. However, we believe that the MTCS-R and information from the questionnaires could be applied to other medication tapers in addition to methadone.

We believe that there are best-practice recommendations that can be made to help other clinicians planning to discharge patients on complex medication tapers. First, clinicians could use a tool like the MTCS-R to evaluate the complexity of a medication taper. At this point, there are insufficient data to support a correlation between high MTCS-R scores and perceived caregiver complexity. However, it seems prudent that if a patient has a high

MTCS-R score, clinicians should simplify tapers when possible, including fewer dose changes, frequency changes, and so on. For example, if a taper is considered to be of medium (MTCS-R 13-22.9) or difficult complexity (MTCS-R 23-42), it may be warranted to revise the taper to limit the complexity, especially if there are health literacy concerns with the caregiver.^{8,19} Second, ongoing education should be given to providers who discharge these patients. Education could include strategies for discussing IOAS and methadone with caregivers, challenges caregivers face, decrease in the complexity of medication tapers, and the importance of a standardized process for follow-up to evaluate outcomes. Additionally, pharmacists or other clinicians could use the MTCS-R as a screening tool to determine which caregivers may benefit from additional counseling based on the degree of taper complexity. In general, caregivers with a child on a medium or complex taper based on the MTCS-R would benefit from additional counseling, including a direct observation session. These counseling sessions may take a significant amount of time, so using the MTCS-R would help target those caregivers with the most complex regimens. If it is determined that a caregiver has difficulty in appropriately measuring methadone doses or has low health literacy, providers may contact the patient's pharmacy to determine if they can provide each medication dose in a prefilled syringe. In many cases, pharmacies may charge a small fee for this service to cover the cost of the oral syringes; however, it may prove beneficial. We recommend that caregivers be provided with a calendar that lists the appropriate dosing

information (listed in milligrams and milliliters) and specific times for administration of the medication(s). Although we do not have evidence to support this practice, it is our opinion that a medication calendar may also be helpful for methadone tapers. In addition to the calendar, we recommend providing caregivers with a standardized information sheet that includes an overview of symptoms written at an appropriate education level. We would also recommend that they be provided a checklist to help them keep track of symptoms to document outcomes, which can be provided to their PCP at a follow-up visit. After discharge, we believe that conducting a follow-up telephone call could be beneficial to see if caregivers are having any difficulties in administering the taper and could assist in addressing questions. Overall, we recognize that caregivers may be confident in their abilities but may face challenges in administering a taper; so it is important to provide adequate counseling to each caregiver to ensure understanding.

Conclusion

There has been a paucity of data on caregivers' knowledge and self-efficacy of IOAS and methadone tapers. Caregivers appeared confident in their own abilities, yet experienced difficulties based on information derived from the questionnaire and observation session. Based on these results, there is need for presenting information with minimal medical jargon, conducting a counseling/observation session, and utilizing the teach-back method with caregivers.

Appendix A

Caregiver Questionnaire About Methadone Taper for Child (Study Phase I)

Study Number: _____

Today's Date (MM/DD/YYYY): ____ / ____ / ____

Directions: Please answer the following questions by checking the selected box corresponding to your response.

The following are common symptoms of opioid withdrawal:

1. Sweating	☐ Agree	☐ Disagree	☐ Unsure/Don't Know
2. Constipation	☐ Agree	☐ Disagree	☐ Unsure/Don't Know
3. Being Fussy	☐ Agree	☐ Disagree	☐ Unsure/Don't Know
4. Being Tired	☐ Agree	☐ Disagree	☐ Unsure/Don't Know

If my child experiences symptoms of opioid withdrawal, I would:

5. Increase the methadone dose	☐ Agree	☐ Disagree	☐ Unsure/Don't Know
6. Skip a dose of methadone	☐ Agree	☐ Disagree	☐ Unsure/Don't Know
7. Give an extra dose of methadone	☐ Agree	☐ Disagree	☐ Unsure/Don't Know
8. Call the primary care physician	☐ Agree	☐ Disagree	☐ Unsure/Don't Know
9. Continue methadone as prescribed	☐ Agree	☐ Disagree	☐ Unsure/Don't Know

Review the dosing calendar below and please answer questions 10, 11, and 12 that follow.

