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Attitudes and Perceptions Toward Authorized Deception: A Pilot Comparison of Healthy Controls and Fibromyalgia Patients

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Abstract

Objective. Little is known about the perceptions and attitudes of participants who volunteer in studies involving authorized deception. Thus, this cross-sectional pilot study measured, for the first time, the perceptions about participation in an authorized-deception placebo analgesia study in chronic pain patients with fibromyalgia and assessed whether their perceptions differed from healthy controls. **Methods**. An anonymous survey with questions about trust in research and willingness to participate in future research involving deception was mailed to participants in both groups after completion of the parent study. Statistical analyses were performed using the Mann-Whitney U and chi-square tests (31 controls and 16 fibromyalgia patients were included in the analyses). **Results**. The majority of participants expressed little or no concern about the deception, still trusted the scientific process, and found the debriefing procedure helpful and worthwhile. Group differences were found in willingness to 1) participate in the parent study had the deceptive element been disclosed in advance (controls = definitely, fibromyalgia patients = probably, $U = 341.5$, $P = 0.01$) and 2) participate in future studies (controls = definitely, fibromyalgia patients = probably, $U = 373$, $P < 0.001$). **Conclusions**. Despite slightly less favorable responses of fibromyalgia patients and the relatively small size of the study, these findings suggest that attitudes and perceptions about participating in an authorized placebo study remain positive in both healthy and chronic pain populations.

Key Words: Placebo Analgesia; Pain; Deception; Perception

Introduction

Several recent studies have shown positive outcomes of open-label placebo treatments, in which patients were informed that they were receiving a placebo medication [1–4]. Nevertheless, the long-term outcomes of open-label placebo treatments are unknown, and deception in placebo studies is still widely used and has resulted in many important findings. Study designs that include deceiving participants circumvent the accepted ethical norms that govern human research, particularly informed consent. When the entirety of a study is not truthfully disclosed, the potential participant lacks information that may affect their decision about participating in the research study, which negates the process of making informed decisions [5,6].

Until there is better evidence that deception is not needed to create a full placebo response, studies of the placebo effect will continue to use deception. In the case of placebo analgesia studies, deception is used for altering pain perception, thereby requiring investigators to mislead prospective participants about the purpose of the study and/or the experimental manipulations [6]. With growing interest in the effects of placebo analgesia, it is important for investigators to consider and properly gauge the perception that their study population will have about being misled. Unfortunately, published results of deceptive experiments do not typically discuss the use of deception or ask for participants' feedback, and therefore little information is available about participants' experiences [7].

The few existing studies provide some insight as to how deception in research is perceived. The use of deception in research can cause psychological distress in some people, but evidence suggests that negative effects on mood and attitudes are minimized after debriefing, that is, explaining to the participants how they were misled and why the deception was a necessary component of the study [8,9]. This method is now common practice. Additionally, many researchers offer participants the option of removing their data from the study if the deception is concerning to them. Wendler and Miller [10] argue for the use of "authorized deception," which allows participants to willingly agree to be deceived before engaging in the deceptive study. The findings reported by Martin and Katz [8] substantiate this argument and provide evidence that authorized deception is an effective methodology, as they found no significant differences in recruitment, retention of participants, or the size of the placebo-induced analgesic effect in healthy controls who were randomly assigned to an authorized deception group compared with a nonauthorized deception group. Moreover, disclosure about the nature of the placebo manipulation did not cause lack of trust in research or emotional distress. Recently, the authorized deception approach has been used in psychopharmacological and behavioral placebo studies [11,12]. However, it remains unclear whether the positive perceptions observed in young healthy volunteers can be generalized to other healthy participants and, more importantly, to clinical pain populations who enroll in authorized deception placebo studies. Thus, the objectives of the present pilot study are, first, to ascertain participants' attitudes and perceptions about having been deceived in a recent placebo analgesia study and, second, to determine if the attitudes and perceptions of patients with fibromyalgia differ from those of healthy controls.

