

# **Presentations from the Australian Society for Quality of Life Studies (OzQol) Conference 1999 Proceedings**

## **Coping Styles and Prison Experience as Predictors of Psychological Well-Being in a Sample of Male Prisoners**

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### **Past Research**

Lack of consistency in outcomes regarding associations between:

- Prisoners' psychological adjustment and time served in prison.
- Adjustment and sentence length.

### **Time Spent in Prison and Sentence Length**

- Psychological adjustment does not deteriorate with increased time served in prison (see review by Bukstel & Kilmann, 1980).
- No predictable relationship exists between sentence length and psychological well-being (e.g. MacKenzie & Goodstein, 1985; Sapsford, 1978, 1983) Wormith, 1984)
- Other studies have shown differences depending on sentence length and time served in prison.

### **Coping Styles**

As a group, prisoners engage in fewer adaptive coping strategies. (Flanagan, 1980; Richards, 1978 ; Zamble & Porporino, 1988, 1990).

Little evidence that the prison experience causes maladaptive coping.

### ***Characteristic Behaviours described as:***

- Confronting
- Impulsive
- Emotional
- Without planning
- Disorganised
- Lacking persistence
- Avoidance-oriented

### **The Present Study**

#### **Broad Aim**

- To further examine psychological well-being of prisoners.

### Specific Aims

- To examine the relationships between prison experience and anxiety, depression, self-esteem and coping style.
- To examine prisoners' subjective quality of life compared to population norms.

### Subjective Quality of Life Normative Data

Cummins (1995; 1998; 2000):

The level of subjective quality of life within western populations is held at:  $75 \pm 2.5$  % of the Scale Maximum score (% SM).

### Participants

A total of **81** male prisoners

**Age:** 18 to 73 years  
 $M = 35.2$  years  
 $SD = 9.8$  years)

Recruited from a maximum security prison (i.e. Her Majesty's Prison Pentridge)

### Education

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Education Level	%
Secondary School (three yrs or less)	32.1
Completed Secondary School	9.9
Trade Qualification	17.0
University Degree	3.7
Post-graduate Degree	6.2

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### Employment History

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Employment Status	%
Full-time Employment	38.3
Part-time Employment	21.0
Unemployed	40.7

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### Previous Institutionalisation

Youth Correctional Institutions	53.1%
Adult Prisons	77.8%

### Representativeness of Prison Population

Participants represented 26.2% of the prison population available on each day of testing.

### Current Time Spent in Prison

$M = 1.73$  years  
 $SD = 1.5$  years  
**Range:** less than one month - 8 years

### ***Sentence Length***

*M* = 5.31 years

*SD* = 5.75 years

*Range:* One month - 22 years

## **Measures**

### **Coopersmith Self-Esteem Inventory** (Coopersmith, 1975)

- A 25 item self-report instrument
- Measures the extent to which respondents judge themselves to be competent, successful, significant and worthy.
- Rating Scale: 'like me' or 'unlike me'
- Good validity and reliability (Coopersmith, 1981).

### **Beck Depression Inventory** (Beck, 1978)

- A 21 item self-report measure
- Assesses cognitions associated with depression
- Rating scale: Four statements from which respondents choose the statement that best describes the way they have been feeling in the last week 'including today'.
- A reliable and valid measure of depression (Beck, Steer & Garbin, 1988).

### **State-Trait Anxiety Inventory** (Spielberger, 1977)

- Comprises two sub-scales (20 items each)
- Each sub-scale assesses state and trait anxiety
- Rating scale:
  - Trait Anxiety*  
a four-point scale (as to how 'generally' feel)
  - State Anxiety:* Endorse the statement describing feelings 'right now'
- A reliable and valid instrument (Spielberger, Gorsuch, Lushene, Vagg & Jacobs, 1983).

### **Comprehensive Quality of Life Scale for Adults (ComQol-4; Cummins, 1993)**

- Measures **objective** and **subjective** dimensions of quality of life via seven life domains.
- Domains include:
  - Material Well-being
  - Health
  - Productivity
  - Intimacy
  - Safety
  - Place in Community
  - Emotional Well-being

Subjective dimension assesses

- Importance
- Satisfaction (7-point 'delighted-terrible' Likert scale)
- In the Present Paper only the satisfaction ratings will be discussed.

- Good reliability and Validity (Cummins, McCabe, Romeo & Gullone, 1994; Gullone & Cummins, 1999).

