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“Everything They Were Discussing, We Were Already Doing”: Hospice Heart Failure Caregivers Reflect on a Palliative Caregiving Intervention

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Introduction

Heart failure (HF) remains a life limiting diagnosis despite improved, guideline directed care.¹ Since the 1990s one in every eight U.S. deaths is either directly or indirectly attributable to HF² making it a large, relatively understudied palliative care population. Currently, HF constitutes the largest condition-specific group of non-cancer patients in hospice.³ Generally each of these individuals with HF have some sort of social network which either helps provide a part of their care or supports them in their self care.^{4, 5} Yet, relatively little is known about the HF caregiver experience when compared with the other two large palliative care populations, cancer and dementia. Both the Heart Failure Society of America and the American Heart Association recommend palliative care, aggressive symptom management, and referral to hospice in end stage HF^{6, 7} yet, once again, empirical evidence remains scarce in guiding this type of care. Specifically there is little to no evidence concerning the efficacy of HF caregiver interventions in hospice populations.⁸

What is known in this emerging area of science is that HF patients and caregivers have distinct needs related to the unique trajectory of HF with its high levels of uncertainty.⁹ HF's cyclical but ultimately downward trajectory comprised of periods of exacerbation coupled with periods of stability results in difficulty in prognostication for clinicians as well as difficulty in care for informal caregivers. Hupcey and colleagues¹⁰ using qualitative methods (n=45) determined that HF palliative caregiving needs differ depending on whether the patient is in a period of exacerbation or medical stability with their need for instrumental support becoming more focused and situation specific in the medically unstable times. For

example, caregivers reported chronic financial concerns throughout routine HF treatment, but these chronic issues escalated when there was an emergent hospitalization. During hospitalization the caregivers were faced with missed work and lost wages at the same time that they had increased expenses related to the hospitalization (travel and lodging expenses) and issues with patient insurance co-pays.¹⁰ Caregivers reported the loss of their jobs or homes while caring for their loved one as an extreme example of the financial pressures of HF.¹⁰

Bekelman and colleagues (n= 33) interviewed HF patients and family caregivers from the outpatient setting and found that patients and caregivers, in general, identified specific desires related to their HF care – that there would be an early integration of palliative care into their current care, that they would receive expert symptom management, and that caregivers would be recognized as vital members of the health care team. However, this study also found that the needs and preferences of this population are shaped both by age and health status of the patient.¹¹

Boyd and colleagues¹² conducted a qualitative study in the United Kingdom (n=36). They determined that HF patient and family caregivers valued a continuing relationship with a key health care provider who would work with them to develop a plan of care, coordinate the implementation of the plan and support them in their self care. So while HF patients and caregivers are able to verbalize needs for earlier palliative care there is no data reporting on their responses to a palliative care intervention which sought to meet these needs.

The purpose of this study was to examine HF caregiver's responses to a hospice caregiving intervention and elicit the recommendations for future interventions from this panel of novice to expert caregivers. This study was a pre-planned sub-analysis of a larger, mixed methods study (1R21NR011224, PI MacMillan, S.).

Methods

The Intervention

The COPE-HF (Creativity, Optimism, Planning, Expert Information) psychoeducational intervention specifically addresses the needs of family caregivers of hospice HF patients in managing symptoms such as dyspnea, edema, pain (angina or other pain), and constipation. *In addition to symptom management the intervention focuses on caregiver's self care. For example there are recommendations regarding the benefits of relaxation techniques, spiritual care, exercise, and relationship building.* The COPE-HF is a problem based intervention involving problem solving training which includes: 1) three visits and six phone calls from a nurse interventionist to introduce and reinforce the method; 2) a manual, the *Home Care Guide for Advanced Heart Disease*¹³, which introduces the COPE-HF method with specific sections on symptom management to help HF caregivers strategize the management of those common symptoms that they face; and 3) symptom diaries to document their regular symptom assessments.

