Development of a questionnaire assessing health-related quality-of-life in dogs and cats with cancer

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Abstract

Health-related quality-of-life (HRQoL) has been studied extensively in human medicine. There is currently no standard HRQoL evaluation for veterinary oncology patients. The aim of this study was to assess the practicality, usefulness and robustness, from a pet owner and clinician perspective, of a questionnaire for the assessment of HRQoL in canine and feline cancer patients. A HRQoL assessment entitled 'Cancer Treatment Form' and two questionnaires entitled 'Owner Minitest' and 'Clinician Minitest' were designed. The first and second were completed by owners of patients presenting to a veterinary oncology referral service and the third by attending clinicians. The 'Cancer Treatment Form' was well received by owners and clinicians and provided a valuable assessment of HRQoL with 98% (82/84) of owners reporting an accurate reflection of their pet's quality-of-life. Following this, minor improvements to the form could be suggested prior to regular use in evaluation of clinical oncology patients.

Keywords chemotherapy, oncology,

radiation therapy, small animal, supportive care, surgical oncology

Introduction

The incidence of cancer in veterinary patients is increasing as improved health care lengthens the lifespan of pets. The availability of intensive therapeutic modalities and increased client willingness to pursue treatment has led to improved survival times in veterinary cancer patients. However, with more intensive therapy, the risk of associated morbidity has also increased and balancing quality-of-life with quantity-of-life has become an important role for the veterinary oncologist.

The concept of health-related quality-of-life (HRQoL) in human medicine has been studied extensively over the last 30 years. Assessing HRQoL in veterinary patients has, nevertheless, received limited attention at least in part because of the difficulties associated with evaluating this parameter in a different species. Preliminary tools designed to prospectively measure HRQoL in patients with

pain secondary to cancer,² cardiac disease,³ chronic pain,⁴ spinal cord injuries⁵ and general screening of healthy and/or sick dogs^{6–9} have been reported in recent years. To our knowledge, there is currently no accepted HRQoL scale used in veterinary oncology.

HRQoL has been variably defined in human oncology and several HRQoL measures have been developed. 10-14 Broadly, HRQoL in veterinary oncology describes the effect of cancer and its treatment on body function and well-being. Monitoring HRQoL has many potential benefits. It can improve continuity between clinicians and treatment centres, aid decision making in cancers with a poor prognosis or where treatment arms have small survival differences, provide prognostic information and evaluate the impact of novel therapies in clinical trials. 15,16 HRQoL evaluation has also been shown to improve doctor-patient interaction in human medicine and may similarly

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improve doctor-client communication in veterinary medicine. 17,18 In a recent study, 86% of owners of veterinary patients with heart disease indicated they would trade their pet's longevity for quality-oflife. 19 Reduced quality-of-life has also been reported to influence the decision for euthanasia in a study of cats with cancer.²⁰ The importance of HROoL assessment and its impact on decision making suggests a widely accepted scale for use in veterinary oncology would be advantageous.

The aim of this study was to assess the practicality, usefulness and robustness from a pet owner and clinician perspective of a questionnaire developed for the assessment of HRQoL in canine and feline cancer patients.

Materials and methods

Three questionnaires were designed and presented to a sample of the target population. Owners of cats and dogs diagnosed with cancer and referred to the Royal (Dick) School of Veterinary Studies Oncology Service from August to November 2009 were administered two questionnaires prior to their initial or revisit consultation. The first was a HROoL questionnaire entitled 'Cancer Treatment Form' (Fig. 1) and the second, an evaluation of this form, entitled 'Owner Minitest' (Fig. 2). The tests were designed to be self-administered and assistance from a qualified veterinary nurse was also provided as required. Signalment and aetiological diagnosis were obtained on all animals that met inclusion criteria.

The 'Cancer Treatment Form' was designed for completion by the owners of pets receiving treatment for cancer. The questions included were developed in 2009 to accompany the cancer drug Palladia[™].21 In developing the questions nine board-certified veterinary oncologists in the United States were asked to detail the most important considerations in assessing quality-of-life in dogs. They were shown a list of terms drawn from previously published surveys and responded with a list of 18 life qualities. The 10 qualities that were suggested by three or more oncologists were chosen as either a domain heading or a question within a domain. In designing the form, each domain was assigned three questions phrased either positively or negatively and scored on a scale of 1-5 indicating increasing agreement with the statement. The wording of the questions was alternated to avoid automatic responses and to encourage thoughtful consideration. Questions were phrased with simple terminology frequently used by owners. In all, the 'Cancer Treatment Form' consisted of 23 multiplechoice questions designed to assess the physical and psychological aspects of health. These questions were divided into domains entitled happiness, mental status, pain, appetite, hygiene, water intake (hydration), mobility and general health. The final question was a Visual Assessment Scale (VAS) evaluation of global health ranging from 'very poor' to 'excellent' and providing an assessment of HRQoL on a continuum. Health was assessed as it was at the time the survey was completed.