### **Coping Inventory for Stressful Situations (CISS; Endler & Parker, 1990a)**

- A 48-item self-report questionnaire
- Measures multi-dimensional coping:
  - (i) Task-oriented coping
  - (ii) Emotion-oriented coping
  - (iii) Avoidance-oriented coping
- Rating Scale:
  - A 5-point Likert scale ranging from 1 = 'Not at All' to 5 = 'Very Much'

Measuring **how much** respondents engage in specific activities or behaviours when facing difficult, upsetting or stressful situations

- Good validity and reliability (Endler & Parker, 1990)

## **Results**

Measure	Prison Sample		Comparison Sample	
	M	SD	M	SD
Self-esteem	57.95	18.68	71.70	18.80
Depression	17.14	7.80	17.48	7.15
State Anxiety	42.70	13.03	35.72	10.40
Trait Anxiety	47.26	11.58	34.89	9.19
Subjective QOL	58.80	3.9	75.00	9.6
<i><b>Coping Style</b></i>				
Task	54.00	8.23	58.56	9.95
Emotion	45.90	9.60	39.21	11.54
Avoidant	46.16	8.09	38.10	9.59

## **Correlation Analyses**

Significant correlations were as follows:

### **Prison Time**

- Task Focused Coping ( $r = .31, p < .01$ )

### **Sentence Length**

- Task-Focused Coping ( $r = .30, p < .01$ )

### **Self-Esteem**

- Subjective Quality of Life ( $r = .29, p < .01$ )
- Task-Focused Coping ( $r = .30, p < .01$ )
- Depression ( $r = -.62, p < .001$ )

- State Anxiety ( $r = -.36, p < .01$ )
- Trait Anxiety ( $r = -.58, p < .001$ )
- Emotion-Focused Coping ( $r = -.50, p < .001$ )

### **Depression**

- State Anxiety ( $r = .44, p < .001$ ),
- Trait Anxiety ( $r = .64, p < .001$ ),
- Emotion-Focused coping ( $r = .47, p < .001$ )
- Task-focused coping ( $r = -.26, p < .05$ ).

### **State Anxiety**

- Trait Anxiety ( $r = .70, p < .001$ )
- Emotion-Focused Coping ( $r = .55, p < .001$ )
- Subjective Quality of Life ( $r = -.36, p < .01$ )

### **Trait Anxiety**

- Emotion Focused Coping ( $r = .77, p < .001$ )
- Subjective Quality of Life ( $r = -.36, p < .01$ )
- Task-Focused Coping ( $r = -.23, p < .05$ )

### **Emotion Focused Coping**

- Avoidance Focused Coping ( $r = .48, p < .001$ )

## **Five Multiple Regression Analyses**

### **Each with the Dependent Variable as:**

1. Self-esteem
2. Depression
3. State anxiety
4. Trait anxiety
5. Subjective quality of life

### **Predictor Variables:**

- Emotion focused coping
- Avoidance focused coping
- Problem focused coping

### **Results**

- All five analyses yielded significant results.
- Between 7% (subjective quality of life) and 62% (trait anxiety) of the variance was explained.
- Emotion focused coping emerged as the most important predictor particularly for trait anxiety, depression, and self-esteem.
- Avoidance focused coping significant for anxiety (both state and trait) and subjective quality of life.

### **Prison Variables**

Standard Regression Analysis:

**Dependent Variable:**

- Task Oriented Coping

**Predictor Variables:**

- Time Spent in Prison
- Sentence Length

The two variables explained 8% of the variance in Task Oriented Coping

**Discussion**

- As a group, prisoners have a markedly lower level of subjective quality of life and self-esteem but a higher level of anxiety and depression amounting to a severely compromised psychological well-being.

*Subjective quality of life* (1.7 standard deviations below the normative mean)

*Depression* (within dysthymic range).

- Male prisoners are more likely to engage in emotion-focused and avoidance-focused coping behaviours, the former of which is highly likely to maintain their low levels of well-being.
- Moreover, the data suggested that prisoners show no signs of returning to normative levels of well-being over time.

**Conclusions**

- As with past research, it can be concluded that no change in well-being over the course of imprisonment indicates no adverse effect of imprisonment

OR

- That the well-being of prisoners deteriorated prior to the beginning of their actual prison term (e.g. upon conviction).
- The apparent stability of psychological dysfunction is, in itself, cause for alarm.
- It appears that the prison environment is acting in such a way as to maintain psychological well-being at dangerously low levels.