Setting and Sample

Ten caregivers, selected from the invention group (n=19) of a two group randomized clinical trial accrued at a large not-for profit hospice in the southeastern United States were contacted for interviews with two refusals and one caregiver who did not complete the interview for personal reasons. No new data resulted after seven interviews so no further interviews were conducted. The sample consisted of these seven HF caregivers. Institutional review board approval was obtained from both the hospice and a nearby university. To be included in the study the caregiver had to care for a patient over the age of 18 with a primary diagnosis of HF, be identified by the hospice as the primary caregiver, and provide at least

four hours of care per day. The caregiver had to consent to the study, have at least a sixth grade education, be able to read and understand English, and achieve a score of at least 8 on the Short Portable Mini-mental Status Exam.¹⁴ These inclusionary criteria were to insure that caregivers were able to give informed consent and then describe their caregiving experience.

Procedure

The caregiver's experience with the COPE-HF intervention was examined using a qualitative descriptive design. Qualitative data were obtained through a onetime semi-structured interview (Table 1) conducted within two weeks of completing the intervention. General questions related to the helpfulness of the intervention were used to begin the interview, with probes regarding the particular parts of the intervention (the caregiving manual, symptom diaries, the timing of the intervention sessions) used to explore more deeply the caregiver's perceptions. Each interview ended with a closing question asking if there was anything further that they would like to share about their experience that had not been asked. These interviews provided the data that was then analyzed to examine the caregiver's experience. Each interview lasted approximately 30 minutes to 1 hour. Field notes of each interview supplemented the audiotaped recording.

Data Analysis

Consistent with qualitative rigor, the analysis involved constant comparison of the interview transcriptions according to established approaches.^{15, 16} Codes were generated through a line-by line reading of the interviews by two investigators (HB, CZ). The coding structure was developed during a two part process. The first part analyzed the caregiver's responses to the intervention specifically, while in the second part there was a general thematic analysis of the overall narrative. This involved an iterative process with the codes becoming refined and denser as the analysis progressed. In the final analysis the two parts were brought back together with the thematic analysis informing the intervention analysis. Credibility and dependability were supported by the use of two independent reviewers, maintaining an audit trail and analytic memos, debriefing with the co-investigators, and discussions with colleagues knowledgeable about end stage HF and hospice caregivers.

Results

The sample consisted of seven out of 19 caregivers (37%) from the intervention group (Table 2). This sample was heterogeneous as to relationship to the patient with four spousal, two adult child (one daughter, one son), and one sibling caregiver. Six of the patients were male and one patient was female. Five of the caregivers were female and two were male. One of the dyads were same sex and the other six were male/female. The ages of the patients ranged from 78 – 94 years of age (average 87.8). The length of stay in the hospice ranged from four weeks to three years (average 44.7 weeks).

Caregiver Responses to the Intervention

Based on length of caregiving—The caregivers' response to the intervention was shaped by the length of time that they had been in the caregiver role. Those caregivers with a longer time of caregiving were less likely to report anything helpful in any part of the intervention. The caregiver who had been providing care for a parent for three years found that the caregiving manual was "not helpful". Another adult child caregiver with 16 months of caregiving experience stated, "we were already doing 95% of what the book had to say". However those caregivers with fewer weeks of caregiving, (four weeks) stated, "I read it a lot...I keep looking back at it.". Another caregiver (12 weeks) stated, "there were sections

that were very, very helpful to me. I skimmed all of it, but...there were a couple of sections that were a real big help.”

Based on their experience with hospice—From the thematic analysis a specific theme of *Response to the hospice experience, for good or bad* shaped the caregiver’s attitude toward the intervention. The most experienced caregiver had been acculturated by the hospice experience to expect her hospice nurse to manage any symptoms. When questioned specifically about how helpful the symptom management component of the COPE-HF intervention was, she stated, “I have hospice taking care of the symptoms. I don’t think about symptoms, I think about daily life...it takes a village”. Her experience of hospice symptom management had been very positive and she now was able to focus on her daily life. This trust in hospice’s support is one of the markers of a positive hospice experience and enabled the caregiver to shift her focus from the day to day physical care to the important existential care of supporting her father in finding meaning in his last days. Another caregiver with over a year of hospice experience, however, preferred to take control of the experience rather than cede it to professional caregivers and when questioned about how he learned to care for his mother’s symptoms stated, “no one ever said you need to do this, you need to do that – it was just stuff that we did to make things easier around here.” He then went on to state that everything that was presented to them in the intervention, they were already doing. Both of these longtime caregiver’s attitudes toward the invention were shaped by how they were responding to the experience – one caregiver responded by letting go of the symptom management while the other caregiver responded by maintaining control.

