

Evaluation of quality of life of carers of Italian spinoni with idiopathic epilepsy

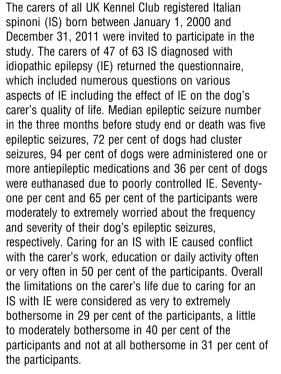
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ABSTRACT

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INTRODUCTION

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Correspondence to: Dr Luisa De Risio; luisa.derisio@aht.org.uk Canine idiopathic epilepsy (IE) has been recently defined as two or more unprovoked epileptic seizures at least 24 hours apart, with no identifiable underlying aetiology other than a suspected genetic origin (Berendt and others 2015). The diagnosis of IE is currently one of exclusion, and is made based on the age at epileptic seizure onset (between six months and six years), unremarkable interictal physical and neurological examinations and exclusion of metabolic, toxic and structural cerebral disorders by means of diagnostic investigations (De Risio and others 2015a). IE is the most common chronic neurological condition in domestic dogs, with an estimated prevalence of 0.6 per cent in the general canine population in the UK (Kearsley-Fleet and others 2013). Breedspecific and country-specific prevalence of IE ranges from 3.1 per cent to 18.3 per cent (Hülsmeyer and others 2015).

Canine epilepsy can substantially reduce the quality of life of the dog and can affect the daily life of its carer (Packer and Volk 2015). Caring for an epileptic dog is a lifelong emotional, time and financial commitment. It involves regular administration of antiepileptic drugs (AEDs) (sometimes as often as every six to eight hours), maintaining an accurate seizure diary, coping with and monitoring for adverse effects of the AEDs, emergency management of potentially life-threatening epileptic seizure activity (such as cluster seizures and status epilepticus), regular veterinary check-ups as well as emergency visits and associated ongoing financial costs. Epileptic seizures may be stressful to witness and manage, and may appear uncontrollable (Packer and Volk 2015). Epileptic seizure occurrence is sudden and unpredictable, and long-term prognosis is difficult to predict in the individual. Therefore the constant feeling of uncertainty can cause emotional distress in the epileptic dog's carer. In addition, the carer's commitment may not be matched by treatment success (Potschka and others 2015) and this may result in further frustration and stress. Studies in human medicine have shown that caring for an epileptic child or adult has a severe impact on the carer's quality of life and psychological health (Lv and others 2009, Ferro and others 2012, Norup and Elklit 2013, Reilly and others 2015).

There is limited veterinary literature on quality of life in epileptic dogs and their carers (Lord and Podell 1999, Chang and others 2006, Wessmann and others 2012, Wessmann and others 2014) and no breed-specific study has been performed. A previous study has identified a set of key questions to evaluate quality of life in carers of dogs with IE (Wessmann and others 2014). There are breedspecific differences in IE onset, clinical characteristics, epileptic seizure severity, disease course, response to antiepileptic treatment and survival (Hülsmeyer and others 2015). These breed-specific IE features could affect the dog's carer's perception of canine epilepsy and quality of life.

The authors have previously investigated the prevalence, clinical characteristics and survival in Italian spinoni (IS) with IE (De Risio and others 2015b). The aim of this study was to evaluate the quality of life of carers of IS with IE.