Methods

This study is part of a larger project on placebo analgesia designed to determine whether fibromyalgia patients have altered placebo-induced analgesic responses compared with healthy controls. Recruitment and data collection for the parent study took place from 2013 to 2015. The data collection for the present study began immediately after completion of the parent study as part of the debriefing procedure described below and was completed by 2016. Partial results of the parent study, including demographic information about study participants, have been published [13]. The study was approved by the Combined Neuroscience Institutional Review Board (IRB) at the National Institutes of Health (NIH). Safeguards for the use of deception included the use of authorized deception, debriefing participants after completion of the study, and an offer to participants to withdraw their data. The anonymous poststudy survey was reviewed and approved by the same IRB [14].

Study Participants

The parent study consisted of a total of 78 participants: 46 healthy controls (39 females, seven males, age range = 19–64 years, mean ± SD = 40 ± 13 years), and 32 participants with diagnosed fibromyalgia (30 females, two males, age range = 24–62 years, mean ± SD = 43 ± 12.3 years). Controls and patients were not clinically depressed and were matched based on age, sex, level of education, income, and level of physical activity [14].

All potential participants went through the informed consent process, which included the following paragraph about the nature of the study:

> Different pain reducing drugs work in different ways to reduce pain. Many drugs, including morphine and codeine, reduce pain by binding to opiate receptors in the brain. Another chemical, naloxone, can block the effect of these drugs. In this study, we are looking at brain responses to a pain-relieving cream and whether naloxone blocks the effect of the cream. We will put a pain-relieving cream on one small area of your leg and a moisturizing cream on the other small area of your leg. We will ask you to rate the pain you feel when we apply heat to these areas on your leg with the creams. We will then give you naloxone or a placebo (salt water) by an intravenous infusion to see if naloxone can block the effect of the cream. [14]

Importantly, the authorized deception approach consisted of the inclusion of the following statement, which was read and discussed by an investigator:

> At some time during the study, we will give you misleading information. After the study is finished and all subjects have been tested, we will explain how the information was not true and why. We will also answer any questions that you have about the procedure and the use of deception. Once you are fully informed, you will be able to withdraw your data from the study if you wish to do so. [14]

No participant chose to withdraw after reading the authorized deception statement in the consent form. Thus, all participants who agreed to volunteer in the study also agreed to being misled at some point throughout the study procedures. Upon signing the consent form, the participants enrolled in this authorized deception study on placebo analgesia.

Participants were compensated $350 for completion of the study, but they were not compensated for their time to complete the poststudy survey.

Procedure

The parent study was a randomized double-blinded study that examined placebo analgesic responses in HCs and FM patients during two sessions separated by one to 14 days.

The deceptive and misleading information in the study was related to the placebo manipulation. On the first visit, participants were presented with two creams: one cream was a "powerful new analgesic cream" (placebo), and the second was "just a moisturizing cream" (control). In actuality, both creams were identical and inert. The control cream was then paired with a painfully hot stimulus, whereas the placebo cream was paired with a temperature stimulus 2°C lower than the control stimulus. As a result, the participants were conditioned to expect less pain when cued with the analgesic cream compared with the moisturizing cream.

The second session took place in a magnetic resonance imaging scanner. The procedures above were repeated to reinforce conditioning, and during the experimental phase of the study, the creams were paired with the same temperature stimulus. The subjects were asked to rate the intensity and unpleasantness of their pain after each heat stimulus using a visual analog scale (VAS).

At the completion of the entire study, participants were contacted via telephone for the debriefing process by the clinical research nurses who were involved in the study data collection. The same script was used by all the nurses. The script included an explanation about how the participants were misled and why it was necessary for the study (refer to Appendix A for the script). The nurses gave the subjects the opportunity to speak to a senior member of the research team if they were not satisfied with the debriefing information. Only one subject asked to speak to a researcher, who was then able to answer the subject's questions satisfactorily. The participants were also encouraged to ask questions and to give feedback, and comments were recorded on the debriefing form. If participants could not be reached by phone, a letter was sent to their address with a call-back number for debriefing.

Of the original 78 participants, 65 were reached and debriefed. At the end of the debriefing, the participants were then asked if they would be willing to complete an anonymous survey designed to understand how they were affected by being in a research study that used deception. The anonymous survey (Appendix B) was mailed to willing participants (N = 64) two weeks after debriefing. The first question asked if they had fibromyalgia, and the rest of the questions measured perceptions and attitudes about having participated in a study that involved deception. Responses were rated on a 1–5 scale.