What worked, what didn’t work from the intervention—Each caregiver was asked to provide feedback on specific parts of the interventions (Table 3). The response to the *Home Care Guide for Advanced Heart Disease* was mixed as reported earlier. The longer that the caregiver had been in hospice the less likely they were to find the manual helpful. The symptom diaries were uniformly ignored. Only one caregiver reported keeping the symptom diary and this was for one day only. The home visits and phone calls from the interventionist, while appreciated and called “helpful” were not particularly meaningful. Few of the caregivers could report specific ways in which the interventionist’s visits were helpful. One caregiver, an older female, reported that at the second visit of the interventionist she “hadn’t completed as much as we thought maybe I needed” in reading the manual. *She then states that her macular degeneration makes it “hard for me to read” and admits that “I haven’t read the entire book”*. She went on to state, “they give you little things they want you to do in between and nobody knows what a caregiver’s going through, especially when you’re 86 years old...I’m weary.” This response to the intervention is particularly troubling as the intervention is meant to decrease caregiver stress and burden and yet in this caregiver appears to increase it with expected reading and documentation of symptoms.

Influence of the Intervention on Caregiving

Despite the mixed responses to the COPE-HF intervention in this group of caregivers, there were interesting effects of the intervention on the caregiver’s experience. Three of the caregiver’s reported that they felt that they were affirmed in what they were already doing for their loved one after reading the material. They reported that when they read the manual there was nothing new in it and they interpreted this to mean that they were doing what a professional would do. A second way in which caregivers used the intervention was for diagnostic purposes. One caregiver stated, “I got a lot of good out of this (the manual) coping with depression because even though I didn’t realize when I started reading this, cause I’d never been a person to get depressed....I just ran myself out.” This caregiver went on to discuss how he reached out for help once he recognized, from the information in the

manual, that what he was experiencing was depression. A third unusual way in which a caregiver used the knowledge gained from the COPE-HF intervention was to treat her own symptoms. She had chronic pain and stated that, “I read (the manual) I didn’t know when you took pain pills they constipated you....(the nurse) has given him (the patient) some pills for constipation and I took 1–3 at a time...and they work.” While it is not a part of the intervention to provide symptom management for the caregiver, in this case the caregiver was empowered by the symptom management information to take care of her own symptoms.

Caregiver Recommendations for Future Interventions

These caregivers, by virtue of their experience, are developing or have developed expertise as HF caregivers. Therefore we asked for their expert opinion on how to improve or strengthen this intervention. Each of them made specific recommendations. *Three of the caregivers suggested targeting specific groups, such as those identified by hospice or newer caregivers, instead of a general offering of the intervention to all caregivers.* Two of these caregivers suggested having the hospice staff identify caregivers “that need the help, a guide to help them in the right direction.” A caregiver who had been providing care for over a year had several insightful recommendations. He first recommended offering the intervention earlier in the caregiving trajectory, “Cause we were probably almost a year in before [this] study came out.” He then recommended discussing symptom management *for a multi-morbid setting, where the patient has more than one chronic illness*, when he stated, “She also has COPD, so – there’s a lot more involved than just heart failure with her”. Finally he made several suggestions related to the presentation of the material. He suggested printing up a pamphlet with information on what to expect related to symptom management with phone numbers of where to call for advice. He recommended having trained, non-medical people available as front line symptom management coaches when he stated that “A lot of people wouldn’t (call a nurse) ‘cause they don’t want to take up the nurse’s time and wait on them to call back.” This suggestion from an expert caregiver highlights that HF caregivers might find an “executive summary” of the intervention and lay support helpful in managing symptoms at home.

Discussion

This qualitative study, conducted in a group of novice to expert HF caregivers, was part of a larger mixed methods randomized clinical trial pilot testing the COPE-HF intervention for caregivers of HF patients in hospice care. The qualitative findings shed interesting light on the COPE-HF intervention. A companion publication¹⁷ reporting on the quantitative findings from this clinical trial found that there were no significant differences on any of the measured variables between the control group (usual care) and the experimental group (usual care + the COPE-HF intervention). What this qualitative study added to these findings was that in the novice caregivers there was an appreciation for and a utilization of the techniques and information provided. However, for the more seasoned caregivers there was an expression that the intervention was too little, too late. The sample size in the pilot study was too small to conduct a subgroup analysis so we were unable to assess this finding quantitatively.

