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Validation and preliminary data from a health-related quality of life questionnaire for owners of dogs with cardiac disease

Lisa M. Freeman1 | John E. Rush1 | Melissa A. Clark2 | Barret J. Bulmer3

Abstract
Background: Cardiac disease in dogs impacts the quality of life (QoL) of their owners, but owners' QoL has not been comprehensively assessed in this population. Objectives: To develop, validate, and provide preliminary data from a health-related QoL (hrQoL) questionnaire for owners of dogs with cardiac disease. Subjects: A total of 141 owners of dogs with cardiac disease were studied. Methods: An owner hrQoL (O-hrQoL) questionnaire containing 20 items related to areas of a person's life that could be impacted by caring for a dog with cardiac disease was developed and administered to owners of dogs with cardiac disease. The highest possible total score was 100, with higher scores indicating a worse hrQoL. Readability, internal consistency, face and construct validity, and item-total correlations were assessed. Results: Median O-hrQoL score was 35 (range, 0-87). The questionnaire had good internal consistency (Cronbach's α = 0.933), construct validity (Spearman's τ = 0.30-0.43; Kendall's τ = 0.30-0.43; all P < .001), and item-total correlation (Spearman's r = 0.38-0.53; Kendall's τ = 0.34-0.66; all P < .001). Fifty percent of owners indicated a negative effect of dogs' cardiac disease on their own QoL, but all owners responded that caring for their dogs either had strengthened (n = 76; 53.9%) or had no effect on their relationship with their dog (n = 65; 46.1%). Conclusions and clinical importance: The O-hrQoL questionnaire had good validity, and results suggest that owners' QoL is significantly impacted by caring for dogs with cardiac disease. Additional research on effective approaches to minimizing the negative effects of a dog's cardiac disease on the owner is warranted.

Keywords: cardiac disease, dilated cardiomyopathy, heart failure, myxomatous mitral valve disease

1 | INTRODUCTION

Health-related quality of life (hrQoL) instruments can provide useful information for veterinarians about an animal's clinical signs and efficacy of treatment, as well as serving as an endpoint for clinical trials. While there are a number of generic hrQoL instruments validated for
2 | MATERIALS AND METHODS

The study was reviewed by the university’s Institutional Review Board and designated exempt (IRB # 1710037). Therefore, owners did not sign an informed consent form but were informed that participation was voluntary and that answers were confidential.

2.1 | Participants

Owners of all dogs with degenerative mitral valve disease (DMVD) or dilated cardiomyopathy (DCM) visiting the cardiology services at either of the university’s 2 veterinary hospitals (1 veterinary teaching hospital and 1 specialty practice) with cardiology services between 28 December 2017 and 12 October 2018 were eligible for the study. Owners were invited by a veterinarian, veterinary technician, or veterinary student to complete the questionnaire while in the waiting area before an appointment with the cardiology service or while waiting for the echocardiogram to be completed. Owners were not compensated for their participation.

The severity of each dog’s heart disease at the time of questionnaire completion was categorized using the American College of Veterinary Internal Medicine (ACVIM) classification.21 The number of cardiac medications being administered to each dog was also recorded.

2.2 | Measures

2.2.1 | Owners’ health-related quality of life

Based on a review of the human and veterinary literature, interviews with owners of dogs with cardiac disease, and the authors’ clinical experience, a list of items related to areas of a person’s life that could be impacted by caring for a dog with cardiac disease was generated. These included items on the effect of the dog’s illness on the owner’s life, including social life, burden of cost of care, worry, and sleep disruption. From this information, 25 items were identified to assess an owner’s perception of the degree to which the dog’s cardiac disease affected the owner’s lifestyle during the preceding 30 days (eg, by affecting their work schedule or by causing problems because of excessive urination; Appendix). For each item, the owner was asked to rate how much a given part of his or her life was affected by the dog’s dyspnea. Another limitation of the previous study was that owner demographics were not collected so their role could not be evaluated. In addition, construct validity could not be assessed because an independent question on owner-reported hrQoL was not included. Finally, the data for that study were collected before the launch of pimobendan and owner hrQoL could be different with widespread use of this medication. Therefore, the objective of our study was to develop an owner hrQoL instrument for owners of dogs with cardiac disease; assess its readability, internal consistency, face and construct validity, and item-total correlations; and provide preliminary data from owners of dogs with cardiac disease.
Word (Word 2000, Microsoft Corp, Bellevue, Washington), that is designed to estimate the grade level needed to comprehend written text. The O-hrQoL questionnaire was assessed to be written at a level of 6.3, meaning that owners with a 6th-grade reading level or higher should be able to comprehend the questionnaire and that it would be easy to read by 75% of readers at that level.

