

Predicting quality of life outcomes as a guide for decision-making: the challenge of hitting a moving target

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Abstract

In animal care, when current decisions are made to maximise long-term quality of life (QoL), a key necessity is being able to make accurate predictions about how current choices will affect the animal's future QoL. However, in the procession of any individual's life, many factors that influence QoL change — some are foreseeable, many are not. Moreover, QoL has no fixed anchor points; it is dynamic, mutable, with a shifting frame of reference over time. In addition to actual changes in QoL over time, numerous factors have been identified that influence one's ability to adopt the mindset of the individual at a later point in time — for one's self as well as that of others. It has been shown that in people, across a wide range of health conditions, individuals with illness or disability typically report greater happiness and QoL than do healthy people envisioning themselves in similar circumstances ('the disability paradox'). Difficulties in QoL outcome prediction fall into two categories: (1) predictions made with the wrong mindset, in which there is a mismatch between the mindset of the assessor/predictor and that of the assessee/experiencer; and (2) predictions made on the basis of unforeseen or incorrectly estimated psychological changes in the assessee/experiencer.

Keywords: adaptation, animal welfare, disability paradox, happiness set-point, quality of life, scale recalibration

Introduction: the shifty nature of quality of life

As has been made clear in many of the other presentations of this Symposium, producing a single accurate measurement of quality of life (QoL) at a present point in time is exceptionally challenging. In caring for animals, a key necessity for optimal decision-making is being able to make more than present QoL assessments: it requires accurate predictions about how potential choices will affect the animal's *future* QoL. However, QoL has no fixed anchor points, is dynamic and mutable with a constantly shifting frame of reference. Choosing a course of action that will, in the end, be the one that produces the highest QoL creates the very real challenge of hitting a moving target.

How elusive is QoL as an object of foresight? Consider just a few of the conundrums that QoL prediction must accommodate:

- The human disability which many regard as a worst-case life scenario is paralysis from spinal cord injury. Yet when victims of such catastrophic trauma were interviewed more than 20 years later, 75% rated their current QoL as either good or excellent (Whiteneck *et al* 1992). How could people regard something that results in such a high QoL to be a worst-case scenario?
- If a person paralysed by an automobile accident and confined to a wheelchair later rated his own QoL as excellent, what would happen to his QoL if he were to regain the use of his limbs? Would it go up? If it does, will he end up with a QoL higher than before his disabling

injury? If it does not, why would he care whether he was ever able to walk again?

- News item, 2006: Using an avian model of a specific congenital blindness in children, scientists at the University of Florida delivered a gene through an eggshell that restored sight to genetically modified Rhode Island Red chickens that are normally born blind (Williams *et al* 2006). Similar advances in humans and other animals are likely to follow. Now, consider that if QoL is measured in two adult women, one with normal sight and the other born blind, their self-rated QoL, on average, is likely to be similar (Gilbert 2006). If the vision deficit of the congenitally blind woman had been corrected *in utero* as accomplished in the chickens, would this woman's QoL as a normally sighted adult be any different from that of a woman blind from birth? If the QoL outcomes for the individual with and the individual without sight restored are the same, then would not the logical conclusion be that the sense of sight has no effect on QoL?
- It is commonly believed that children with severe mental disabilities have a reduced QoL and that an important focus of the care of these children should be on increasing their QoL (Hatton 1998). Is this a proper goal? Does raising their QoL entail trying to give them what 'normal' people have? How do we know they would want this? And how do we know that giving them this would increase their QoL?

Quality of life is closely related, and is likely to be equivalent, to a number of other concepts of subjective life experience such as *well-being* (often specified as

subjective, emotional, psychological, or mental well-being), *welfare*, *happiness*, *life satisfaction*, and *contentment*. As for all of these concepts, QoL changes and evolves over one's lifetime. Personal experiences, developmental changes, and pathologic processes all contribute to the overall experience of life as it acquires new values and priorities, likes and dislikes, and conditions for comfort — both physical and mental. All of these constantly changing factors comprise important parts of one's QoL, and as they change so too does any fixed standard or anchor for measuring that QoL.