However, the intriguing and vital feedback from caregivers on the COPE-HF supports the growing contention that we need to move palliative care and palliative care interventions upstream.¹⁸ This may be particularly true for the HF population with its uncertain end stage trajectory. The COPE-HF intervention, with its focus on symptom management is a palliative care intervention. However, implementing the COPE after HF caregiver’s have already been providing significant amounts of symptom management resulted in, at best, an ignoring of the information and at worst increased stress on this already burdened population

of caregivers. Upstreaming palliative care, defined as delivering palliative care with its focus on quality of life, optimal functioning, and symptom relief¹⁸, at an earlier stage in the trajectory of a life limiting condition such as HF is an idea that is gaining credence as greater numbers of both clinicians and patients are calling for more humane, patient-centered care.^{19, 20} The press of an aging population with its increased health care utilization and costs makes upstreaming palliative care a more critical issue than ever.²¹ What our study adds to this discussion is that delaying a palliative care intervention until the patient is clearly identified as “end of life”, as happens when they are admitted to hospice, results in caregivers having to develop their own systems of informal caregiving and symptom management, which may help to explain some of the symptom management failures common in HF. From our interviews we heard in the caregiver’s voice an ethos of “Where were you when we needed you two years ago?” This finding is supported by Bekelman and colleague’s¹¹ study where the caregivers also requested earlier support in HF. Targeting the primary care setting for research related to an earlier delivery of a symptom management intervention as well as infusing the principles of palliative care into the existing disease management framework are two ways in which palliative care can be realistically upstreamed.¹⁸

The caregivers’ recommendations for the future of the COPE-HF are the strength of this study. In particular, one caregiver had given thought to ways in which the COPE-HF could be improved moving forward. Caregivers are very busy people with multiple expectations and tasks related to both their role as caregiver but also to their other roles as employee, spouse, sibling, or other roles that they fulfill. Expecting them to read, or skim, a long manual may not be realistic. This caregiver recommended developing an “executive summary” of sorts, in pamphlet form covering the information in the manual which would enable the caregiver to access targeted information quickly. Linking that information to readily available coaches on the telephone was a further recommendation. His contention that this coach did not need to be a medical person was particularly interesting. Like current emergency medical systems (911) a trained lay person could assess the situation from a protocol, provide scripted directions, and triage more serious calls quickly to medical personnel, such as the nurse. Palliative care interventions of the future would do well to listen to this expert advice.

Future recommendations arising from this study are twofold. For HF clinicians the recommendation is to assess the caregiving situation at every patient visit, specifically, when there are changes in condition indicating disease progression.²² When patient self care begins to fail, indicated by emergent hospitalizations or caregiver reports of difficulty managing HF at home, this should be an indicator for referral to palliative care and a palliative care skill building intervention. With added supportive care, patients may be more safely maintained at home for a longer time period. For researchers it is recommended that first, there needs to be a better understanding of what the HF patient/caregiver dyad needs to increase the likelihood that they will be successful in self care and less likely to need hospitalization to maintain homeostasis. Granger and colleagues²³ found that HF patients were readily able to parrot back educational information related to HF but felt a severe lack of practical strategies for implementing them in real-world situations. Interventions moving forward should focus on this skill building in HF symptom management. The COPE-HF intervention provides such a skill building component. The second research recommendation relates to when such a skill building intervention would result in the greatest efficacy. From our experts, we heard the recommendation that earlier in the disease trajectory, rather than at the end is preferable, however, we don’t know how early is “early” or if it is possible to deliver it too early. This calls for additional research to determine the ideal time to provide such an intervention.

All studies suffer from some limitations, as does this current study. *In particular, with the small sample size we are not able to state that we reached saturation in the data despite hearing no further new information after these seven interviews.* There may have been equally valid voices that were not heard in the analysis. However, the heterogeneity in the sample increased the likelihood that we heard many different views in our interviews resulting in a rich description of the experience. A second limitation of the study relates to the sample, again. This sample was fully Caucasian. Our findings may or may not have applicability in other ethnic or racial groups and should be replicated in these groups to provide evidence for their validity. *A further limitation is that we don't know what, if any, palliative care services the caregivers and patients may have received before their admission to hospice. This may have resulted in prior symptom management education that made this intervention less valuable to them. However, because of the scarcity of outpatient palliative caregiver services, particularly for HF, this is perhaps a rare but not unreasonable limitation to keep in mind when reviewing our findings.*

Conclusion

In summary, this qualitative study has provided remarkable data on HF caregiver's responses to a hospice caregiving intervention and their recommendations for improving care and moving the science forward. In future studies this research team will use these findings to improve the care provided to this vital group.