2.2.2 | Owner QoL

To assess how the hrQoL assessment did or did not differ from the owners’ overall QoL, 2 additional questions were included about the owners’ overall QoL: “How would you rate your overall quality of life?” and “What impact has your dog’s heart disease had on your quality of life?”

2.2.3 | Distress

To determine whether owners’ hrQoL differed from other measures of well-being, 1 question about general distress was asked: “How often do your worries about caring for your dog overwhelm you?”

2.2.4 | Additional questions

While not part of the validation of the O-hrQoL instrument, owners were also asked, “How has caring for your dog’s heart disease changed your relationship with him or her?” Finally, a space for additional comments was also provided.

2.3 | Analysis

Item reduction was performed to identify the underlying components characterizing O-hrQoL using the most efficient subset of items as possible. From the initial 25-item instrument, item reduction was performed by conducting principal components analysis with varimax rotation. Items with factor loadings >0.5 within a single factor were considered related and combined into a subscale. Cronbach's $\alpha$ reliability was computed for each subscale. After computing an initial Cronbach's $\alpha$ for each subscale, items were assessed to determine the effect of deleting items from the subscale to improve efficiency. An item was deleted if doing so did not drop the overall Cronbach's $\alpha$ for the subscale below 0.90. Clinical perspective was combined with a review of each item’s performance in the above analyses. An abbreviated 20-item instrument was generated (O-hrQoL questionnaire), which was used for all subsequent analyses.

Internal consistency of the O-hrQoL questionnaire was assessed by calculating Cronbach’s $\alpha$. Internal consistency was considered excellent when Cronbach’s $\alpha \geq 0.90$, good when Cronbach’s $\alpha$ was $0.80$, and acceptable when Cronbach’s $\alpha$ was $0.70$. Owners’ hrQoL scores were compared between owner sex and dog disease groups with Mann-Whitney $U$ tests, while scores were compared among multiple groups (eg, owner age groups) using Kruskal-Wallis tests. Owners’ hrQoL scores were compared with the number of cardiac medications being administered to the dog using Spearman’s rank correlation and Kendall’s $\tau$ analysis. Construct validity, measured with 3 different variables (ie, total O-hrQoL score versus the 2 overall owner QoL questions and total O-hrQoL score versus ACVIM classification), was assessed using Spearman’s rank correlation and Kendall’s $\tau$ analysis, with the hypothesis that the total O-hrQoL score would be significantly positively correlated with both overall O-QoL questions and with ACVIM classification. Item-total correlation was assessed using Spearman’s rank correlation analyses to determine if any individual item had limited correlation with the total owner hrQoL score. Cohen's $d$ effect size was interpreted as small ($\geq 0.2$), medium ($\geq 0.5$), or large ($\geq 0.8$). All quantitative analyses were performed using commercial statistical software (Systat 13, Systat, Inc., San Jose, California, and SPSS 24.0, IBM Corp., Armonk, New York), with $P < .05$ considered statistically significant. Finally, qualitative data from additional comments provided by owners were categorized according to similar themes.