The 'Owner Minitest' form consisted of eight questions. The first required owners to state whether their pet was visiting as an initial consultation or follow-up visit. The following five questions were multiple-choice and designed to evaluate the completeness, length, ease, practicality and accuracy of the 'Cancer Treatment Form'. The seventh was a 'yes/no' question to determine whether the 'Cancer Treatment Form' made the owners feel more involved in their pet's treatment and the final question allowed owners to suggest changes.

The 'Cancer Treatment Form' and 'Owner Minitest' were then reviewed by a clinician and the 'Clinician Minitest' (Fig. 3) completed. This consisted of two multiple-choice and four 'yes/no' questions evaluating the usefulness and accuracy of the 'Cancer Treatment Form'. The seventh question allowed for suggestions for changes to the 'Cancer Treatment Form'. The 'Owner Minitest' and 'Clinician Minitest' were designed for this study.

Results

Sixty-six dogs and 12 cats were included in the study. As some patients had follow-up appointments, a total of 116 questionnaires were collected. Ninetynine of the questionnaires were from the owners of dogs and 17 from the owners of cats. Included dogs ranged in age from 0.5 to 13 years (mean 8 years). Included cats ranged in age from 2 to 14 years (mean 9 years). Of the dogs included, 42% (28/66) were

RVEY DATE	PET OWNER					
ME OF PERSON COMPLETING SURVEY	PETOWNER					
T NAME WEIGH	т	SPECIES				_
STRUCTIONS: Please indicate your ass providing your op EXAMPLE:	essment by circling the inion on your pet's CUI I 2	RRENT healt			each q	uestio
V000001-00000-1-000	_	Disagree	N	eutral	Ag	gree
HAPPINESS						
My pet wants to play		1	2	3	4	5
My pet responds to my presence		1	2	3	4	5
My pet enjoys life		1	2	3	4	5
MENTAL STATUS				24370		
My pet has more good days than bad d	lays	1	2	3	4	5
My pet sleeps more, is awake less		1	2	3	4	5
My pet seems dull or depressed, not ale	ert	1	2	3	4	5
DAIN						
PAIN My pet is in pain		1	2	3	4	5
My pet pants frequently, even at rest		1	2	3	4	5
My pet shakes or trembles occasionally		1	2	3	4	5
ny per summes or members seemstoning				3	4	,
APPETITE						
My pet eats the usual amount of food		1	2	3	4	5
My pet acts nauseous or vomits		1	2	3	4	5
My pet eats treats / snacks		1	2	3	4	5
HYGIENE		(840)	14714	100000		i de l'ore
My pet keeps him/herself clean		1	2	3	4	5
My pet smells like urine or has skin irr	100000000000000000000000000000000000000	1	2	3	4	5
My pet's hair is greasy, matted, rough	looking	1	2	3	4	5
NATED INITAKE (UNDOATION)						
WATER INTAKE (HYDRATION)			2	-		-
My pet drinks adequately		1	2	3	4	5
My pet has diarrhea		1	2	3	4	5
My pet is urinating a normal amount		1	2	3	4	5
MOBILITY						
My pet moves normally		1	2	3	4	5
My pet lays in one place all day long		1	2	3	4	5
My pet is as active as he/she has been		1	2	3	4	5
Y I		-		3		,
GENERAL HEALTH						
General health compared to last evalua	tion	1	2	3	4	5
6 - 11 - H		Worse		Same		Bett
General health compared to initial diag	gnosis of cancer	1	2	3	4	5
Current quality of U.S.	V D	Worse		Same	P	Bett
Current quality of life	Very Poor				Ex	cellent

Figure 1. The 'Cancer Treatment Form' designed to assess HRQoL of dogs and cats with cancer.

neutered male, 23% (15/66) were entire male, 26% (17/66) were spayed female and 9% (6/66) were entire female. Of the cats included 42% (5/12) were neutered male and 58% (7/12) were spayed female.