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References

1. Roger VL, Go AS, Lloyd-Jones DM, et al. Heart Disease and Stroke Statistics—2012 Update. *Circulation*. 2011
2. Lloyd-Jones D, Adams R, Carnethon M, et al. Heart disease and stroke statistics--2009 update: a report from the American Heart Association Statistics Committee and Stroke Statistics Subcommittee. *Circulation*. 2009; 119:e21–181. [PubMed: 19075105]
3. NHPCO facts and figures: hospice care in American 2011. 2012. http://www.nhpco.org/files/public/Statistics_Research/2011_Facts_Figures.pdf
4. Dunbar SB, Clark PC, Quinn C, Gary RA, Kaslow NJ. Family influences on heart failure self-care and outcomes. *Journal of Cardiovascular Nursing*. 2008; 23:258–265. [PubMed: 18437068]
5. Riegel B, Moser DK, Anker SD, et al. State of the science: promoting self-care in persons with heart failure: a scientific statement from the American Heart Association. *Circulation*. 2009; 120:1141–1163. [PubMed: 19720935]
6. Lindenfeld J, Albert NM, Boehmer JP, et al. HFSA 2010 Comprehensive Heart Failure Practice Guideline. *Journal of cardiac failure*. 2010; 16:e1–194. [PubMed: 20610207]
7. Jessup M, Abraham WT, Casey DE, et al. 2009 focused update: ACCF/AHA Guidelines for the Diagnosis and Management of Heart Failure in Adults: a report of the American College of Cardiology Foundation/American Heart Association Task Force on Practice Guidelines: developed in collaboration with the International Society for Heart and Lung Transplantation. *Circulation*. 2009; 119:1977–2016. [PubMed: 19324967]
8. Lorenz KA, Lynn J, Dy SM, et al. Evidence for Improving Palliative Care at the End of Life: A Systematic Review. *Annals of internal medicine*. 2008; 148:147–159. [PubMed: 18195339]
9. Hupcey JE, Penrod J, Fenstermacher K. Review Article: A Model of Palliative Care for Heart Failure. *American Journal of Hospice and Palliative Medicine*. 2009; 26:399–404. [PubMed: 19357374]

10. Hupcey JE, Fenstermacher K, Kitko L, Fogg J. Palliative Needs of Spousal Caregivers of Patients with Heart Failure Followed at Specialized Heart Failure Centers. *J Hosp Palliat Nurs*. 2011; 13:142–150. [PubMed: 21818178]
11. Bekelman DB, Nowels CT, Retrum JH, et al. Giving voice to patients' and family caregivers' needs in chronic heart failure: implications for palliative care programs. *Journal of palliative medicine*. 2011; 14:1317–1324. [PubMed: 22107107]
12. Boyd KJ, Worth A, Kendall M, et al. Making sure services deliver for people with advanced heart failure: a longitudinal qualitative study of patients, family carers, and health professionals. *Palliat Med*. 2009; 23:767–776. [PubMed: 19926645]
13. McMillan, SC.; Buck, H.; Dunbar, SB. The Home Care Guide for Advanced Heart Disease (Cope-HF). 2007. unpublished
14. Pfeiffer E. A short portable mental status questionnaire for the assessment of organic brain deficit in elderly patients. *Journal of the American Geriatrics Society*. 1975; 23:433–441. [PubMed: 1159263]
15. Hsieh HF, Shannon SE. Three approaches to qualitative content analysis. *Qual Health Res*. 2005; 15:1277–1288. [PubMed: 16204405]
16. Sandelowski M. Whatever happened to qualitative description? *Research in nursing & health*. 2000; 23:334–340. [PubMed: 10940958]
17. McMillan S, Small BJ, Haley WE, Zambroski C, Buck HG. The COPE Intervention for Caregivers of Patients with Heart Failure: An Adapted Intervention. in review.
18. Buck HG, Zambroski CH. Upstreaming palliative care for patients with heart failure. *The Journal of cardiovascular nursing*. 2012; 27:147–153. [PubMed: 22210148]
19. Tinetti ME, FTR, Boyd CM. Designing health care for the most common chronic condition—multimorbidity. *JAMA: The Journal of the American Medical Association*. 2012; 307:2493–2494. [PubMed: 22797447]
20. National Consensus Project for Quality Palliative Care. Clinical practice guidelines for quality palliative care. 22009. <http://www.nationalconsensusproject.org>
21. Jaarsma T, Beattie JM, Ryder M, et al. Palliative care in heart failure: a position statement from the palliative care workshop of the Heart Failure Association of the European Society of Cardiology. *European Journal of Heart Failure*. 2009; 11:433–443. [PubMed: 19386813]
22. Goodlin SJ. Palliative care for end-stage heart failure. *Curr Heart Fail Rep*. 2005; 2:155–160. [PubMed: 16138952]
23. Granger BB, Sandelowski M, Tahshjain H, Swedberg K, Ekman I. A Qualitative Descriptive Study of the Work of Adherence to a Chronic Heart Failure Regimen: Patient and Physician Perspectives. *Journal of Cardiovascular Nursing*. 2009