3 | RESULTS

The O-hrQoL questionnaire was administered to 141 owners of dogs with cardiac disease: 83 at hospital 1 and 58 at hospital 2. There were no significant differences in the results between the 2 hospitals, so data were combined for all subsequent analyses. The population included 85 male dogs (74 castrated) and 56 female dogs (53 spayed). Mean age of the dogs was $11.0 \pm 3.0$ years, and underlying diseases included DMVD ($n = 121$) and DCM ($n = 20$). The ACVIM classifications included B1 ($n = 6$), B2 ($n = 52$), C ($n = 71$), and D ($n = 12$). The time since diagnosis of heart disease ranged from 8 to 2632 days (median = 450 days). The median number of cardiac medications being administered was 3 (range, 0-8). Owner age categories included 18 to 30 years ($n = 3$), 31 to 45 years ($n = 36$), 46 to 60 years ($n = 52$), and >60 years ($n = 47$), with 3 owners declining to respond to this question. One hundred fourteen owners were female, 25 were male, and 2 declined to respond to this question.

The initial 25-item instrument was reduced to a 20-item abbreviated instrument through principal components analysis. The 5 items that were removed are listed in Table 1. All further analyses are for the final 20-item instrument (O-hrQoL questionnaire; Appendix). Cronbach’s $\alpha$, which measures internal consistency, for the 20-item O-hrQoL questionnaire was 0.933, indicating excellent internal consistency. The median total O-hrQoL score was 35 (range, 0-87, with a total possible score of 100), where higher scores represented worse O-hrQoL. Median overall QoL of the owner was 2 (range, 1-5, with 5 indicating worse QoL). For the impact of the dogs' cardiac disease on the owners’ overall QoL, 11 owners (7.8%) responded that the dogs' cardiac disease had a positive effect on the owners’ QoL, 58 (41.1%) owners indicated no effect, and 70 (49.7%) owners indicated a negative effect (with 2 owners not responding to this item). Owner hrQoL score was not significantly different among owners of different age groups (18-30 years: median = 49
TABLE 1  Item-total correlation comparing individual items from the 20-item owners' health-related quality of life (O-hrQoL) questionnaire for owners of dogs with heart disease to the total O-hrQoL score

| Item                                                                 | Spearman's r | Kendall's τ | P value |
|----------------------------------------------------------------------|--------------|-------------|---------|
| How much did your dog's heart disease negatively affect your quality of life during the last 30 days by: |              |             |         |
| 1. Disrupting your sleep habits (eg, because your dog is restless, coughing, or needs to go out) | 0.62         | 0.49        | <.001   |
| 2. Making you reluctant to leave home for social activities or vacations | 0.72         | 0.56        | <.001   |
| 3. Causing problems due to your dog's increased urination, such as having accidents in your home | 0.53         | 0.43        | <.001   |
| 4. Causing you to change your plans or avoid making plans | 0.71         | 0.55        | <.001   |
| 5. Affecting your work schedule | 0.69         | 0.56        | <.001   |
| 6. Making it hard to give medicines to your dog | 0.44         | 0.34        | <.001   |
| 7. Making it hard to give medicines at the recommended times or keeping track of medicines | 0.53         | 0.42        | <.001   |
| 8. Creating high costs for medical care | 0.57         | 0.45        | <.001   |
| 9. Having to make decisions about when to give more or less of a medicine (such as furosemide) depending on your dog's breathing | 0.58         | 0.46        | <.001   |
| 10. Making you feel overwhelmed | 0.79         | 0.66        | <.001   |
| 11. Making you feel stressed | 0.74         | 0.60        | <.001   |
| 12. Making you feel physically tired | 0.79         | 0.65        | <.001   |
| 13. Making you feel sad | 0.77         | 0.61        | <.001   |
| 14. Making you feel guilty that you cannot do enough to manage your dog's heart disease | 0.75         | 0.60        | <.001   |
| 15. Making you worry whether your dog is having difficulty breathing | 0.77         | 0.61        | <.001   |
| 16. Making you anxious about what your dog will experience with recommended testing and recheck exams | 0.61         | 0.46        | <.001   |
| 17. Making you worry that your dog cannot or should not exercise | 0.69         | 0.54        | <.001   |
| 18. Making you concerned that you cannot or should not feed foods that your dog enjoys | 0.60         | 0.48        | <.001   |
| 19. Making you worry that your dog could die suddenly | 0.66         | 0.52        | <.001   |
| 20. Making you worry that you will have to decide on the right time to put your dog to sleep | 0.71         | 0.56        | <.001   |