**Future Research**

- Studies should be designed so that it is possible to determine the level of prisoner well-being and coping styles prior to their prison sentence.
- More research is required that examines the effect of imprisonment on female prisoners to determine whether the reported findings can be generalised across gender.

# Childhood epilepsy syndrome, demographics and specific HRQOL: A two-stage graphical analysis of interrelationships.

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## Brief Description of Powerpoint Slides

**Note:** Except for the first slide, slides are numbered in the lower right-hand corner.

**Slide 1: Cover.** The children in this study all had intractable epilepsy where intractable means seizures occurring at least once per month despite appropriate medication. The paper was presented by David Cairns but the full list of authors was Mark Sabaz, David R. Cairns, John A. Lawson, Natalina Nheu, Andrew F. Bleasel, & Ann ME Bye. See the abstract for their affiliations.

**Slide 2: Overall Study.** This slide shows the overall study which included epilepsy variables, neurological variables, demographic variables and quality of life (HRQOL) variables. The ellipse around epilepsy, demographic and HRQOL shows that this presentation involves parts of the overall study. The HRQOL scale is a specific QOL scale developed for this population of children. Other general QOL measures were collected but not reported on in this presentation. The children in this research came from two Sydney children's hospitals and were aged between 4 and 18 years.

**Slide 3: This Presentation.** This slide gives further information about this presentation. It identifies the variables included within the demographic, epilepsy and HRQOL groupings.

**Slide 4: The Graphical Approach.** The title of this presentation describes the analysis as a two-stage graphical analysis. This slide identifies the two stages. Stage I is a graphical investigation of the relationship between the epilepsy and demographic variables while Stage II is a mapping onto the Stage I solution of the HRQOL variables. It should be noted that the HRQOL variables are external to the Stage I solution meaning that they were not used to develop the Stage I solution. The Stage I solution is an ordination which shows the patterns among the children based on epilepsy and demographic variables.

**Slide 5: Comparison of Inferential and Visual Approach to Data Analysis.**

**Slide 6: Visual Approach to Data Analysis.** This slide gives further information about how Stage I was conducted. The data matrix contains 34 rows, being the children in the study, and columns which are the epilepsy and demographic variables. This data matrix can be visualized as a column space, row space, or joint space. The various statistical techniques to achieve this visualization are listed on the right.

**Slide 7: The Output of Stage I.** A row space was produced using the PRINCALS program in the SPSS/CATEGORIES module. The output shows 34 points each representing a child in the study. Each point is a summary of the child's information across the epilepsy and demographic variables. SPSS calls the row space an "object diagram". Children who are similar across the variables will be close together in this space and children who are dissimilar will be far apart. We can see groups of children in this space. What variables are associated with these groups?

**Slide 8: Epilepsy Syndrome.** This slide shows the same object diagram however each point has been identified by its epilepsy syndrome type. The ellipses around the points are 66% confidence ellipses. Clearly we can see that the groupings of children are related to epilepsy syndrome with generalised in the upper left, frontal in the upper right and temporal in the lower right region of the space.

**Slides 9, 10, & 11: Relating Demographic Variables to the Epilepsy Regions.** These slides show the object diagram identified by each of the demographic variables. What we are looking for are regions of demographic variables which are similar in pattern to the regions of epilepsy types. In the top right of each slide a schematic representation of the epilepsy regions is given. On slide 9 we can see that Age of Onset is related to epilepsy with Frontal being mainly associated with After School age and Generalised and Temporal being associated with At Birth and Before School. By comparison there is no relationship between Gender and Epilepsy types.

**Slide 12: Summary of Stage I.** This slide summarises what was found by looking at slides 9, 10 and 11 and shows that there is a relationship between demographic variables and epilepsy syndrome. These relationships must be kept in mind when one is talking about epilepsy syndromes.