Table 1

Interview guide

Opening question	I want to get your opinion of the [COPE-HF] –was it helpful, what led you to participate in the study?
Prompts	What did you find, specifically, that was helpful in the [manual, nurse interventionist visits, symptom diary]? Could anything be changed or improved? What do you think is missing? Are there certain things about being a caregiver that we didn't include? Did it give you strategies that were new to you? Did you end up using the [manual, symptom diaries] at all between visits? Can you give me some examples [of using the manual, symptom diaries]? Did participating in the study influence your care of your [loved one] in any way?
Concluding questions	Is there anything else that you need to tell me? Is there anything you can think of that we should know to help other caregivers in the future? Anything else you want me to know?

Table 2

Demographic Characteristics (n=7)

	N (%)	Mean (SD)
Age		69.2 (15.1)
Years of School		13.0 (1.7)
Years since patient diagnosis of HF		11.4 (8.98)
		range .08–25.0
Gender		
Male	2 (29%)	
Female	5 (71%)	
Marital status		
Married	4 (57%)	
Widowed	1 (14%)	
Divorced	2 (29%)	
Relationship to patient		
Wife	4 (57%)	
Daughter	1 (14%)	
Son	1 (14%)	
Brother	1 (14%)	
Ethnicity		
Caucasian	7 (100%)	
Living arrangement		
Live with spouse/partner	4 (57%)	
Live alone	1 (14%)	
Other	2 (29%)	
Household income		
Less than 10,000	0	
10,000–19,999	2 (29%)	
20,000–29,999	3 (43%)	
30,000–49,999	0	
50,000–69,999	2 (29%)	
70,000–99,999	0	
Caregiver working		
No	5 (71%)	
Yes	1 (14%)	
Missing	1 (14%)	

Table 3

Caregiver's Reflections on a Palliative Care Intervention

	Manual	Interventionist Visits	Symptom Diaries	Recommendations for Future Interventions
Positive Caregiver Comments	"I wish that my kids would read it" "I read it a lot" "It explains everything pretty good....It's down to earth." "I went through it front to back"	Looked forward to the visits – remembered the interventionist by name "We became friends"		"offer it (the COPE-HF) to people where I think the nurse might tell you" "the program for a younger person would be fantastic" " get information out there faster." Develop a pamphlet – this is what you can expect, this is the way that you can deal with it, have numbers to call, have someone to talk to (doesn't want to "take up the nurses time" or "wait on them to call back"
Negative Caregiver Comments	"not helpful" "hard to read with macular degeneration" "wouldn't change anything I am doing"	Felt "rushed" at subsequent visits after the first visit when the reading wasn't completed Agreed that visits were helpful but couldn't provide specifics	Four out of seven caregivers responded that didn't use the diary at all. The other three caregivers attempted to use it but then didn't. "I'm not keeping a log like asking him every day, 2, 3 times a day..." "I started out doing it... and he said, "I'm not in any pain!... That wasn't helping me."	