Items that were removed after principal components analysis were:

- Affecting the amount of time you spend on the TV or computer
- Affecting the foods that you eat
- Having to make decisions about the best diet for your dog
- Making you worry about your dog's overall condition
- Making you worry that your dog might be in pain

There was a significant positive correlation between O-hrQoL score and ACVIM classification (Spearman's r = 0.53; Kendall's τ = 0.43, both P < .001). Each individual item in the item-total correlation, in which individual items were compared with the total O-hrQoL score, was significant (all P < .001), but the r value was lowest for the item about difficulty giving medications (Spearman's r = 0.44; Kendall's τ = 0.34) and highest for the items on making the owner feel physically tired (Spearman's r = 0.79) and making the owner feel overwhelmed (Spearman's r = 0.79; Kendall's τ = 0.66; Table 1).
responding that their worries overwhelmed them sometimes and 20 owners (14.2%) responding that their worries overwhelmed them often or always. Examples of additional open-ended comments provided by participants about how the dogs' condition impacted the owners' lives included: "A low stress level that never goes away," "Lack of sleep, exercise, and eating. All I do is research how to fix his disease and pray it will reverse," and "The hardest long-term thing I have ever done. I would not wish this on anyone." Nonetheless, owners responded that caring for their dogs' heart disease had either strengthened their relationship with the dog (n = 76; 53.9%) or had no effect on the relationship (n = 65; 46.1%). In fact, the most common additional comments were about how their dogs' heart disease made them love/appreciate them more ("Every day she has with us is a gift" and "Makes me enjoy/appreciate time with him more"). The second most common theme of the additional comments was concerns about the dog's death or unknown future for the dog (eg, "I fear for the inevitable," "The one thing that worries me is losing him," and "The worst part is the unknown.")

4 | DISCUSSION

The results of this study demonstrated that this O-hrQoL questionnaire had good face and construct validity, readability, and internal consistency. Most comments from the open-ended questions served to reinforce the importance and impact of the various items on the O-hrQoL. In addition, all individual items in the final 20-item instrument were significantly associated with the total O-hrQoL score, although the correlation coefficients ranged from 0.44 to 0.79. However, even for the item with the lowest correlation coefficient (ie, difficulty giving medications [r = 0.44]), some owners gave a high score, indicating a large effect of this issue on their QoL. Therefore, it appeared that all 20 items in the final instrument were useful to include in the questionnaire. After gathering additional feedback from caregivers, we propose revised wording for the item on difficulty giving medications (question 6; Appendix) so that it is clearer that this item refers to the physical act of administering a medication.

From the preliminary testing in dogs with cardiac disease, there was a wide range in the total O-hrQoL scores (0-87). The total O-hrQoL score was significantly associated with severity of disease and number of cardiac medications, but not with age or sex of the owner or with the dogs' underlying disease. In people, caregiver physical and mental health can be affected by both caregiver factors, such as age, social support, and income, as well as patient factors, such as severity of disease, symptom burden, and mental health. Results from 1 study in cats with cardiac disease showed that many owners had moderate to extreme difficulty giving medications to their cats and that many perceived administering medications had a negative effect on their cats' QoL. Studies in people with heart disease have also emphasized the fact that some owners will be markedly affected by the care of their dogs with cardiac disease. Assessing the impact that the dogs' cardiac disease is having on the owners' QoL might be important to address areas of difficulty or distress (eg, disruption of sleep habits, difficulty giving medications, dietary decisions/restriictions, and cost). Providing individual or group support facilitated by a mental health professional, such as a licensed social worker, psychologist, or professional counselor might help to address the high caregiver burden found in some owners.