The most common dog breeds were Labrador Retriever (23%, 15/66), Cross breed (12%, 8/66), Border Collie (9%, 6/66) and Cocker Spaniel (9%, 6/66). Multi-centric lymphoma (18%, 12/66) and

 Before my pet's fi 	rst treatment	At the time of a follow-up	visit for treatment
	was the "Cancer treatmen		
□ Yes		□No	•
Explain why		Explain why	
3) According to you,	what was the length of th	e "Cancer treatment form	"?
☐ Adequate length ☐ Too			☐ Too short
4) How would you a	ssess the easiness to unde	rstand and answer all the	questions?
☐ Very easy	☐ Somewhat easy	□Not very easy	\square Not easy at all
5) According to you,	were the questions asked	practical?	
☐ Very practical	☐ Somewhat practical	□Not very practical	□Not practical at a
6) Do you think that	the questions asked refle	et accurately your pat's au	ality of life at home?
	the questions asked rener	□ No	anty of me at nome:
Yes Explain why		Explain why	
. ii ii 	<u> </u>		
	*		
7) Did completing th treatment?	ne "Cancer treatment form	" help you feel more invol	ved in your pet's curre
□Yes		□No	
		-	
		-	
	ggestion to add/remove qu	estions or to change anyt	hing in the
questionnaire			

Figure 2. The 'Owner Minitest' designed to evaluate the 'Cancer Treatment Form' from the pet owner's perspective.

cutaneous mast cell tumour (17%, 11/66) were the most common canine cancers presented. The most common cat breed was Domestic Short Hair (67%, 8/12) with multi-centric lymphoma (25%, 3/12),

pulmonary tumours (17%, 2/12) and oral tumours (17%, 2/12) most frequently presented.

Of surveys administered, 36% (42/116) received an initial consultation and 64% (74/116)

	CLINIC	CIANS MINITEST		
	did the "Cancer treatment quality of life of the pet at		you with valuable information to	
☐ Very valuable	☐ Somewhat valuable	☐ Not very valuable	☐ Not valuable at all	
2) Do you feel that pet's history provid		rm" provided you with co	omplementary information to the	
☐ Yes		□ No		
Explain why		Explain why		
		-		
3) In your opinion,	did the answers to the "	Cancer treatment form"	reflect the pet's clinical attitude	
	ical examination/lab findin			
☐ Excellent reflexio	n 🗆 Somewhat reflective	☐ Not very reflective	☐ Not reflective at all	
A) If ab is is a seable	ask wists and the surress to	-d filled - "Conser Toos	tment Form" previously, did you	
•			us one filled by the owner for this	
☐ Yes		□No		
in the pet's clinical s	status?	□No	on useful to evaluate the changes	
Explain why		Explain why		
		<u> </u>		
6) Would you sugge	st to:			
☐ Keep the "Cancer	Treatment Form"	☐ Propose some		
unchanged		"Cancer Treatmen	t Form"	
7) If you have answ	ered "Propose some chang	es" at the previous questi	on, could you provide insight on:	
Questions to change	and which changes you wo	ould suggest:		
Question to remove	:			
Question to remove				

Figure 3. The 'Clinician Minitest' designed to evaluate the 'Cancer Treatment Form' from the clinician's perspective.

a follow-up appointment. Ninety-six percent (111/116) of 'Cancer Treatment Forms', 72% (84/116) of 'Owner Minitests' and 100% (116/116) of 'Clinician Minitests' were completed. Of the 'Owner Minitests' that were not completed, 59%

(19/32) received the questionnaire at follow-up appointments.

Ninety-seven percent (81/84) found the 'Cancer Treatment Form' to be of adequate length, 2% (2/84) found it to be too long and 1% (1/84) found

it to be too short. Eighty-three percent (69/84) found the 'Cancer Treatment Form' to be very easy to complete, 14% (12/84) somewhat easy, 2% (2/84) not very easy and 1% (1/84) not easy at all to complete. Seventy-nine percent (66/84) found it to be very practical and 21% (18/84) found it to be somewhat practical.

Where completed, 98% (82/84) of owners felt that the 'Cancer Treatment Form' reflected their pet's quality-of-life. The two owners who did not find that the 'Cancer Treatment Form' reflected their pet's quality-of-life both commented that the form was not easy for them to complete.

Where completed, 81% (66/81) felt the 'Cancer Treatment Form' made them feel more involved in their pet's treatment. Ninety-nine percent (81/82) of owners found the 'Cancer Treatment Form' detailed and complete enough. The owner of a dog with cancer who did not find the form complete enough commented that the form did not sufficiently include pre-existing conditions separate from cancer.

Ninety-five percent (105/111) of completed 'Cancer Treatment Forms' were found to be valuable by the clinician. Those that were not found to be valuable by the clinician were noted to have contradictory answers, disease other than cancer reducing quality-of-life or significant symptoms omitted.