**Slide 13: The Graphical Approach.** This slide begins Stage II of the graphical analysis.

**Slide 14: Ways of Mapping External Variables.** This slide demonstrates two ways of mapping external information onto the object diagram. The external variables to be mapped were the 17 HRQOL scales which were all numeric scales. Appropriate diagrams for numeric external variables are the bubble plot and the contour plot. In the bubble plot each child point is represented as a bubble where the size of the bubble is determined by the value of the external variable. In the contour plot a “weather map” is produced with “isobars” determined by the value of the external variable. For this presentation both bubble plot and contour plot methods were used for each graph. This slide shows the two plots separately for the external HRQOL variable Attention/cognitive subscale. The Generalised region of the space seems to have smaller bubbles and “colder” isobars which represents lower QOL on this subscale.

**Slides 15, 16, 17 and 18. Four Mappings.** These slides show the bubble/contour plots for four more external HRQOL subscale variables.

**Slide 19: Summary of Stage II.** This slide summarises what was found by looking at slides 15 through 18 and the other external mappings not included in the presentation. This shows that there is a relationship between HRQOL subscales and epilepsy types, however, it should be remembered that there is a relationship (confounding) between epilepsy types and demographic variables.

**Slide 20: Why Graphical Analysis.** This slide presents some points for discussion concerning the issue of p-values for non-experimental exploratory research.

**Slide 21: In Praise of Graphs.** Just reiterating my personal preference.

# Making Life Better: The science and the politics

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## Introduction

A book just published in the United States, *Myths of Rich and Poor – Why we're better off than we think*, argues: 'Poor households of the 1990s in many cases compares favourably with an average family in the early 1970s in owning the trappings of a middle class life. For example, almost half of the poor households had air-conditioners in 1994, compared to less than a third of the country as a whole in 1971. The pattern holds true for dryers, refrigerators, stoves, microwaves and colour televisions'

A reviewer of the book, Kevin Kelly, says the authors, a business reporter and an economist, demonstrate that 'rationally measured (by hours worked to gain something) most Americans have more leisure time, more disposable income, and vastly higher standards of living than ever before'. Our notions of rich and poor are antiquated.

Kelly, himself the author of a recent book, *New Rules for the New Economy*, that extols the promises of the new digital economy, concludes his review by saying that 'life really, really is getting much, much better'. I emailed him to say that more antiquated than any notion of rich and poor is the notion that more equals better. I went on to outline why this notion is antiquated – which is, in part, also the subject of this talk.

He replied: 'The reason why I said the scenario of a world getting better is worth considering is because while the happiness index isn't changing much, the wealth index is. So one parameter is static, while the other parameter is improving -- therefore things are getting better. It is worth keeping in mind that it is opportunities that we want more of, not necessarily more stuff, more materials, or more money. My definition of wealth is beyond merely having access to money, but rather increasing access to opportunities.'

But he agreed with me that something was lacking: if we were so rich how come we were so aimless, so incoherent, so jaded and full of doubt about everything, he said. 'I'm not so ready to wrap all these feelings under the heading of (un)happiness, because I think it is possible for people to feel happy - content, invigorated, satisfied - and still lack meaning in their lives. I read a lot of history and I don't have the feeling that people are *less* happy now. They are less certain who they are, less centered, and less prepared for death, but in a funny way, no less happy. My image of the modern person is someone who has no idea who they are; all they know is that they are very important, above average in intelligence, and mostly happy. And they are increasingly rich, or at least richer.'

Kelly's comments highlight some of the subtleties and complexities of defining 'a better life' and so the difficulties of measuring it.

## Outline

Quality of life (QoL) research seems to basically fit into two camps – general QoL and health-related QoL. I won't be discussing health-related QoL, with which many of you are concerned. However, I believe research in that area can inform the bigger picture – and vice-versa. For example, some of the first exposure I had to notion of adaptation in QoL came

from the literature on QoL in psychiatric patients. It notes, for example, that patients with a long-term disorder 'adapt their standards downward'. One study found patients in long-stay hospital wards reported high levels of satisfaction, and while moving from hospital back into the community improved objective life domain indices, life satisfaction rating showed no significant change.

I want to take a very 'big picture' view of QoL – mainly a national level. This view is based on several assumptions, which are also tested. These include that:

- The 'macro' economic, social, cultural and environmental changes taking place impact on QoL – for better or worse.
- Politics – ie, the exercise of power and influence in the management of social affairs - is or should be about improving QoL.
- Understanding these macro impacts is therefore important to political processes.
- And research and analysis can elucidate these impacts, and so inform political debate, leading – hopefully – to a better QoL.