The other presentations in this Symposium have utilised some common language for discussing QoL. What is interesting is that some of the most familiar phrases take on an enormous additional significance when used in the context of how QoL predictions guide decision-making. As we will see, each of these ideas is rooted in factors that will go through changes — sometimes drastic — throughout life. “Measuring quality of life against the subject's own declared priorities and needs” (Ahmedzai 2006), “By understanding what animals do and do not want out of life...” and “...do the animals have what they want?” (Dawkins 2006). In the procession of life, every change in priorities, needs, and wants destabilises any anchor QoL may have.

Even the seemingly most dependable anchors for QoL are not fixed. One typical method of QoL measurement in people is the Visual Analogue Scale, a single-item measure in which the patient indicates his or her QoL on a line or scale. The anchors of the scale are usually the two ends: ‘best possible QoL’ and ‘worst possible QoL’ (de Boer *et al* 2004). However, such anchors are illusions. An individual's QoL can *always* go lower than ‘worst possible QoL’. (No matter how poorly a person's life is faring there are innumerable ways that it can worsen. Even if someone were to have every known disease and disability, they could then be swindled out of their life savings, lose all friends and family members in a terrorist attack, become unable to pay the heating bill and struggle to live in sub-freezing temperatures, and so on.) Moreover, it is simply not possible to know when one's QoL has reached ‘worst possible’. A person afflicted with a painful disease may be in excruciating pain and be unable to imagine it feeling any worse. And then the next day it does. And again the next day. He rates his QoL ‘worst possible’ day after day for several weeks. On which day is a rating of ‘worst possible QoL’ correct? Can there ever be such a day? Nevertheless, these end anchors play an important role in human health measurement scales, used in conjunction with pain scores to document evidence for response shift (ie changes) over time.

There is general agreement that QoL assessment should be made, as much as is possible, from the perspective of the individual whose life quality is being evaluated. A common application of this notion is to ‘put yourself in the other's shoes’, which is to say that the evaluator adopts the viewpoint of the individual. However, it is not always clear to what degree this can — or should — be done. To illustrate the problem, consider how (or whether) a line may be

drawn between the process of placing oneself ‘in another's shoes’ and looking at the circumstances of another's life and deliberating the notion of ‘I would/wouldn't want this for myself’. Although the two processes appear on the surface to be quite similar, there is a crucial distinction. The former assumes the assessor's successful adoption of the assessee's mindset, such that ‘seeing things through his or her eyes’ is actually ‘seeing things through his or her *mind*’. In contrast, the latter is seeing through the other's eyes but still processing what is seen by using one's own mind. What we are learning about the nature of QoL, and especially QoL outcome prediction, is that the yardstick of what one would or wouldn't want for themselves is a poor guideline for assessing another's current *or* future QoL.

The disability paradox: a demonstration of the moving target

The previous section included a study containing a highly counterintuitive finding: that the large majority of those who actually experience something that the rest of us would consider devastatingly destructive to our quality of life — permanent paralysis — ultimately end up with a self-assessed QoL as high as, if not higher than, that of the general population (Whiteneck *et al* 1992). This phenomenon, of course, greatly complicates any decision-making process based on predicted QoL.

In Western culture people seem to dread growing old, despite numerous studies showing that well-being actually improves with age. Lacey *et al* (2006) compared the self-reported happiness of younger adults (mean age = 31) and older adults (mean age = 68) with the same subjects' estimates of what they believed happiness levels would be for people at different ages in life. The results confirmed that happiness increases with age, yet both younger and older participants believed that happiness declines. In other studies, many people report satisfaction in situations that the majority of the population believe (and hence predict) that they would find unbearable. Birnbacher (1999) writes of cancer patients who successfully adapt to a health situation they had thought intolerable at the time of onset of their disease. QoL in patients with spinal cord injury (SCI) has been examined in numerous studies similar to the long-term follow-up study cited earlier. In a commentary praising the success of current SCI treatments, DeLisa (2002) notes how multiple researchers have found that “the assumptions of those of us who are able-bodied bear little relationship to the realities of life for the people with SCI”. In a review of the research of QoL in SCI patients, Hammell (2004) looked at only those studies involving high (ie neck region) SCI. He concluded that “Reflecting prevailing cultural beliefs, health care professionals have been found to underestimate significantly the QoL experienced by people with high SCI”. He believes that medical care decisions may be heavily influenced by society's negative presuppositions about QoL in people with impairment.