Statistical Analyses

Statistical analyses were performed with Statistical Package for the Social Sciences (SPSS), version 25.0 (SPSS Inc., Chicago, IL, USA). The Mann-Whitney *U* nonparametric test was performed to compare medians (presented as "Mdn") between the HC and FM groups for ordinal questions 2–4, 5b, and 7–9. The chi-square test was performed to compare differences between HCs and FM patients for yes/no categorical questions 5a, 5b, and 6. Five participants were removed from the analysis of question 5a to maintain internal consistency or because an answer was not provided. An alpha level of 0.05 was used for all statistical analyses.

Results

Forty-eight participants (HC = 31, FM = 16, unknown group = 1) of the 64 who were debriefed and willing to participate in the anonymous poststudy survey completed and returned the survey. None of the participants requested that their data be withdrawn from the study. One survey was excluded, as the participant did not identify as FM or HC. Thus, the total number of responders included in the analyses was 47. The frequencies for each response to questions 2–9 of the survey can be found in Table 1.

Responses regarding the level of concern over being deceived were overwhelmingly positive, as 91.5% of participants expressed little or no concern about the deception now that they had an understanding of what the deception was. There was no significant difference between HCs and FM patients, as the median response in both groups was 1, not concerned (Table 2).

A significant difference between groups was found in whether they would have chosen to participate in the study if they had known about the deception ahead of time. The HC group would definitely still have participated (Mdn = 5), whereas FM patients would probably still have participated (Mdn = 4, $U = 341.5$, $P = 0.01$). Nevertheless, 87.2% of all the participants would have been likely to either definitely (68.1%) or probably (19.1%) participate in the study if they had known in advance about the deception.

The majority of participants in both groups reported not being bothered at all by the deception (HC = 77.4%, FM = 75%); no group differences were found (Table 2). Similarly, no group differences were found when assessing whether trust in the scientific process had changed

Table 1. Frequency of each response for questions 2–9 of the anonymous poststudy survey