When asked how the dogs' cardiac disease affected their own QoL, many of the owners (50%) responded that cardiac disease negatively affected their own QoL and additional comments provided by the owners often reflected this (eg, "My quality of life is based on my dog's quality of life."). However, none of the participants said that caring for the dogs weakened their relationship. In fact, 54% said it strengthened relationship (and 46% said no effect). This information might be useful to address in future studies or to better prepare owners regarding the care of dogs with cardiac disease.

While the median score for distress was only 2 (ie, worries about caring for their dogs rarely overwhelsm them), approximately 50% of owners reported that their worries about caring for their dogs overwhelmed them sometimes, often, or always (with 14% responding that their worries overwhelmed them often or always). These results suggest that this is something clinicians should consider when communicating with owners. If owners are having a high degree of distress because of caring for their dogs with cardiac disease, providing information that might reduce the level of distress or referring the owner to a mental health professional might be helpful.

The current O-hrQoL questionnaire included 2 items that addressed the dogs' death (ie, "making you worry that your dog could die suddenly" and "making you worry that you will have to decide on the right time to put your dog to sleep"), but additional comments provided by participants commonly addressed their dogs' death or unknown future (eg, "I fear for the inevitable," "The one thing that worries me is losing him," and "The worst part is the unknown"). Although these are only preliminary data, this suggests owners of dogs with cardiac disease might benefit from more patient-centered discussions about end-of-life care. Studies in human heart failure patients have shown that key intervention priorities include not only education on disease specifics, but also recommendations to help enhance QoL and cope with heart failure, and discussions of future outlook and care decisions. Studies of veterinarians using undisclosed standardized clients to assess patient-centered communication during discussions about euthanasia showed that veterinarians frequently discussed the patient's disease, but there was "lack of exploration of client feelings, ideas, expectations, and the effect of the illness on the animal's function" (even though the veterinarians thought they addressed these components).

There are a number of limitations of the current study that are important to address. One of the major limitations was that validated instruments were not used as part of the determination of construct validity (ie, the 2 questions on overall owner QoL) or for the additional question on owner distress. Using validated instruments were considered during design of the study but the long length of the instruments and the additional time they would take for owners to complete was of concern. Therefore, we elected to keep the instrument and number of items as short as possible. Additional construct validation against full-length, validated instruments would be useful. Participants were limited
to owners of dogs with DVMD or DCM. This could limit the generalizability of the instrument. However, since these are the 2 most common canine cardiac diseases, it should be applicable to most dogs with cardiac disease. Further research is needed to determine whether the instrument is also applicable for caregivers of dogs with other forms of cardiac disease. This instrument also was developed specifically for dogs. Given some differences found in previous studies of hrQoL in dogs versus cats,7,8 we believe that having separate instruments for the 2 species is important. Studies to evaluate the effect of feline cardiac disease on owner hrQoL are warranted. Another limitation is that only 2 hospitals in 1 geographic region were included although they represented 1 teaching hospital and 1 referral practice. Additional research in other types of veterinary hospitals and other regions would help to ensure the results are generalizable to other regions. The study population only included owners who came to a specialty hospital and excluded owners of dogs that had already died. Including these other populations may have provided different results. Similarly, very few owners were in the 18 to 30 year age group and a large proportion of them were female, so further validation studies that include younger age groups and with men would be useful. Some additional adjustment of wording of the items may be beneficial. For example, it is unclear whether the wording of some of the items could have led the respondents toward a more negative response. We did not evaluate test-retest reliability in our study so this would be important to do in future studies. The current results provide preliminary data on the QoL for owners of dogs with cardiac disease, but further research is needed. Finally, no questions about the relationship between the dog and the owner were included. Assessment of how long the pet was owned and degree of attachment (eg, Companion Animal Bonding Scale)39 could provide valuable information to help advance research on hrQoL and caregiver burden in owners of dogs with cardiac disease. Although much additional research is needed to better understand these issues, hrQoL questionnaires for both dogs and owners might help to identify areas for discussion regarding medications, diet, home care, costs, and end-of-life care to optimize the care of dogs with cardiac disease.