Both owners and clinicians provided positive feedback and suggestions for improvements via the 'Owner Minitest' and 'Clinician Minitest'. The following symptoms were suggested for inclusion: restlessness, coughing, prehension abnormalities, polydipsia, polyphagia, inability to jump, laboured breathing, capricious appetite, lameness, polyuria, dysuria, constipation, weight loss or gain and difficulty medicating. It was suggested that 'shaking occasionally' and 'smells like urine' be removed and that 'my pet is as active as he/she has been' be reworded to improve clarity. It was suggested that the word 'treatment' be removed from the title of the form as some patients were not undergoing treatment, that the five-point scale was reduced to a three-point scale and the appearance of the form simplified. Phrasing all questions similarly (all positively or all negatively) was also suggested as was leaving room for owner comments. Removing 'cancer' from the title of the form was suggested as some clients found this distressing. Finally, altering the scale of the global HRQoL to acategorical scale of 1-10 was proposed (Figs 4-6).

Discussion

The 'Cancer Treatment Form' and 'Clinician Minitest' completion rate were excellent. No reason was obtained for 'Cancer Treatment Forms' that were not completed. Those completed were carried out so prior to consultation. The acceptable, but lower, number of 'Owner Minitests' completed may be because of the owners tiring of completing forms after completing the 'Cancer Treatment Form' or as a result of anxiety and distraction at the anticipation of assessment of their pet with cancer. Furthermore, the higher number of incomplete 'Owner Minitests' at follow-up appointments may suggest that owners tired of completing forms by followup consultation, that they felt more comfortable choosing not to fully participate when familiar with staff and surroundings or that their opinion of the 'Cancer Treatment Form' was unchanged (if they had previously completed the 'Owner Minitest'). Those who repeated the questionnaire at followup appointments may also have repeated previous answers. 'Owner Minitests' that had less than two questions incomplete were included for assessment of the completed component. This accounts for the 84 completed with only 82 included in the assessment of whether the 'Cancer Treatment Form' was detailed and completed and 81 included in the evaluation of whether the form made them feel more involved in their pet's treatment.

Only canine and feline oncology patients were included in this study as evaluating HRQoL in other species would require alternative parameters. The sample size was sufficient for the purposes of this study and it is assumed that the completeness, length, ease and practicality of the 'Cancer Treatment Form' can be assessed for both dogs and cats with cancer with the sample size obtained. The length of the 'Cancer Treatment Form' was very well accepted and revision will attempt to maintain the current length as closely as possible.

Acceptable levels of ease and practicality were reported, which are encouraging but suggest room for improvement at revision. Phrasing questions

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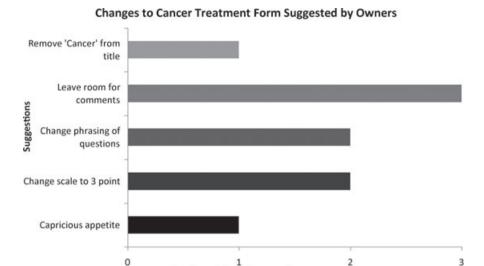


Figure 4. Suggestions for changes to the 'Cancer Treatment Form' made by owners in the 'Owner Minitest'.

Number of Times Suggested

with all positive or negative emphasis may improve ease and practicality although it risks compromising the time and consideration that each question receives. The phrasing of questions will be reviewed and ease and practicality improved where possible. Extending the time frame to either the preceding 24 h or preceding week will also be considered as it may improve ease and practicality. It is generally accepted in human medicine that time frames

of less than 1 week are incorporated in HRQoL questionnaires.²² Balancing completeness of the 'Cancer Treatment Form' with simplicity and ease of understanding is a challenge and review of the form in light of this study's findings will endeavour to improve simplicity.

Included patients received a variety of therapies including chemotherapy, surgery and radiation therapy. Some included patients did not receive

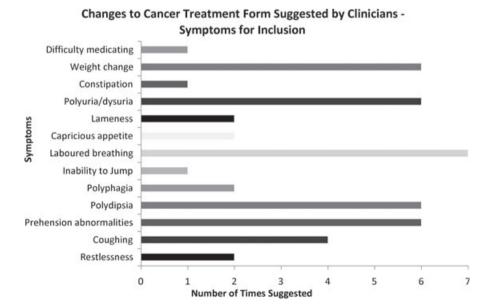


Figure 5. Symptoms suggested for inclusion in the 'Cancer Treatment Form' suggested by clinicians in the 'Clinician Mintest'.