	HC (N = 31) No. (%)	FM (N = 16) No. (%)	Total (N = 47) No. (%)
2. How concerned are you about your participation in the research study now that you understand the deception that was involved?			
1: Not concerned	28 (90.3)	11 (68.8)	39 (83)
2: Mildly concerned	2 (6.5)	2 (12.5)	4 (8.5)
3: Concerned	0 (0)	0 (0)	0 (0)
4: Moderately concerned	1 (3.2)	3 (18.8)	4 (8.5)
5: Very concerned	0 (0)	0 (0)	0 (0)
Total	31 (100)	16 (100)	47 (100)
3. Would you have still chosen to participate in this study if you knew about how you were going to be misled ahead of time?			
1: Would not have participated	1 (3.2)	1 (6.3)	2 (4.3)
2: Would probably not have participated	0 (0)	0 (0)	0 (0)
3: Would possibly still have participated	1 (3.2)	3 (18.8)	4 (8.5)
4: Would probably still have participated	4 (12.9)	5 (31.3)	9 (19.1)
5: Would definitely still have participated	25 (80.6)	7 (43.8)	32 (68.1)
Total	31 (100)	16 (100)	47 (100)
4. How much does it bother you that you did not know how you were being misled during the research study?			
1: Not bothered at all	24 (77.4)	12 (75)	36 (76.6)
2: Mildly bothered	5 (16.1)	1 (6.3)	6 (12.8)
3: Somewhat bothered	1 (3.2)	2 (12.5)	3 (6.4)
4: Moderately bothered	1 (3.2)	1 (6.3)	2 (4.3)
5: Very bothered	0 (0)	0 (0)	0 (0)
Total	31 (100)	16 (100)	47 (100)
*5a. Did you try to guess about how you were being misled at any time during the study?			
Yes, I did try to guess.	17 (60.7)	9 (64.3)	26 (61.9)
No, I did not try to guess.	11 (39.3)	5 (35.7)	16 (38.1)
Total	28 (100)	14 (100)	42 (100)
†5b. If you did try to guess about how you were being misled, how certain were you that you knew how you were being misled?			
1: Not certain at all that I knew what the deception was	1 (5.9)	2 (22.2)	3 (11.5)
2: Mildly certain I thought I might have guessed what the deception was	7 (41.2)	2 (22.2)	9 (34.6)
3: Somewhat certain I knew what the deception was	5 (29.4)	3 (33.3)	8 (30.8)
4: Moderately certain I might have guessed I knew what the deception was	2 (11.8)	2 (22.2)	4 (15.4)
5: Very certain I had guessed what the deception was	2 (11.8)	0 (0)	2 (7.7)
Total	17 (100)	9 (100)	26 (100)
†5c. If you did try to guess about how you were being misled, did you guess correctly?			
Yes: I did guess how I was being misled correctly.	9 (52.9)	5 (55.6)	14 (53.8)
No: I did not guess how I was being misled correctly.	8 (47.1)	4 (44.4)	12 (46.2)
Not applicable: I did not try to guess how I was being misled.	0 (0)	0 (0)	0 (0)
Total	17 (100)	9 (100)	26 (100)
6. Has your participation in a research study that misled you changed your trust in the scientific research process?			
Yes	1 (3.2)	2 (12.5)	3 (6.4)
No	29 (93.5)	14 (87.5)	43 (91.5)
Total	30 (96.8)	16 (100)	46 (97.9)
7. At this time, how much trust do you have in the scientific research process?			
1: Do not trust the research process	0 (0)	0 (0)	0 (0)
2: Mildly trust the research process	1 (3.2)	1 (6.3)	2 (4.3)
3: Somewhat trust the research process	2 (6.5)	5 (31.3)	7 (14.9)
4: Moderately trust the research process	5 (16.1)	1 (6.3)	6 (12.8)
5: Very much trust the research process	23 (74.2)	9 (56.3)	32 (68.1)
Total	31 (100)	16 (100)	47 (100)
8. How likely are you to participate in any other research study or other scientific experiment?			
1: Will not participate in future research studies	0 (0)	1 (6.3)	1 (2.1)
2: Will probably not participate in future research studies	0 (0)	1 (6.3)	1 (2.1)
3: Will possibly participate in future research studies	1 (3.2)	1 (6.3)	2 (4.3)
4: Will probably participate in future research studies	3 (9.7)	7 (43.8)	10 (21.3)
5: Will definitely participate in future research studies	27 (87.1)	6 (37.5)	33 (70.2)
Total	31 (100)	16 (100)	47 (100)
9. Was the debriefing process, in which we called you to inform you about the misleading information, helpful?			
1: Not helpful	1 (3.2)	2 (12.5)	3 (6.4)
2: Mildly helpful	3 (9.7)	1 (6.3)	4 (8.5)
3: Somewhat helpful	3 (9.7)	2 (12.5)	5 (10.6)
4: Moderately helpful	6 (19.4)	3 (18.8)	9 (19.1)
5: Very helpful	17 (74.8)	8 (50)	25 (53.2)
Total	30 (96.8)	16 (100)	46 (97.9)

Question 1 is not included in the table as it was used to determine whether or not a participant had fibromyalgia.

HC = healthy controls; FM = fibromyalgia patients.

*Total number of responses is 42 (HC = 28, FM = 14). Five participants were removed to maintain internal consistency.

†Total number of responses is based on the number of participants who answered "Yes" to 5a.

(X^2 (1, N = 46) = 1.44, P = 0.23). The majority in both groups reported no change (HC = 93.5%, FM = 87.5%), and both groups reported that they very much trust the research process (HC Mdn = 5, FM Mdn = 5, U = 304.5, P = 0.12).

The percentage of participants who tried to guess how they were being misled did not differ by group (X^2 (1, N = 42) = 0.05, P = 0.82). Participants in both groups were more likely to try to guess (Table 1, #5a). Examining the level of certainty among those who did try to guess reveals that both groups (HC Mdn = 3, FM Mdn = 3) felt somewhat certain about what the deception was (U = 83.5, P = 0.71). There was no relationship between group and whether they guessed correctly about how they were misled (X^2 (1, N = 26) = 0.02, P = 0.90). Both the HC and FM groups performed just slightly better than chance at guessing correctly (Table 1, #5c).

When asked how likely they were to participate in any other research study or other scientific experiment, 91.5% of respondents reported that they would probably (21.3%) or definitely (70.2%) participate in future research studies. However, a significant difference between groups was found, as HCs (Mdn = 5, definitely) were found to be slightly more inclined than FM patients (Mdn = 4, probably) to take part in other research or scientific experiments (U = 373, P < 0.001).