The data show consistently and convincingly that it is common for people to mispredict (ie incorrectly predict) the emotional impact of unfamiliar circumstances such as

chronic illnesses and disability and the effect they will have on their well-being and QoL. Across a wide range of health conditions, people with illness or disability typically report greater happiness and QoL than do healthy people envisioning themselves in similar circumstances — this has been termed ‘the disability paradox’ (Ubel *et al* 2005). So common that it would not be unreasonable to consider it the norm, people routinely presume that they would be miserable if they experienced serious illness or disability. And most would be wrong.

How could the disability paradox apply to decision-making in animal QoL? Certainly we are not talking here about animals making complex decisions based on (mis)predictions of their own global QoL outcomes. However, the decisions made by humans that are based on predictions of future QoL may be highly influenced by this phenomenon. Consider that if the disability paradox shows that we do not see our *own* future QoL clearly, there is no reason to believe that we would be more successful in predicting an animal’s future QoL.

There is, as of yet, a paucity of studies in this area, but the few available support the view that animal-care decisions are influenced by the disability paradox. For example, in a survey of 50 blind dogs, over 50% (28 out of 50) of the dogs’ owners had encountered people who had suggested it was unkind to keep a blind dog (Chester & Clark 1988). In this study, the view of many members of the general public appears to be based on a presumption that blindness would so negatively affect QoL that keeping such a dog alive would be wrong. In a study of pet owner responses to amputation for their animal, 100% (7 out of 7) of those whose main objection to the amputation was a prediction of a decreased QoL later stated that their concern was unfounded (Withrow & Hirsch 1979). In the clinical practice of veterinary medicine, decisions regarding euthanasia are frequently based on predicted QoL outcomes of the available options. A well-publicised story from the UK in 1998 is a typical illustration of how decisions in veterinary care may be influenced by the disability paradox. Two stray Jack Russell terriers were found together roaming the streets of Essex, England (Anonymous 1998). At the time they were found, one of the dogs had a sharp stick protruding from each eye socket. When it was determined that both eyes were too severely damaged to regain sight, most of the veterinarians caring for the dogs recommended euthanasia on the basis of a prediction of a poor QoL (Becher Y, personal communication 1999). Instead, both of the dog’s eyes were surgically removed and the two dogs were then adopted out to live together in a loving home. A year after the adoption, the woman who adopted them told me in a telephone conversation that the life of the blind dog, which she had named Ben, like that of his companion, Bill, was full of boundless energy, play, and fun (Becher Y, personal communication 1999). It seems clear that the recommendation for euthanasia was, in retrospect, based on an incorrect prediction of Ben’s future QoL.

It might seem that the disability paradox, in the context of a human making a proxy assessment of an animal’s (predicted) QoL, is biased by human values. It may be, but

anthropocentrism is not the explanation for the disability paradox. Because the paradox functions when we are making QoL predictions for *other humans* (not to mention our own individual future *selves*), it arises from a mistaken notion of the negative impact of an adverse event on any individual’s future QoL.

The basis for mispredictions of QoL outcomes: why does the target move?

The reasons behind the difficulties and inaccuracies of QoL outcome predictions can be divided into two categories: (1) predictions made with the wrong mindset; and (2) predictions made on the basis of unforeseen or incorrectly estimated psychological changes. The first category includes those situations where the state of the assessor’s mind imparts an influence that does not permit the future QoL to be seen from the perspective of the individual who actually later experiences that QoL, seeing, rather, a distorted view of a future QoL. There is a mismatch between the mindset of the assessor and that of the assessee. In the second category, the assessor is handicapped by not knowing what psychological changes — in terms of wants, desires, preferences, and perspectives — will occur between the present day decision and the time the assessee’s QoL outcome becomes reality. Without accurate predictions of these changes, any QoL that is influenced by the changes is likely to be mispredicted.

(1) Predictions made with the wrong mindset

Four processes involve the wrong mindset being used to forecast QoL. They are: (1) the focussing illusion; (2) underestimation of adaptation; (3) limitations of the brain’s ability to detect slow change; and (4) the effect of momentary mood.

Focussing illusion

When people look ahead to an unpleasant change in life, there is a strong tendency to focus on the adversity and all its implications for one’s life and well-being (Schkade & Kahneman 1999; Ubel *et al* 2005). Ubel *et al* (2005) offer the example of a person facing a decision on undergoing a colostomy to treat colon cancer. They ask the reader to imagine what his or her life would be like if the colostomy were performed.