MATERIAL AND METHODS

The carers of all UK Kennel Club registered IS born between January 1, 2000 and December 31, 2011 were sent a letter inviting them to participate in the study, which involved two phases. The aim of phase I was to estimate the prevalence of IE in the IS in the UK (De Risio and others 2015b). Sixty-three (5.3 per cent) of the 1192 IS whose carers responded to the phase I questionnaire were diagnosed with IE based on revision of the questionnaire and the primary veterinarian's and, when available, the veterinary neurologist's medical records. IE was defined as recurrent epileptic seizures (≥two epileptic seizures occurring >24 hours apart) with an onset between six months and six years of age in dogs with normal interictal physical and neurological examinations, and results of haematology and biochemistry profiles within the normal reference ranges. Median follow-up time from first epileptic seizure to study end or death was 35 months (range, 5-124 months) (De Risio and others 2015b). The carers of the 63 IS diagnosed with IE were invited to complete a phase II questionnaire containing 110 questions on various aspects of epilepsy (De Risio and others 2015b) including the effect of IE on the dog's carer's quality of life, and their perception of epileptic seizure severity, AED adverse effects and use of rectal diazepam (Table 1). The part of the questionnaire investigating the epileptic dog's carer's quality of life and perspectives on IE was developed based on a previously published veterinary study (Wessmann and others 2014). Epileptic seizure frequency was evaluated based on seizure diaries provided by the epileptic IS's carers. Cluster seizures were defined as more than one epileptic seizure within 24 hours with full recovery of consciousness between epileptic seizures. Status epilepticus was defined as continuous epileptic seizure activity lasting at least 5 minutes or at least two discrete epileptic seizures between which there is incomplete recovery of consciousness. IS carers were requested to provide information on AEDs administered, AED-related adverse effects, date and cause of death of their IS (when applicable).

RESULTS

Data on the IS included in the study

The phase II questionnaire was returned for 47 IS. Mean±sd age at onset of IE was 39±19 months (median 35 months; range 11–72 months). Thirty-one (66 per cent) IS were male (of which 16 were neutered) and 16 (34 per cent) were female (of which 11 were spayed).

Cluster seizures and status epilepticus occurred in 34 (72 per cent) and 10 (21 per cent) of 47 IS included in this study. Mean \pm sd number of epileptic seizures in the three months before study end or death was 8 \pm 10 (median 5 epileptic seizures, range 0–38 epileptic seizures). Only nine IS had been epileptic seizure-free for three or more months before questionnaire completion or death. Information on epileptic seizure occurrence in the three months before questionnaire completion or death was unknown in seven IS.

Three (6 per cent) IS were not administered AEDs, 32 (68 per cent) IS were treated with one or two AEDs and 12 (26 per cent) IS were administered three or more AEDs. The numbers of IS administered phenobarbitone, potassium bromide, levetiracetam, imepitoin, gabapentin, topiramate and zonisamide were 40, 26, 11, 2, 2, 2 and 1, respectively. Of the 15 IS that received monotherapy, 14 were treated with phenobarbitone and 1 with imepitoin.

AED-related adverse effects were reported in 36 (82 per cent) of 44 IS on AED and persisted to some degree after the first three weeks or three months (for potassium bromide) from AED initiation or dose increase in 30 (83 per cent) of 36 IS with adverse effects. The AED-related adverse effects most commonly reported were polyphagia, polydipsia, weight gain, sedation and ataxia.

Twenty-two (47 per cent) IS were dead at the time of data collection end. Of these 22 IS, 17 (77 per cent) had been euthanased due to IE and 5 (23 per cent) died for causes unrelated to IE. Mean survival of the 22 IS that died was 31±27 months (median 27 months). Mean survival of the 17 IS that were euthanased due to IE was 23±17 months (median 19 months). At the time of the carer filling out the phase II questionnaire, 3 IS were alive and 19 IS were dead.

Effect of IE on the IS carer's quality of life

The answers of the 47 IS carers to the questions related to the effect of caring for an epileptic IS on their life are summarised in Table 1. Response rate to each question was incomplete ranging from 70 per cent to 96 per cent. When results are analysed as a per cent of the total number of participants for a specific question, caring for an IS with IE caused conflict with the carer's work, education or daily activity often or very often in 50 per cent (20/40) of the participants and limited the carer's social life and independence often or very often in 36 per cent (14/39) and 41 per cent (16/39) of participants, respectively. Overall the limitations on the carer's life due to caring for an IS with IE were considered as very to extremely bothersome in 29 per cent (13/45) of the participants, a little to moderately bothersome in 40 per cent (18/45) of the participants and not at all bothersome in 31 per cent (14/45) of the participants. Only 16 per cent (6/38) and 13 per cent (5/40) of the participants were not worried about epileptic seizure frequency and severity, respectively. Fifty-three per cent (20/38) and 48 per cent (19/40) of the participants