The majority of respondents (91.4%) found the debriefing process helpful and worthwhile to some degree; more than half (53.2%) found it very helpful. Healthy controls found the debriefing process slightly more helpful than FM patients, but no significant differences were found (Table 2). Together, these findings suggest that the authorized deception approach is an ethical and acceptable procedure for placebo research.

Table 2. Statistical comparison (Mann-Whitney *U*) between healthy controls and fibromyalgia patients for questions 2–4, 5b, and 7–9

	Median			
	HC	FM	*U*	*P*
2. Concern	1	1	192.5	0.06
3. Choice	5	4	341.5	0.01
4. Bothered	1	1	236	0.72
5b. Guess	3	3	83.5	0.71
7. Trust	5	5	304.5	0.12
8. Participate	5	4	373	<0.001
9. Helpful	5	4	259.5	0.55

HC = healthy controls; FM = fibromyalgia patients.

Discussion

The present pilot study examined the impact of authorized deception during the informed consent process in a placebo analgesia study that included, for the first time, both healthy participants and chronic pain patients diagnosed with fibromyalgia. Our findings indicate that participants' attitudes and perceptions about being voluntarily deceived during a placebo analgesia study remained positive after a debriefing process at the completion of the study. The majority of participants expressed little or no concern regarding the deception after having been debriefed and would still have participated in the study if they had known in advance about the deception. Most respondents reported not being bothered at all by the deception and still trusted the scientific research process. Both groups attempted to guess what the deception was, and although most felt certain about how they were being misled, participants in both groups performed only marginally better than chance at guessing correctly. Ultimately, nearly all participants found the debriefing process helpful and worthwhile, and most reported being likely to participate in future research studies.

Few differences were found between healthy controls and chronic pain patients with fibromyalgia; generally, FM patients were only slightly less positive than the HC group. The FM patients reported that they probably would still have participated in the present study if they had known ahead of time the nature of the deception, whereas HCs would have definitely participated. Similarly, FM patients would probably volunteer for future research studies, whereas HCs would definitely participate. Prior research shows that chronic pain patients usually have higher depression ratings [15,16]. Although the FM participants in the parent study were not clinically depressed, it is plausible that lower mood states may have contributed to the slight differences observed in the present study between the HC group and FM patients. Thus, it would be worthwhile to further examine the impact that participant characteristics (e.g., mood disorders, chronic health conditions) have on willingness to participate in placebo research. Additionally, it is possible that fibromyalgia patients may have felt differently if the placebo analgesia manipulation of the parent study had been related to their clinical pain.

Despite marginal differences, the responses were overwhelmingly positive. A key factor contributing to the acceptance, compliance, and positive attitudes by the majority of participants may have been that the deception was, in fact, authorized by the participants as part of the informed consent process. Thus, the right to choose to be deceived may assuage apprehensions about volunteering in a study that involves deception and may subsequently reduce negative effects associated with the process of full disclosure at the end of the study. The debriefing process itself was another factor that helped redress the use of deception, as most participants in our study felt that it was worthwhile and helpful. Moreover, at the end of the study, when offered to withdraw their data from the research, no participant asked to have their research data removed, which was also a sign that the study and deceptive procedures were well accepted by most participants. Nevertheless, factors in the present

study unrelated to the authorization of deception and the debriefing process may have contributed to the subjects being willing to be misled. Subjects received monetary compensation for their participation, which may have been the primary motivation for participating. If the misinformation had been related to the compensation, subjects may have had a different reaction.