“When most people imagine the situation, images of plastic pouches come to mind. They think about being unable to go outside in a bathing suit because of their colostomy. And whereas all those imaginings might be accurate, there is a whole world of imaginings that people typically leave out. They do not consider the hundreds of routine daily activities that will be unaffected by their colostomy — things like watching TV shows, enjoying good conversations, savoring tasty meals, and the like” (Ubel *et al* 2005).

When predicting QoL outcomes, the healthy person looks at the future scenario with a mindset focussed disproportionately on the problem, often almost to the exclusion of the other important aspects of life. This mindset contrasts sharply with the mindset of the assessee–experiencer, who has had time for all of the other parts of his or her life to

regain their importance and hence possesses a mental focus that is redistributed to more closely match the proportions it was prior to the adverse event. The focussing illusion has proved to be a very powerful force and extremely difficult to disregard when one looks to his or her own future situation. Schkade and Kahneman (1999) noted that even when the persons predicting a QoL (including their own) are aware of this influence, it is particularly difficult to exclude from predictions of well-being. Accordingly, expectations of being able to adopt the mindset necessary for an accurate forecast of the most likely QoL outcomes may be unrealistic.

As is true for the other factors and forces contributing to faulty QoL predictions, this one has important applications to animals in that it is the same human mind that misjudges its own future QoL that is predicting the animal's QoL as a guide for decision-making. It would be reasonable to assume that mispredictions for one's own QoL would translate into even less reliable forecasts for a nonhuman's QoL, regardless of the degree of the person's knowledge of and familiarity with the animal. As long as the focussing illusion exerts its effect then the assessor cannot assume the mindset necessary to accurately foresee anyone's QoL outcome, including his or her own.

Underestimation of adaptation

Studies in humans and animals have identified a robust psychological trait shared by many species, and seemingly present in all mammals, that allows them to mentally adjust to wide-ranging changes in their life circumstances (Lykken 1999; Argyle 2001). Ample evidence exists that as an individual comes to terms with the conditions of long-term illness, disability, or emotional trauma, psychological changes occur that help to preserve one's life satisfaction, and individuals can judge their QoL as good even when severe limitations exist on their physical abilities (Leplege & Hunt 1997). Argyle (2001) has suggested that it is this trait of adaptation that may explain the finding that although elderly people are in poorer health, more likely to be socially isolated, and less well-off financially, they are not, on average, less satisfied with life than young people, and in fact may be more satisfied.

Numerous studies have shown that in humans it is unusual for any single event — good or bad — to create a lasting alteration of the individual's sense of well-being, a phenomenon that holds true even for the greatest extremes of tragedy and triumph (Suh *et al* 1996; Lykken 1999). The death of a cherished companion or spouse, severely disabling and permanent injuries and illnesses such as paralysis, loss of vision, or the diagnosis of a progressive fatal disease — or, conversely, receiving a major promotion, highly esteemed honour, or coveted award; winning a major professional competition or tournament championship; and even winning multimillion dollar prizes in gambling ventures — all lead to extreme emotional lows and highs that, in time, usually recover to the prior level of happiness (Myers 1992; Lykken 1999; Argyle 2001). Studies of people seriously injured in car accidents found that less than one month after victims suffered paralyzing spinal cord injuries,

their pre-injury levels of happiness had often returned (Myers 1992; Lykken 1999).

By making the mental impact of events impermanent, adaptation equips the individual with the ability to rebound from the emotional lows (and highs [Suh *et al* 1996; Lykken 1999]) of life's events. This psychological mechanism ensures that the individual is not incapacitated from psychological trauma, prevents complacency in the event of sudden good fortune, and appears overall to ensure that the individual is able to effectively respond to the subsequent challenges he or she encounters in life.