Monday	Tuesday	Wednesday	Thursday	Friday	Saturday	Sunday
2 mg (2 mL) every 8 hours	2 mg (2 mL) every 12 hours	2 mg (2 mL) every 12 hours	1.6 mg (1.6 mL) every 12 hours	1.6 mg (1.6 mL) every 12 hours	1.2 mg (1.2 mL) every 12 hours	1.2 mg (1.2 mL) every 12 hours

10. On Tuesday, I would give my child ____ doses of methadone. ☐ 1 ☐ 2 ☐ 3 ☐ 4
11. I would change the dose of methadone ____ times. ☐ 1 ☐ 2 ☐ 3 ☐ 4
12. On Saturday, I would give my child the following dose (circle your answer):

*Directions: We would like to know how **confident** you are in doing certain activities related to the **methadone taper**. For each of the following questions, please circle the number from the scale that corresponds to your **confidence** that you can do the tasks regularly at the present time.*

*For the purpose of this study, **confident** is: being sure or certain in your ability to do something.*

*For the purpose of this study, **taper** is: the process of slowly decreasing the amount of medication until it is completely stopped.*

	Not at all confident							Completely confident
13. I can recognize symptoms of opioid withdrawal.	N/A	1	2	3	4	5	6	7
14. I can judge when I should take my child to the primary care physician.	N/A	1	2	3	4	5	6	7
15. I can give the methadone to my child as prescribed.	N/A	1	2	3	4	5	6	7
16. I can prepare the correct dose of methadone for my child.	N/A	1	2	3	4	5	6	7
17. I can explain to my child's other caregivers the methadone taper.	N/A	1	2	3	4	5	6	7

Directions: Please answer the following questions related to a diazepam taper by checking the selected box or filling in the blank in the second column.

18. Will your child also be going home on a diazepam taper? ☐ Yes Go to Question 19 ☐ No Go to Question 20
19. Do you think having the diazepam taper will make the regimen more difficult for you to manage? ☐ Yes (please explain) _____
☐ No (please explain) _____

Directions: Please answer the following questions related to your participation in this study by checking the selected box or filling in the blank in the second column.

	Top of Form		
20. What is your sex?	☐ Male		
	☐ Female		
21. What was your age at your last birthday?	_____ years		
22. Are you of Hispanic origin?	☐ Yes		
	☐ No		
23. How would you best describe your race?	☐ African American		
	☐ Caucasian		
	☐ Asian American		
	☐ Native American		
	☐ Other (specify) _____		
24. What is your highest educational level?	☐ GED		
	☐ High School Diploma		
	☐ Some technical school/college coursework		
	☐ 2 year technical school/college degree		
	☐ 4 year technical school/college degree		
	☐ Graduate School		
	☐ None of the Above		
	☐ Other (specify) _____		
25. Are you a healthcare provider?	☐ Yes		
	☐ No		
26. What is your relationship to the patient?	☐ Mother		
	☐ Father		
	☐ Grandparent		
	☐ Other caregiver (specify) _____		
27. How many different people may potentially administer medications to the patient?	_____ people		
28. How many other children less than 12 years of age do you have at home?	_____ children		
29. Have you or anyone you know ever been prescribed methadone?	☐ Yes	☐ No	☐ Unsure/don't know
30. Have you ever followed a drug taper before?	☐ Yes	☐ No	☐ Unsure/don't know

Have you used the following measuring devices before to give the patient medication?

31. Measuring Cup	☐ Yes	☐ No
32. Oral Syringe	☐ Yes	☐ No
33. Household Spoon	☐ Yes	☐ No
34. Medication Dropper	☐ Yes	☐ No

35. How confident are you filling out medical forms by yourself?

☐ Not at all	☐ A little bit	☐ Somewhat	☐ Quite a bit	☐ Extremely
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Appendix B

Caregiver Questionnaire About Methadone Taper for Child (Study Phase 2)

Study Number: _____

Today's Date (MM/DD/YYYY): ____ / ____ / ____

*Directions: We would like to know how **confident** you are after completing your child's **methadone taper**. For each of the following questions, please circle the number from the scale that corresponds to your **confidence** that you can do the tasks*

regularly at the present time. For the purpose of this study, **confident** is: being sure or certain in your ability to do something. For the purpose of this study, **taper** is: the process of slowly decreasing the amount of medication until it is completely stopped.