I propose to discuss this macro view of QoL from three perspectives, using a lot of trend data, and commenting briefly on these:

- Objective measures used in measuring progress or QoL.
- Subjective measures of personal QoL or well-being.
- Subjective measures of social – societal – QoL or well-being.

I want to suggest two definitions of QoL that are suitably broad, significantly different, and both relevant to what I have to say:

- QoL = total well-being – physical, mental, emotional, social and spiritual.
- QoL is 'the gap between a person's expectations and achievements' (Calman).

Bacon might have been defining QoL when he said, talking about medicine, that its 'office... is but to tune this curious harp of man's body and reduce it to harmony.'

### **Objective measures**

National progress is usually measured in terms of growth in Gross Domestic Product (GDP), the total value of final goods and services produced in the market economy. In other words, standard of living is equated with quality of life. Australians are, on average and in real terms, almost five times richer now than at the turn of the century. If the Commonwealth Government meets its target of maintaining economic growth at over 4% a year we will be twice as rich as we are now in about 20 years' time, and ten times as rich as we were 100 years ago. Life expectancy is another commonly used measure of progress. Australians' life expectancy has increased by about 30 years or 60% since the 1880s. As yet, it shows no sign of reaching a natural limit.

On these measures, life is clearly getting better.

However, other measures are not so reassuring. Unemployment is one, reflecting not just material standard of living but also social exclusion and participation. The unemployment rate was at historically low levels during the post-war period of rapid growth – until the mid-

1970s, when slower growth rates, accelerating technological change, globalisation and other structural economic changes saw the unemployment rate ratchet up with each recession. The result: unemployment in the 1990s has been at its highest levels outside the 1890s and 1930s depressions. Per capita energy use, a broad measure of resource consumption and waste production, has increased with per capita GDP, and is also about five times higher than 100 years ago. Australia's population has also increased about fivefold, so that total economic activity and energy use are about 25 times greater now than 100 years ago.

Globally, we are still moving away from ecological sustainability, not towards it. The World Wide Fund for Nature's 'Living Planet Index', based on an assessment of forest, freshwater and marine ecosystems, declined by about 30% between 1970 and 1995, 'meaning that the world has lost nearly a third of its natural wealth in that time'. WWF also says that, globally, consumption pressure, a measure of the impact of people on natural ecosystems based on resource consumption and pollution data, is increasing by about 5% a year. At this rate, consumption pressure will double in about 15 years.

Another global issue is equity. Whether the gap between the world's rich and poor is currently widening is hotly contested and can depend on the statistics used. But historically it is clearly the case that the rich have got richer much faster than have the poor, many of whom have got poorer.

Over the past few decades, and especially in the 1990s, the belief that economic growth (as currently defined and derived) both enhances well-being and is sustainable has come under challenge. This has fueled interest in the development of new measures of progress, such as the Genuine Progress Indicator, that adjust GDP for a wide range of social, economic and environmental factors that GDP either ignores or measures inappropriately. They include income distribution, unpaid housework and voluntary work, loss of natural resources, and the costs of unemployment, crime and pollution. These 'GDP analogues' show that trends in GDP and social well-being, once moving together, have diverged since about the mid-1970s in all countries for which they have been constructed, including the United States, United Kingdom and Australia.

The reasons for this divergence may vary between nations, but include: the growing costs of environmental damage and resource depletion, including greenhouse gas emissions; increasing income inequality; unsustainable foreign debt; the rising cost of unemployment and overwork; the failure to maintain capital investment; and the transfer of (unpaid) household production to the market. The American non-profit, public-policy organisation, Redefining Progress, which developed the Genuine Progress Indicator, argues that much of the current growth in GDP derives from three things: 'fixing blunders and social decay from the past; borrowing resources from the future; or shifting functions from the traditional realm of household and community to the realm of the monetised economy'.

The trends in indices such as the GPI support the notion that there is a threshold effect in the relationship between growth and well-being. In the late 1980s, the Chilean economist, Manfred Max-Neef, and his colleagues undertook a study of 19 countries, both rich and poor, to assess the things that inhibited people from improving their well-being. They detected among people in rich countries a growing feeling that they were part of a deteriorating system that affected them at both the personal and collective level. This led the researchers to propose a threshold hypothesis, which states that for every society there seems to be a period in which economic growth (as conventionally measured) brings about an improvement in

QoL, but only up to a point - the threshold point - beyond which, if there is more economic growth, QoL may begin to deteriorate.