The influence of adaptation on QoL prediction cannot be overstated. It not only exerts powerful changes on QoL, but also exerts them for both directions of emotional deviation. Adaptation to negative influences on an individual's QoL occurs by a positive shift of QoL toward pre-change levels. This creates a tendency to *underestimate* QoL outcomes to negative events; that is, to predict a lower QoL than actually results. Conversely, adaptation to positive influences occurs by a negative shift with movement back to pre-change levels. This creates a tendency to *overestimate* QoL outcomes to positive events — predicting a higher QoL than actually results. To use a sports analogy, one may visualise a field with goalposts (eg rugby or American football) with 'good QoL' behind the goalposts and 'poor QoL' in front. For negative influences on QoL, adaptation moves the goalposts up, or nearer, such that what originally appeared as if it would fall in the zone of 'poor QoL' actually ends up *behind* the repositioned goalposts — in the 'good QoL' zone. In the same way, for positive influences on QoL, adaptation moves the goalposts back, or further away, such that what originally appeared as if it would fall in the zone of 'good QoL' actually ends up *in front of* the receding goalposts — in the 'poor QoL' zone. Of course, not every adaptation shift results in a crossover from good to poor QoL or *vice versa*, but the shifts follow the same pattern of movement in all gradations between very good and very poor.

Although it is widely agreed that the capacity for adaptation evolved as a useful psychological tool for coping with adversity (as well as with extremely pleasant events), the precise mental mechanisms behind adaptation are not well understood. It is currently unclear whether adaptation represents a diminished emotional response to events (habituation), active coping strategies, changes of perspective and one's own standards as to what comprises a satisfying life, or some combination of these or other unknown factors (Diener & Lucas 2000).

Studies and anecdotal observations suggest that adaptation works similarly in animals and in humans. A study of dogs that had become paralysed in their hind legs showed that their mental attitude, as judged by their owners, was as good three months after as before the paralysis in 85% of the animals (Bauer *et al* 1992). In a survey of dog and cat owners whose pet had undergone a limb amputation, all respondents (17 out of 17) said that after their pet had adjusted it was as active and happy as it had been before the

amputation (Withrow & Hirsch 1979). In another study of animals having had amputations performed, 100% (74 out of 74) of pet owners reported that their pets led normal lives after healing from the surgery (Carberry & Harvey 1997). (It is important to note that none of these studies addressed the potential of respondent bias, such as incorrectly reporting the pet's QoL as higher than it actually is in order to justify the decision to treat.) Anecdotally, pet animals in a household have been observed to experience emotional upsets and signs of clinical depression when a new pet or human infant is added to the home or when the pet loses an animal or human companion (Overall 1997, 2002, 2004). From a clinical impression but lacking hard data, in my (McMillan 2005) and others' (Dodman 1997) experience, the recovery rate of these animals back to their original emotional well-being appears to be roughly the same as seen in humans recovering from similar emotional troubles.

A concept of psychological adjustment has been characterised which appears to be a manifestation of adaptation. Current evidence suggests that for humans and at least some nonhuman species, a stability in the average emotional life of individuals exists that transcends the momentary fluctuations in mood. Life events produce upward and downward shifts in momentary affect, but when moods are assessed over several weeks or months, these shifts average out to reveal one's mean level of emotion (Diener & Larson 1984). This stability and relative constancy of one's level of subjective well-being (SWB) represent a concept that has been termed 'the happiness set point' (Lykken 1999). Base happiness levels appear analogous to a temperature thermostat, which, in time, always tends to return to the set point. Furthermore, the set point level has a strong genetic influence and differs substantially between individuals; some people have a high set point (persons reporting a high level of happiness), and others have a low set point (persons with self-reported unhappiness) (Lykken 1999). The transient nature of emotional fluctuations in animals suggests the presence of a happiness set point not dissimilar to that in humans.

Adaptation is an enormously beneficial process for the animal to which it occurs, but it creates correspondingly enormous obstacles for accurately predicting QoL. The problem occurs because the person making the QoL forecast has a mindset that differs from the adapted mindset of the experiencer of the predicted QoL. It is quite difficult for the assessor to adopt a mindset that has undergone the transitional process of adaptation. If healthy people do not take the adaptation process into account, or underestimate its power, they are bound to arrive at overly pessimistic predictions about the enduring QoL impact of illness, disability, aging, and emotional trauma on an animal, another human, or themselves.