TABLE 1: Summary of questions and answers on the effect of caring for an epileptic IS on the carer's life and their perception on epileptic seizure severity, AED adverse effects and use of rectal diazepam (data on 47 IS)

Questionnaire themes and questions	Epileptic IS carer's answers					
Restrictions on the carer's life	Never	A few times	Sometimes	Often	Very often	Not answered
In the last three months, how often did you feel that caring for your epileptic IS caused conflict with your work, education or daily activities?	12 (26%)	4 (8%)	4 (8%)	6 (13%)	14 (30%)	7 (15%)
In the last three months, how often did you feel that caring for your epileptic IS limited your social life?	15 (32%)	5 (11%)	5 (11%)	5 (11%)	9 (19%)	8 (17%)
In the last three months, how often did you feel that caring for your epileptic IS limited your independence?	19 (41%)	1 (2%)	3 (6%)	6 (13%)	10 (21%)	8 (17%)
Frustrations due to caring for an epileptic IS	Not at all bothersome	A little bothersome	Moderately bothersome	Very bothersome	Extremely bothersome	Not answered
How bothersome have the limitations on your work, education or daily activities been due to caring for your epileptic IS?	18 (38%)	12 (26%)	4 (9%)	4 (9%)	7 (15%)	2 (4%)
How bothersome have the limitations on your social life been due to caring for your epileptic IS?	17 (36%)	11 (23%)	5 (11%)	5 (11%)	7 (15%)	2 (4%)
Overall, how bothersome have the limitations on your life been due to caring for your epileptic IS?	14 (30%)	12 (25%)	6 (13%)	7 (15%)	6 (13%)	2 (4%)
Carer's anxiety due to the seizures	Not worried	A little worried	Moderately worried	Very worried	Extremely worried	Not answered
In the last three months, how much have you been worried about the frequency of the seizures in your epileptic IS?	6 (13%)	5 (11%)	7 (15%)	5 (11%)	15 (32%)	9 (19%)
In the last three months, how much have you been worried about the severity of the seizures in your epileptic IS?	5 (11%)	9 (19%)	7 (15%)	1 (2%)	18 (38%)	7 (15%)
Carer's perception of seizure severity	Very mild	Mild	Moderately severe	Severe	Very severe	Not answered
In the last three months, the severity of your epileptic IS seizures has been	0	6 (13%)	12 (25%)	8 (17%)	7 (15%)	14 (30%)
Carer's perception of adverse effects of AEDs	Not at all bothersome	A little bothersome	Moderately bothersome	Very bothersome	Extremely bothersome	Not answered
Overall how bothersome are the side effects of the AEDs on your epileptic IS?	8 (18.2%)	6 (13.6%)	8 (18.2%)	7 (15.9%)	8 (18.2%)	7 (15.9%)*
Carer's perception of rectal diazepam use for emergency management of seizures at home	Never	A few times	Sometimes	Often	Very often	Not answered
If your vet advised to give rectal diazepam, have you ever been uncertain when to give it?	14 (52%)	2 (7%)	7 (26%)	1 (4%)	1 (4%)	2 (7%)†
If your vet advised to give rectal diazepam, have you ever been worried how much or how many times you are supposed to give it?	16 (59%)	1 (4%)	6 (22%)	1 (4%)	1 (4%)	2 (7%)†
*AEDs were administered to 44 of the 47 IS †Rectal diazepam was used in 27 of the 47 IS AEDs, antiepileptic drugs; IS, Italian spinone						

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were very or extremely worried about epileptic seizure frequency and severity, respectively. Epileptic seizure severity was considered mild or moderate in 55 per cent (18/33) of the participants and severe to very severe in 45 per cent (15/33) of the participants. Overall the adverse effects of the AEDs were considered very to extremely bothersome in 40 per cent (15/37) of the participants, a little to moderately bothersome in 38 per cent (14/37) of the participants and not at all bothersome in 22 per cent (8/37) of the participants. Fifty-six per cent (14/25) and 64 per cent (16/25) of the participants knew when to administer rectal diazepam for emergency seizure management and were not worried about diazepam dosage, respectively.