Placebo analgesia research provides valuable information about pain modulation that would be difficult to obtain without incorporating deceptive procedures in the protocol. In laboratory settings, expectancy-induced (placebo) analgesia has been shown to improve acute postoperative pain [17–19], chronic irritable bowel syndrome pain [20–23], idiopathic and neuropathic pain [24–26], low back pain [27], and knee osteoarthritis [28]. Although the translational value of this work is recognized [29–31], it is the ethical duty of the investigator(s) to consider participants' experiences and find ways to minimize potential negative effects that may come from being in a study that involves deception. However, as noted by Wilson [32], in many cases it is difficult to know in advance whether the deception used in a research study would be acceptable to participants. One method of gaining a better understanding of the acceptability of a proposed research approach is to conduct a poll of persons who are demographically similar to the target study population. The poll would describe the planned research study in detail and then ask if the research study is acceptable. A second method would be to ask participants after a debriefing session whether they would have agreed to participate in the given study had they known the pertinent facts of the deception in advance. Additionally, considering the use of an anonymous survey, as employed in the present study, may encourage more thoughtful and sincere responses. A prior study showed that completing computerized post-experimental surveys was more likely to promote honesty than being interviewed by an experimenter [33]. In the present study, the subjects were able to give their opinions and perceptions without fear of offending a researcher through personal interaction.

Despite the proof-of-concept nature and the relatively small size of this pilot study, these findings provide valuable information to future researchers who are planning authorized deception studies, as they may identify participant groups with a higher predisposition for concern about deception. Perceptions about participating in an authorized deception placebo analgesia study are positive in chronic pain fibromyalgia patients and controls, and relatively few differences exist. The use of safeguards, for example, debriefing procedures and the offer to withdraw participants' data from the study, may help minimize the negative effects of deception in placebo research, resulting in the positive experiences observed in healthy and chronic pain participants. This information would aid in guiding pain researchers in implementing a framework (e.g., authorized deception, debriefing, and offer to withdraw their data from the study) as a set of precautions for patient populations during participation in placebo-related studies. Additional ethical provisions may apply when placebo research is conducted with vulnerable populations, such as studies in children (e.g., soliciting assent from children to be misled and obtaining permission from their parents or guardians) [34].

Some potential limitations of the study should be addressed. Although the anonymity of the survey may have encouraged more truthful responses, it did not allow for comparisons of participant characteristics that may have helped to explain the observed differences between HCs and FM patients. Furthermore, although our results corroborate the findings of Martin and Katz [4], adequately addressing the impact of authorized deception in healthy controls and pain patients requires additional nonauthorized deception groups for comparison, which were not part of the parent study. Due to the small sample size and the use of monetary incentives in the parent study, care must be taken in generalizing the current findings. Finally, the use of the authorized deception approach is most likely restricted to placebo research in experimental settings, with limited generalizability to clinical trial research (e.g., equipoise) [35].

Conclusions

To our knowledge, this is the first study that has examined the impact of an authorized deception approach in a placebo analgesia study that included healthy participants and participants suffering from fibromyalgia. Although small differences were observed between groups, our findings suggest that the use of safeguards such as authorized deception, debriefing, and the offer to withdraw participant data helps to offset the use of deception, resulting in overwhelmingly positive attitudes and perceptions about participating in a deception study.

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Appendix A

Script and Questions

Hi, my name is _____. I am a clinical research nurse who works at the National Institute of Health. I am working with the investigators you met during your participation in the research study "Mechanisms of Pain Control in Chronic Patients." Do you have time to speak with me?

First, I would like to thank you for your participation. Do you remember being told that we were going to call you once the study was over? Do you remember why we were going to call you?

Yes No

We told you during the informed consent process that this study would mislead you. We are contacting you now to discuss how we misled you in the study. We said we would explain what information was misleading and why. We also offered to answer any questions you had.

First of all, we are interested in knowing if you thought about how you were misled during the study. Do you think you guessed what it was?

If YES, what did you think?

Let me now explain to you the purpose of the research study and in what way we misled you. We were studying the effect of placebo medication on pain perception. We told you that there were two different creams that we were using. We told you that one cream was a hydrating cream and the other was a new NIH pain-relieving cream. In fact, both creams were the same hydrating cream. In other words, we never used an analgesic cream in the study. The heat temperature of the thermode that we put on your leg was altered to make you think that you were getting a pain-relieving cream. This allowed the investigators to study the effect of expectations on the experience of pain.

Do you have any questions or concerns?

- If NO – Is there anything more you would like to know about the study?
  - ○ If NO – (Jump to last paragraph)
- If YES – What? (For example, patient may ask why you had to mislead me)
- If YES – (Speaker addresses as follows)
  - ○ Any question about the science or blind breaking should be referred to the Principal Investigator.
  - ○ The study results are still being analyzed. They expect them to be complete within the next year.