Limitation of the brain's ability to detect slow change

The vertebrate brain is remarkably sensitive to changes — in light, sound, temperature, pressure, size, weight, and movement. However, the brain's detection capabilities are limited to a specific range of the rate of the change. Changes

that occur extremely slowly will be undetectable. The human brain, for example, can detect movement of a clock's second hand, but not of the minute or hour hand — even though they are in constant motion. The same is true for flowers blooming and the sun moving across the sky. The rate of the change required to set off the brain's detection circuitry varies between species, but it appears that there is a lower limit for detection for any species. To illustrate, consider one extreme — the expanding cosmos we inhabit. The stars in the sky are steadily moving apart from one another, yet it seems rather safe to say that if every living creature on Earth (with adequate vision) were to gaze at the night sky, not one would detect any movement. This limitation, as for other sensory limitations, makes evolutionary sense, since it seems likely that changes that occurred slowly over lengthy time periods were too infrequently associated with threats to well-being in our ancestors' pasts to have guided the evolution of a mental defence mechanism able to perceive such change.

Because the brain–mind–individual is not alerted to changes that happen slowly, we accept gradual changes that we would reject if they happened suddenly. A very gradual decline in eyesight, gain or loss of weight, decrease of stamina, or restriction in joint flexibility can progress imperceptibly to a point far beyond that where the change would have been detected had it occurred rapidly. Acceptance of QoL-influencing changes that occur too gradually to detect is a passive process that occurs below the level of consciousness. It is an adaptation-like process, but it is distinguishable by the individual's total lack of awareness that the changes are occurring. The change is simply incorporated — also unconsciously — into the individual's life as it occurs. Rapid changes, in contrast, *are* detected and adaptation and coping responses are elicited.

The difficulty that this imposes on QoL prediction is that the assessor's mindset involves complete and instant conscious awareness of the factor influencing QoL. This contrasts markedly with that of the experiencer, who has no such perceptions. For negative QoL influences, here, as in simple adaptation, the mismatch of assessor and assessee mindsets is likely to lead to a tendency to underestimate QoL outcomes. To accurately project a future QoL, the assessor would have to do so with a mindset lacking — or able to suppress the awareness of — knowledge of the change, yet incorporate knowledge of the *impact* this undetected change would probably have on the individual's QoL. The likelihood of this being accomplished seems very remote.

Effect of momentary mood

Substantial evidence exists suggesting that moment-to-moment mood states assume a major role in global QoL self-assessments. It has been shown, for example, that when making global assessments, people place disproportionate weight on their recent mood, resulting in an inordinately strong influence by current moods on self-rated global QoL (Suh *et al* 1996; Heinonen *et al* 2004; Steptoe & Wardle 2005). In proxy ratings, current mood influences may

produce a mismatch of mindsets between assessor and assessee, which could result in an incorrect QoL prediction.

The implications of this in pet animal care could be quite substantial. One of the most difficult decisions made in animal care — euthanasia — is based on QoL prediction. The euthanasia option in veterinary medical care arises at a time when the pet is or will be suffering, and it becomes clear that the pet owner now faces the loss of her companion. Accordingly, the euthanasia decision is being made at the very time when the pet owner is experiencing a number of extremely powerful negative emotions. This creates a highly undesirable situation: at the time when accuracy of QoL prediction is most essential, the predictor is often emotionally distraught. No researchers have yet pursued this line of investigation, but if current mood influences proxy assessment of QoL outcome in animals in the way it does for human self-assessment, then it is quite possible that QoL outcomes are being mispredicted in substantial numbers.

(2) Predictions made on the basis of unforeseen or incorrectly estimated psychological changes

Two processes are known to involve the confounding factor of unforeseen or incorrectly estimated psychological changes. They are: (1) scale recalibration, and (2) changing priorities (values, preferences, interests, and domain weights).

Scale recalibration

With no fixed reference points to keep QoL anchored there is nothing to prevent it from moving in one direction or another relative to the individual to whom it is being applied. For the same reason, if the scale shifts position there is no known way to accurately measure the shift. This introduces further complexity into the problem of the disability paradox and the moving target nature of QoL.