DISCUSSION

This is the first study investigating the effect of caring for an idiopathic epileptic dog focused on a specific canine breed. There are breed-specific differences in the prevalence, clinical characteristics and severity of canine IE (Hülsmeyer and others 2015). The prevalence of IE in IS (5.3 per cent) is higher than in the general canine population (0.6 per cent) in the UK, and IE in IS has a severe phenotype and low remission rate (De Risio and others 2015b). In the 47 IS included in this study, median epileptic seizure number in the three months before study end or death was five epileptic seizures, 72 per cent of dogs had cluster seizures, 26 per cent of dogs were administered three or more AEDs and 36 per cent of dogs were euthanased due to poorly controlled IE. Therefore it is not surprising that 71 per cent and 65 per cent, of the participants were moderately to extremely worried about the frequency and severity of the epileptic seizures, respectively. Epileptic seizure severity was perceived as moderately severe to very severe by the carers of 82 per cent IS. These results are in agreement with those of a previous study including 128 dogs with IE from 42 breeds, in which 69 per cent and 74 per cent of participants were moderately to extremely worried about the frequency and severity of the epileptic seizures, respectively (Wessmann and others 2012). In this multibreed study, epileptic seizure frequency was higher than a single epileptic seizure or cluster seizure every three months in 63 per cent of the dogs, and epileptic seizure severity was considered moderate to severe by 67 per cent of the participants (Wessmann and others 2012).

Caring for an IS with IE caused conflict with the carer's work, education or daily activity and limited their social life and independence often or very often in 50 per cent, 36 per cent and 41 per cent of participants, respectively. A previous study including dogs of various breeds selected from a referral population reported similar findings as 54 per cent (13/24) carers reported that caring for an epileptic dog had caused them conflicts with their work and day-to-day activities and 60 per cent (15/25) felt that caring for an epileptic dog had an

effect on the organisation of their free time (Chang and others 2006). Interestingly, in this previous study, approximately 50 per cent of the carers indicated that their dog's epilepsy had affected their ability to stay away overnight as they were too worried to leave their epileptic dog, they were unable to find someone able to care for an epileptic dog, or their dog usually had epileptic seizures when the carer was away or after return (Chang and others 2006). Conversely, in the only other veterinary study which assessed quality of life in the epileptic dog's carer, the carers felt that the work involved in caring for an epileptic dog was not a burden or a substantial detriment to their own quality of life (Lord and Podell 1999). This study included only 19 dogs of various breeds (of which 10 had IE and 9 had structural epilepsy). Of these 19 dogs, 12 (63 per cent) dogs had up to one epileptic seizure in 90 days, 3 (16 per cent) dogs had two epileptic seizures in 90 days and 4 (21 per cent) dogs had more than two epileptic seizures in 90 days; phenobarbitone was the only administered AED and AED-related adverse effects were infrequent. Occurrence of cluster seizures and status epilepticus was not mentioned (Lord and Podell 1999). In the present study, median epileptic seizure frequency in all 47 IS was five epileptic seizures in three months, cluster seizures and status epilepticus occurred in 72 per cent and 21 per cent of IS, respectively, 61 per cent IS were administered two or more AEDs and AED-related adverse effects persisted in 83 per cent IS. Therefore the discrepancy in the carers' perception of their quality of life between the present study and the study by Lord and Podell (1999) is likely to be due to differences in the dogs' epileptic seizure frequency and severity, number of AEDs administered and occurrence of AED-related adverse effects.