### **Subjective personal QoL**

Let me turn now to the realm of subjective measures. With these the result you get, and the picture or trend that emerges, can depend critically on the question asked. A new Gallup Poll in the United States offers an interesting example of this. The poll found that the proportion of American adults who want to lose weight or weigh more than their ideal weight was unchanged between 1990 and 1999 at 52% and 62% respectively. The proportion actively trying to lose was up slightly from 18% to 20%. Yet the self-reported weight of the nation's adults increased almost 10 pounds (4.5 kilograms). However, because their notion of their ideal weight had also increased, fewer considered themselves to be overweight today than they did then: 39% in 1999 compared to 48% in 1990.

With this cautionary tale in mind, let me look firstly at subjective measures of personal QoL or life satisfaction.

The most remarkable thing about the trend here is that the proportion of people who are basically happy or satisfied with their lives has remained stable over the past several decades – the past two in Australia, but US data show this over a five-decade span – even though we have been, on average, growing richer. The relative independence of life satisfaction from income is also apparent in the relationship between satisfaction and income in populations: the gradient is surprisingly flat, with a substantial difference occurring only at the extremes – that is, the richest group do appear to be happier than the poorest. This has been explained in terms of a dynamic equilibrium model (Headey and Wearing) or homeostatis (Cummins).

The evidence suggests that people adjust expectations and use illusions to maintain over time a relatively stable, and positive, rating of life satisfaction or QoL. Indeed, their health and sanity may depend on this adaptability. This does not mean that what happens in the social, economic and political spheres does not matter at a personal level, but that the relationship between the objective and subjective worlds is not linear – that is, a change in the former does not produce a corresponding and equal change in the latter.

For example, there appears to be a significant element of genuine, and necessary, illusion about people's personal situation - what has been called the 'human sense of relative superiority' (Headey and Wearing). In almost all countries that have been studied, most people rate their subjective well-being well above average. Headey and Wearing suggest that this might be because almost all human beings explicitly believe that their own performance in major life roles is well above average. A sense of relative superiority appears to be normal and an important aspect of human psychology. 'People who feel average (let alone below average) in their main roles have lost a crucial prop to self-esteem and well-being.'

Cummins and Nistico say there is 'an intimate relationship between illusory self-beliefs and life satisfaction'. The factor most closely associated with subjective QoL is satisfaction with the self, and, in particular, positive beliefs of self-worth, control and optimism, they say. Illusions allow the existence of these self-beliefs as 'buffers of reality' – that is, the beliefs do not accurately reflect the objective realities of life. 'The non-specific and unfalsifiable nature of illusions makes them a robust mechanism for the maintenance of self-satisfaction.'

Whatever the explanations, there is clear evidence for a positive bias in responses to personal questions. Pusey (1998a) asked his sample of middle Australians who were the winners and losers from 'the economic change that Australia has experienced over the last 15 years or so'. The proportion saying 'people like me' were losers was considerably smaller than that for 'ordinary people generally', 'people in the middle' or 'wage and salary earners', while the proportion saying 'people like me' were winners was correspondingly higher than for the other categories.

Another illusion used to maintain life satisfaction concerns hope and optimism. Both US and Australian survey data show that people tend, in terms of life satisfaction, to see life as getting better: they rate the present better than the past and expect the future to be better than the present. For example, Gallup has asked Americans to picture life as a ladder where the top step (10) represents the 'best possible life for you' and the bottom step (0) the 'worst possible life for you'. It asked them to state which step of the ladder they stood on at the present time, five years ago, and which step they thought they would stand on in about five years. They've asked this question eight times since 1964. Between 1964 and 1998, the proportion choosing steps 8 to 10 ranged from 25-29% for the past, 31-44% for the present, and 52-72% for the future.

The positive bias in life satisfaction measures is also evident if we compare these with mental health figures. Public surveys consistently indicate that roughly 5% of people, or less, say they are unhappy or dissatisfied. Yet in Australian surveys in the late 1980s, about 20% of people agreed their lives were 'coming apart at the seams'. Mental health surveys show that about 20% of Australians have experienced mental health problems in previous 12 months.