Ubel *et al* (2005) pointed out that when a person reports that his or her overall QoL is ‘8 out of 10’, this response carries very little inherent meaning. What one person means by ‘8 out of 10’ (or ‘very good’, ‘below normal’, ‘high’, or any other description or unit of measure) could be different from what another person means by the same rating. To illustrate, consider a vibrant, energetic, and optimistic 28-year-old man, and a 78-year-old man who has diabetes, arthritis, a heart condition, and failing eyesight, both rating their QoL as ‘90 out of 100’. Consider too that the young man has expressed in a confidential interview that he would be miserable if he were that same elderly man. In light of this, does a score of 90 mean the same thing for the two men? Many researchers believe that it does not. A concern among QoL and mood researchers is that the subjective scales used in such research are susceptible to *scale recalibration*. As Ubel *et al* (2005) explain, the QoL scale has shifted, such that a ‘90’ for the elderly man means something different from a ‘90’ for the young man. When people’s health declines, or when their age or disability progresses, they might start reinterpreting what these response numbers, or what the maximum, mean (Ubel *et al* 2005). There appears to be a shift in the internal standard, which does not reflect a change in the basic structure of QoL for that individual, but results in a changed expectation of QoL more in fitting

with the individual’s current situation in life (Schwartz & Sprangers 1999; Sprangers & Schwartz 1999).

Scale recalibration is routinely applied in animal QoL assessment. For example, a typical comment from the owner of an elderly dog is ‘He’s doing pretty well, considering his age’. The key phrase here is ‘considering his age’. This qualifying comment *is* the scale recalibration — it signals that the owner is applying a different standard to this dog than she would to a young dog. In addition, the ‘pretty well’ is like the ‘90’ in the above human example — it has no specific meaning in and of itself. Such a rating does not necessarily mean the same thing for a 17-year-old Cocker Spaniel as it would for a two-year-old.

Changing priorities (values, preferences, interests, and domain weights)

Personal priorities, values, and interests — represented in many QoL instruments by domain weights — are well accepted as important determinants of an individual’s QoL. The assumption underlying the evaluation by a proxy of another’s QoL is that the proxy knows or is capable of rendering a good estimation of someone else’s values and priorities (von Essen 2004). However, numerous studies have demonstrated quite clearly that values and priorities are not stable over time; rather, they vary substantially with life events and experiences, and these changes may play an important role in altering perceived QoL (Bernhard *et al* 2004; Hammell 2004; Lowy & Bernhard 2004; von Essen 2004). Accordingly, accurately predicting a future QoL assumes that the proxy will be able to know or foresee any important changes that might occur over time in the individual’s priorities.

The need to detect and follow changes in priorities and values is critically important in the task of predicting QoL outcomes to guide current decision-making. Stewart *et al* (1999) point out that values change at various stages in life and that what was once important may at a later point in life seem insignificant, while things once ignored may acquire greater weight. They noted that terminally ill patients, during different phases of the dying process, may attach more importance to one aspect such as the cognitive ability to recognise family and friends than to other, formerly vital, matters such as walking or even bodily functions. Lowy and Bernhard (2004) write that changing ideas about what constitutes the quality of one’s life may invalidate comparison of later with earlier time points. They provide an example: “a bed-bound patient may adapt to his or her lack of mobility to such an extent that it stops having a great impact on the perceived quality of his or her life. If a later QoL score is calculated using an unchanged set of weights, it will fail to take account of the fact that the individual perceives immobility as less relevant to his or her QoL than previously” (Lowy & Bernhard 2004). Another familiar human example is the athlete who bases her current healthcare decisions on the prediction that any loss in her ability to compete in triathlons would be devastating to her future QoL. Any choices she makes to preserve her athletic abilities will later miss the target if she loses her interest in sports endeavours. The process is commonly seen in decision-making for animals. In domestic dogs, geriatric-onset separation anxiety

creates an intense emotional need for nearly constant human companionship and visible signs of severe distress when left alone. At the present time we have no ability to predict which dogs will develop this emotional disorder in their ageing years, and any current care decisions may well fail to take into account the drastic future changes in the dog's emotional interests and needs. On a more mundane note, virtually any cat owner can attest to the changes of interest cats show to toys and other methods of amusement. Animal care decision-making is based on predictions — sometimes simply best guesses — of the factors that will in the future be important to that animal's QoL.

Several researchers have noted that the changes in domain weights over time are not accounted for in most QoL instruments (Duggan & Lysack 2001; Hammell 2004; Lowy & Bernhard 2004), an approach to QoL assessment that is based on the implicit assumption that it is appropriate to use a fixed set of weights when calculating QoL as a weighted sum of a set of domain scores (Lowy & Bernhard 2004). There is increasing agreement among researchers, however, that QoL instruments should account for potentially changing domain weights over time (Lowy & Bernhard 2004).