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CONFLICT OF INTEREST DECLARATION
Authors declare no conflict of interest.

OFF-LABEL ANTIMICROBIAL DECLARATION
Authors declare no off-label use of antimicrobials.

INSTITUTIONAL ANIMAL CARE AND USE COMMITTEE (IACUC) OR OTHER APPROVAL DECLARATION
Authors declare no IACUC or other approval was needed.

HUMAN ETHICS APPROVAL DECLARATION
Authors declare human ethics approval was not needed for our study.

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APPENDIX A

The following questions refer to the effects that your dog’s heart disease has had on your quality of life in the last 30 days. If you believe a question does not apply to you or it is not related to your dog’s heart disease, then circle 0 (Not at all) and go on to the next item. If the question does apply to you, then circle the number rating how much it has impacted your life. If there is any question that you are uncomfortable answering, just leave it blank (this will not affect your dog’s care in any way).

How much did your dog’s heart disease negatively affect your quality of life during the last 30 days by (please circle one answer for each question):

| Question                                                                 | Not at all | Very little | Very much |
|--------------------------------------------------------------------------|------------|-------------|-----------|
| 1. Disrupting your sleep habits (for example, because your dog is restless, coughing, or needs to go out). | 0          | 1           | 2         |
| 2. Making you reluctant to leave home for social activities or vacations. | 0          | 1           | 2         |
| 3. Causing problems due to your dog’s increased urination, such as having accidents in your home. | 0          | 1           | 2         |
| 4. Causing you to change your plans or avoid making plans.               | 0          | 1           | 2         |
| 5. Affecting your work schedule.                                        | 0          | 1           | 2         |
| 6. Making it hard to give medicines to your dog.                         | 0          | 1           | 2         |
| 7. Making it hard to give medicines at the recommended times or keeping track of medicines. | 0          | 1           | 2         |
| 8. Creating high costs for medical care.                                | 0          | 1           | 2         |
| 9. Having to make decisions about when to give more or less of a medicine (such as furosemide) depending on your dog’s breathing. | 0          | 1           | 2         |
| 10. Making you feel overwhelmed.                                        | 0          | 1           | 2         |
| 11. Making you feel stressed.                                           | 0          | 1           | 2         |
| 12. Making you feel physically tired.                                   | 0          | 1           | 2         |
| 13. Making you feel sad.                                                | 0          | 1           | 2         |
| 14. Making you feel guilty that you cannot do enough to manage your dog’s heart disease. | 0          | 1           | 2         |
| 15. Making you worry whether your dog is having difficulty breathing.    | 0          | 1           | 2         |
| 16. Making you anxious about what your dog will experience with recommended testing and recheck exams. | 0          | 1           | 2         |
| 17. Making you worry that your dog cannot or should not exercise.       | 0          | 1           | 2         |
| 18. Making you concerned that you cannot or should not feed foods that your dog enjoys. | 0          | 1           | 2         |
| 19. Making you worry that your dog could die suddenly.                  | 0          | 1           | 2         |
| 20. Making you worry that you will have to decide on the right time to put your dog to sleep. | 0          | 1           | 2         |

**General questions (please circle one answer for each question).**

| Question                                                                 | Excellent 1 | Very Good 2 | Good 3 | Fair 4 | Poor 5 |
|--------------------------------------------------------------------------|-------------|-------------|--------|--------|--------|
| 1. How would you rate your overall quality of life?                       |             |             |        |        |        |
| 2. What impact has your dog’s heart disease had on your quality of life?  | Positive effect 1 | No effect 2 |        |        |        |
| 3. How has caring for your dog’s heart disease changed your relationship with him or her? | It’s made our relationship stronger 1 | No change 2 |        |        |        |
| 4. How often do your worries about caring for your dog overwhelm you?     | Never 1 | Rarely 2 | Sometimes 3 | Often 4 | Always 5 |

Please provide any additional comments about the effect of your dog’s heart disease on you: __________________________________________________________
____________________________________________________________________
____________________________________________________________________