The adverse effects of the AEDs were considered moderately to extremely bothersome by 58 per cent of IS carers who answered this specific question. Similarly, 49 per cent (54/110) of participants in the study by Wessmann were concerned about the adverse effects of the AEDs (Wessmann and others 2012) and 58 per cent (7/12) of participants in the study by Chang considered AED-related adverse effects one of the reasons for a decreased quality of life in their dogs. Prevalence and type of adverse effects (e.g. polyphagia, polydipsia, sedation and ataxia) were similar between the present study study by Chang and others (2006). the and Phenobarbitone and/or potassium bromide were administered to all dogs included in the study by Chang and were the most commonly used AEDs in the present study.

AED-related adverse effects, epileptic seizure control and occurrence of status epilepticus have been reported amongst the factors correlated with quality of life in carers of children with epilepsy (Lv and others 2009). Parents of children with epilepsy have a lower quality of life and a higher incidence of anxiety and depression than parents of healthy children (Lv and others 2009). The levels of anxiety and depression are higher and the quality of life is lower in the parents of children with poorly controlled epilepsy compared with those of the parents of children with well-controlled epilepsy (Lv and others 2009). In a prospective study of children with new-onset epilepsy, 28 per cent of mothers without clinically relevant levels of depressive symptoms at baseline were at risk of clinical depression by 24 months after epilepsy onset (Ferro and others 2012). Parents of children with epilepsy have to learn to cope with stress that is ongoing, as epilepsy is a chronic illness and epileptic seizure occurrence is unpredictable (Duffy 2011). Parental adjustment to caring for a child with epilepsy was negatively associated with the severity of the child's epilepsy and positively correlated with satisfaction of social support (Pal and others 2002). Epileptic seizure frequency and severity, AED-related adverse effects, anxiety and depression were amongst the variables playing a significant role in the development of posttraumatic stress disorder in partners living with an epileptic patient (Norup and Elklit 2013). High levels of social support decreased the level of traumatic stress (Norup and Elklit 2013).

Thirty-six per cent (17/47) of IS in this study were euthanased due to IE. This high mortality rate may reflect the severity of IE in IS as well as the impact of the disease on the carer and the challenges in coping with the demands of caring for an epileptic dog.

One limitation of this study is that response rate was not 100 per cent for each of the questionnaire's questions, therefore the impact of each domain could be assessed in a subset of participants only and this may have partly biased the results. The questions with the higher response rate (96 per cent) were those to assess the frustrations due to caring for an epileptic dog, whereas the question about the carer's perception of epileptic seizure severity achieved the lowest response rate (70 per cent). Another limitation of this study is that the carers of 19 IS filled in the phase II questionnaire after their IS had died and this could have biased their responses.

This study did not evaluate various factors that could have influenced the impact of IE on the dog's carer such as the dog's insurance status, the number of carers involved in the management of the epileptic dog, the carer's sex, age, physical and psychological health, employment, financial, social, and education status, as well as presence and type of emotional support. Investigating some of these aspects may have been perceived as inappropriate or intrusive in the context of a veterinary study. The phase II questionnaire contained 110 questions on various aspects of IE in IS and additional questions on the carer's personal life may have negatively affected the response rate. Participants were recruited through the UK Kennel Club and did not meet the investigators. This allowed a broad sample to be obtained across the UK however there was not an established personal relationship between the

investigators and the dog's carer which may have facilitated obtaining additional information. The part of the questionnaire investigating the epileptic dog's carer's quality of life was based on a previous study which identified a set of key questions to evaluate quality of life in carers of dogs with IE (Wessmann and others 2014).

In conclusion, the results of this study suggest that IE has an impact in the majority of IS carers and the epileptic seizure frequency and severity are the greatest concerns. Optimising treatment of IE and providing adequate education on IE as well as emotional and logistic support to the carer is likely to improve quality of life of the epileptic dog's carer.

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Contributors LDR designed and conducted the study and wrote the manuscript. JF and AS assisted with data management and analysis and revised the manuscript.

Competing interests None declared.

Patient consent Obtained.

Provenance and peer review Not commissioned; externally peer reviewed.

Data sharing statement No additional data are available.

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