Changes to Cancer Treament Form Suggested by Clinicians - General

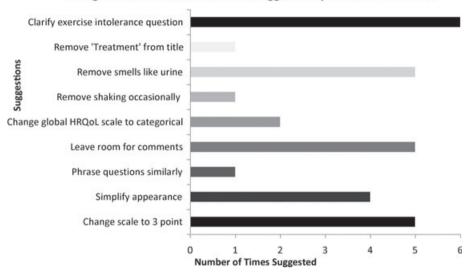


Figure 6. General suggestions for changes to 'Cancer Treatment Form' suggested by clinicians in the 'Clinician Minitest'.

treatment. As this was a preliminary assessment of the HRQoL in all patients with cancer, the variety of patient treatments should have improved our ability to detect omitted symptoms. All owners of feline patients reported the form to be detailed and complete. To reduce the impact of the lower numbers of feline patients included, the primary study clinician has carefully reviewed the 'Cancer Treatment Form' and suggested symptoms for inclusion of particular relevance to feline patients. Only one dog owner reported the 'Cancer Treatment Form' to be not sufficiently detailed and complete because of low sensitivity at detecting conditions other than cancer. As this HRQoL assessment is intended to evaluate the impact only of cancer and its therapy on quality-of-life, this comment will not impact revisions of the current form. However, all symptoms suggested for inclusion above will be reviewed and evaluated. Visual analogue scales and categorical scales of global health assessment are both used in HRQoL assessment in human medicine and have been shown to be of equal value.²³ As a result, this is unlikely to be altered.

In human medicine, there is much contention with regard to whether HRQoL questionnaires are of benefit in clinical practice²⁴ and whether there is a benefit to multi-dimensional assessments over a single rating of HRQoL.²⁵ As there is no clear precedent, we have chosen to evaluate HRQoL from a multi-dimensional perspective and to develop a questionnaire for use in both clinical practice and clinical trials.

Reducing morbidity and improving HROoL without compromising survival rates are the ultimate goals when designing novel therapies in oncology.26 As such, quantifying morbidity as objectively as possible is part of human clinical trial protocols where an intervention is proposed to have negative or positive effects on HRQoL.^{26–28} HRQoL assessment is particularly important in palliative therapy where treatment is aimed at improving quality-of-life and a cure is not possible. 28,29 It follows that HRQoL should be measured in veterinary clinical oncology trials as a primary outcome as measuring tumour response alone may or may not indicate the true benefit to the patient.²⁹ Importantly, the questions used in the 'Cancer Treatment Form' have recently been included as a means to evaluate HROoL as a primary outcome in veterinary clinical trials of the novel cancer agent Palladia[™]. ²¹ Results showed that Palladia[™] treated responders scored higher on HRQoL than Palladia™ treated non-responders.²¹

Quality-of-life is based on each animal's unique genetic make up, personality, learned experiences and priorities.9 Objectively assessing such a subjective phenomenon has many limitations. One clear limitation of veterinary HRQoL studies is the necessity for proxy reporting which allows for the observer's personality and inferences to impact on quality-of-life assessment. 16,26,30 Proxy reporting of problems that are more externalized and observable have been shown to be more accurate than reporting internalized problems in human medicine.31 In veterinary medicine, this is further complicated by the need to interpret the HRQoL priorities and behaviour of another species.

In paediatric medicine, proxy reporting has variably correlated with child reporting but ultimately provided useful information for HRQoL assessment.³² The preferred choice of proxy is generally accepted to be the family caregiver with higher patient correlation than physicians presumably because of increased frequency of contact. 33-35 Similarly, in veterinary medicine the owner is generally the preferred proxy reporter.³⁶ Clinician proxy reporting has been shown to correlate poorly with owner reporting in veterinary oncology.³⁷ For the above reasons, the owner was the chosen proxy reporter in this study; further evaluation of the correlation between the clinician and the pet owner assessment of quality-of-life maybe required.

The 'Cancer Treatment Form' was, overall, well received. The objective of this study was not to assess quality-of-life in veterinary oncology patients but to undertake preliminary assessment of a novel instrument to measure HRQoL. The suggestions for improvement will be reviewed and minor improvements made. This study provided preliminary assessment of the ease, length, practicality and completeness of the 'Cancer Treatment Form'. Further evaluation of the questionnaire will require larger sample sizes and may include assessment of its validity (ability to measure what it intends to measure), test-retest reliability (ability to provide similar results when re-administered) and responsiveness (ability to change with patient's condition).

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Conflict of interest

None.

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