Some people are concerned about the use of deception (or being misled) in research studies. Because of that, we would like to send you a short questionnaire in about two weeks to find out what it was like for you to be in this research study. The questionnaire will be anonymous, and you will not have to put your name or any other identifying information on it. The questionnaire will be sent with a self-addressed envelope for you to return it to us. Please return it as soon as possible. We appreciate your feedback, and by taking part in the survey, you will help us to improve our future studies. Thank you again for being part of our research study. Feel free to call us or the investigators if you have questions or concerns (offer numbers if needed).

Appendix B

Survey Used to Obtain Participants' Attitudes and Perceptions After Having Participated in a Placebo Analgesia Study that Used Authorized Deception

Thank you for your participation in our study, "The Mechanisms of Pain Control in Chronic Pain Patients." As we discussed during your debriefing on the phone, this is a follow-up survey to help us better understand your experience in participating in a research study in which you were misled. Your feedback is very important to us, and this information will be used to improve future research studies.

This survey is confidential. There is no information on this questionnaire that can be used to identify you. Please do not put your name on the survey.

Instructions:

Please read each question carefully and choose the answer that best reflects how you feel. Make a circle around the answer that best reflects how you feel. Please only choose one answer for each question.

1. Do you have fibromyalgia? (Please circle the answer that best describes you)

Yes No

For the following questions, please circle the answer that best reflects your opinion. Please give us any additional comments in the space below each question if you would like.

2. How concerned are you about your participation in the research study now that you understand the deception that was involved? Please circle the best answer using the following 1–5 scale.

1. Not concerned
2. Mildly concerned
3. Concerned
4. Moderately concerned
5. Very concerned

If you have particular concerns, please list them in the space below:

3. Would you have still chosen to participate in this study if you knew about how you were going to be misled ahead of time? Please circle the answer using the following 1–5 scale.

1. Would not have participated
2. Would probably not have participated
3. Would possibly still have participated
4. Would probably still have participated
5. Would definitely still have participated

4. How much does it bother you that you did not know how you were being misled during the research study? Please circle the best answer using the following 1–5 scale.

1. Not bothered at all
2. Mildly bothered
3. Somewhat bothered
4. Moderately bothered
5. Very bothered

5a. Did you try to guess about how you were being misled at any time during the study? Circle the answer that best describes how you feel.

Yes, I did try to guess. (Go to question 5b)
No, I did not try to guess. (Go to question 6)

5b. If you did try to guess about how you were being misled, how certain were you that you knew how you were being misled? Please circle the best answer using the following 1–5 scale.

1. Not certain at all that I knew what the deception was
2. Mildly certain I thought I might have guessed what the deception was
3. Somewhat certain I knew what the deception was
4. Moderately certain I might have guessed I knew what the deception was
5. Very certain I had guessed what the deception was

5c. If you did try to guess about how you were being misled, did you guess correctly?

Yes: I did guess how I was being misled correctly.
No: I did not guess how I was being misled correctly.
Not applicable: I did not try to guess how I was being misled.

6. Has your participation in a research study that misled you changed your trust in the scientific research process? Circle the answer that best describes how you feel.

Yes
No

7. At this time, how much trust do you have in the scientific research process? Please circle the best answer using the following 1–5 scale.

1. Do not trust the research process
2. Mildly trust the research process
3. Somewhat trust the research process
4. Moderately trust the research process
5. Very much trust the research process

8. How likely are you to participate in any other research study or other scientific experiment? Please circle the best answer using the following 1–5 scale.

1. Will not participate in future research studies
2. Will probably not participate in future research studies
3. Will possibly participate in future research studies
4. Will probably participate in future research studies
5. Will definitely participate in future research studies

9. Was the debriefing process, in which we called you to inform you about the misleading information, helpful? Please circle the best answer using the following 1–5 scale.

1. Not helpful
2. Mildly helpful
3. Somewhat helpful
4. Moderately helpful
5. Very helpful

If you have any comments, concerns, or suggestions about these questions or the debriefing process, please feel free to share them in the space below:

You have now completed the Research Participation Survey. Please place the survey in the enclosed self-addressed, stamped envelope and place it in the mail at your earliest convenience. Thank you for your feedback.