The concordance of changing priorities and the QoL instrument reflecting these changes is an important aspect of the moving target nature of QoL. Several QoL researchers have stated that if a QoL instrument that is employed to serially monitor QoL changes uses fixed domain weights, then the changes measured may not represent actual QoL changes (Bernhard *et al* 2004; Lowy & Bernhard 2004). Unless the instrument has a method for incorporating changes in importance of domains to the individual, then it may not be capable of measuring changes in QoL. As a result, what the instrument is measuring over time will be something other than QoL (Bernhard *et al* 2004; Lowy & Bernhard 2004). For example, imagine a QoL instrument recording an animal's QoL over time as 87 on a scale of 100, then 73, then 61, and then 45. If this instrument has no mechanism for imputing changes in domain weights and these weights do change from the animal's perspective, then the changing numbers may not represent a decline in QoL; the numbers may not, after a period of time, even be reflecting QoL at all. If an evaluation method does not detect change that is occurring in the determinants of the factor being measured, then that factor and the score generated become independent of one another. In fact, it is conceivable that if domain weights on the QoL instrument do not change over time while in the individual's eyes they do, a changing score for QoL could actually occur as QoL stays the same or even changes in the opposite direction.

Because of the necessity for a proxy rater to have reasonable knowledge of the priorities, interests, and values of the individual being evaluated, proxy ratings of QoL present a considerable challenge even when the evaluation process is focussed on one single, present point in time. The challenge is much more formidable, however, when QoL assessment crosses a span of time, as in the task of QoL outcome prediction. To correctly predict the outcome of a specific choice on QoL at a later time, the assessor must be able to make reliable predictions of future values and priorities.

Conclusions

The unsecured, shifting, slip-sliding nature of QoL — and, specifically, the disability paradox that derives from it — renders any method of QoL assessment based on 'I would/would not want this for myself' highly unreliable. While this type of assessment has a distinct intuitive appeal — it *feels* right — this method is ill-suited to generate accurate QoL predictions upon which optimal decision-making can be based. Indeed, in animal QoL assessment, these methods would be unreliable even if the animal could express in detailed human language what it would or would not be happy with — eg 'I could never be happy if I lost my vision' — because we know from the numerous studies cited above that even humans make such resolute assertions about themselves, yet those who have actually experienced the adversity often adapt and ultimately rate their QoL as surprisingly high.

The disability paradox must be taken seriously in any attempt to predict QoL for any person or animal. In earlier writings (McMillan 2003; McMillan & Lance 2004) I had proposed an informal test consisting of subjective questions. One of the questions included was:

"Imagine that you are a pet animal of the same species as your pet and that you have the best quality of life you can imagine a member of this species having. On a scale of 1 to 10, 1 being extremely unwilling and 10 being extremely willing, how willing would you ... be to exchange your life for the life your pet is now living?" (McMillan & Lance 2004).

With our current knowledge of the disability paradox, it is clear that no matter how intuitively appropriate this question might appear, the actual validity of the question is low. The fundamental error in this type of question is best addressed by Kahneman (1999), who points out that predictions of QoL — in, for example, a disability of paraplegia — commonly fail to distinguish appropriately between the state of *being* paraplegic and the event of *becoming* paraplegic. An emphasis on the former is shocking to the senses and predicted to be devastating to one's life. In stark contrast, recognising this distinction and emphasising the latter puts the assessor's viewpoint closer to the actual experience, and one can more easily visualise a process of *transition* — and an acceptance of and adaptation to the disability. The long-term follow-up QoL studies in people with severe chronic illnesses and disabilities suggest that even a score of '1' to my question above would not prevent a person or animal with the unwanted condition from ultimately experiencing a good or even excellent QoL.

To make optimal decisions for an animal's well-being today, we need to be able to formulate an accurate view of the QoL impact of our decision down the road. It is a moving target we are aiming at, and we currently lack the knowledge necessary to firmly anchor that target so that it is easier to hit. Although we cannot now eliminate the factors that give rise to the disability paradox, we can at least be aware of them and factor them into our calculations when predicting QoL outcomes.

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