	Not at all Confident								
1. I was able to recognize symptoms of opioid withdrawal.	N/A	1	2	3	4	5	6	7	
2. I was able to judge when I should take my child to the primary care physician.	N/A	1	2	3	4	5	6	7	
3. I was able to give the methadone to my child as prescribed.	N/A	1	2	3	4	5	6	7	
4. I was able to prepare the correct dose of methadone for my child.	N/A	1	2	3	4	5	6	7	
5. I was able to explain the methadone taper to my child's other caregivers.	N/A	1	2	3	4	5	6	7	

Directions: Please answer the following questions related to a diazepam taper by checking the selected box or filling in the blank in the second column.

6. Did your child also go home on a diazepam taper?	☐ Yes Go to Question 7
	☐ No Go to Question 8
7. Did having the diazepam taper make the regimen more difficult for you to manage?	☐ Yes (please explain) _____
	☐ No (please explain) _____

Directions: Please answer the following questions by checking the selected box corresponding to your response.

8. I felt overwhelmed initially giving my child methadone.	☐ Agree	☐ Disagree	☐ Unsure/Don't Know
9. I found it easy to administer methadone to my child each day.	☐ Agree	☐ Disagree	☐ Unsure/Don't Know
10. I administered the methadone accurately every time.	☐ Agree	☐ Disagree	☐ Unsure/Don't Know
11. It was hard for me to remember the methadone dosing schedule.	☐ Agree	☐ Disagree	☐ Unsure/Don't Know
12. I wasted a lot of the methadone.	☐ Agree	☐ Disagree	☐ Unsure/Don't Know
13. I would feel comfortable administering methadone again.	☐ Agree	☐ Disagree	☐ Unsure/Don't Know
14. Overall, I found this regimen difficult to follow.	☐ Agree	☐ Disagree	☐ Unsure/Don't Know

Directions: Please answer the following questions by checking the selected box or filling in the blank in the second column.

15. What was the name and location of the pharmacy where you had the methadone filled?	Pharmacy Name _____ Specify Location _____
16. Please refer to the right. If the pharmacy gave you the measuring device listed, check "yes." If the pharmacy did not give you the measuring device listed, check "no."	Measuring cup ☐ Yes ☐ No Oral syringe ☐ Yes (specify size) _____ mL ☐ No
17. During the methadone taper, how many other medications was your child taking (not including methadone)?	_____ medications
18. Did you find the regimen difficult to follow?	☐ Yes (Go to Question 19) ☐ No (Go to Question 20)
19. Please read each statement listed to the right. If you found that to be a reason why the regimen was difficult to follow, check "yes." If you did not find that to be a reason why the regimen was difficult to follow, check "no."	Too many dose changes ☐ Yes ☐ No Too many doses per day ☐ Yes ☐ No Too hard to measure ☐ Yes ☐ No

	Two medications being tapered
	☐ Yes
	☐ No
20. Was there a change in your child's methadone schedule after you went home?	☐ Yes (Go to Question 21)
	☐ No (Go to Question 22)
21. Who made the change?	_____
22. How many different people administered methadone to your child?	_____ people
23. Did your child have to go to the emergency department for reasons related to methadone?	☐ Yes (Go to Question 24)
	☐ No (Go to Question 25)
24. Why did you seek medical attention	☐ Child too sleepy
	☐ Child too irritable
	☐ Other (specify) _____
25. Did your child have any scheduled follow-up visits at the primary care physician?	☐ Yes (specify number) _____
	☐ No
26. Did your child have any unscheduled visits at the primary care physician since discharge for reasons related to methadone?	☐ Yes (specify number) _____
	_____ (Go to Question 27)
	☐ No (Stop, the questionnaire is completed.)
27. Why did you seek medical attention?	☐ Child too sleepy
	☐ Child too irritable
	☐ Other (specify) _____

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