To take another example, this time focusing on young people, a recent Victorian survey found 89% per cent of students aged 13-15 were satisfied with 'their life in general these days'. Yet another recent study, again in Victoria, found 25-40% of students 11-18 experienced in previous 6 months: feelings of depression, worries about weight, worries about self-confidence, troubles sleeping, and not having enough energy

These findings are not necessarily incompatible. The life satisfaction surveys are measuring point prevalence, the mental health and well-being studies 12-month, or 6-month prevalence. The nature of life satisfaction may mean that we need to regard the group in the middle of life satisfaction distributions, not just those at the 'unhappy' end, as being psychologically at risk.

My point in making the comparisons is that the two sets of data present very different portraits of people's QoL.

Let me conclude this section with some interesting anecdotal evidence of the extent to which the public face can differ from the private person.

The psychoanalyst, Sue Erikson Bloland, in a fascinating study of her famous father, the celebrated psychologist Erik Erikson, contrast the public face of the man – charismatic, confident, concerned, compassionate, an authority on the psychological development of children and adolescents - with the private person – insecure, vulnerable, plagued by feelings of self-doubt and inadequacy, terror- and grief-stricken at his inability to soothe and comfort his own children.

Bloland notes how often fame and success mask a sense of personal failure and isolation, and are driven by a longing for human connection, for intimacy. She discusses the psychology of our need to idealise others as well as the need to be idealised. 'How much do we hide behind the illusion that we are somehow larger than life, out of fear of acknowledging to others how needy and inadequate we sometimes feel? The need to appear larger than life – like the need to believe in the superhuman status of others – helps us to cope in a frightening universe, but it also limits our capacity for intimacy.

I once met a man who was wealthy, successful and came across as gregarious and enjoying life. 'Life's great, isn't it?' he said, 'You wouldn't be dead for quids.' I later learned he was an alcoholic. I once read a review of a biography of entertainer, Danny Kaye, that described the book as: 'a thorough study of a cruelly mean-spirited, sadly insecure manic depressive who came across to the world at large as a generous, outgoing, happy and well-adjusted fellow'.

The difference between the public and private person raises an interesting question: If we measured, say, Danny Kaye's or Erik Erikson's subjective QoL or life satisfaction, which person would we be measuring?

### **Subjective social QoL**

I want now to turn to subjective measures of social (or societal) QoL. It is, as I've argued in a recent paper for Social Indicators Research, a quite different category of measurement. It concerns people's perceptions, not of their own lives, but of life in their community or country, of how they think people in general, or on average, are faring.

Again, the focus and wording of the question is critical. For example, Gallup regularly polls Americans on whether they are satisfied or dissatisfied 'with the way things are going in the US at this time'. The poll shows that 71% were satisfied in February 1999, an all-time high and up from 24% in January 1996. However, the response appears to be a reflection of transient contemporary political and economic conditions, rather than any long-term shifts in American life. Results are highly variable, swinging over the past 20 years from troughs as low as 12% satisfied to peaks of over 60% satisfied in cycles as short as 5 months (more usually several years). These cycles appear to be linked to economic and political performance and events. Satisfaction may be on the decline again; by April 1999, it had dropped to 51% and in June stood at 55%.

In my own work, I've been experimenting with questions that tap public perceptions about the long-term trend in social QoL. In marked contrast to studies of how people feel about their own lives, these yield much more negative findings. In a June 1997 national poll, we found that 52% of Australians believed 'the overall quality of life of people in Australia, taking into account social, economic and environmental conditions and trends' was getting worse, with only 13% believing it was getting better. A third (33%) said QoL was staying about the same; 2% did not know.

Those on high incomes were more positive than those on low, those aged under 35 more positive than those over 35, city people more positive than country people, and men (slightly) more positive than women. However, the differences are mostly not large; in fact the overall pattern is remarkably consistent across different groups. The percentage saying life is getting better ranged from 9% to 19%, that it was worse from 42% to 59%.

In a 1999 poll, we found the proportion of people saying life was getting better increased to 24% and that saying it was staying about the same rose to 38%, while the percentage saying it was getting worse fell to 36%; 2% did not know. The percentage saying life is getting better ranged from 15% to 36%, that it was worse from 21% to 43%. Thus the spread of opinion across demographic groups may have increased on some measures, notably between genders and income groups on whether life is getting better. Details of the 1997 and 1999 results are given in Table 2.

In a follow up question (not asked in 1997), people were asked 'in about what decade do you think overall quality of life in Australia has been at its highest' (more than one decade could be chosen): 24% said the 1990s (the same the proportion as said life was getting better), 25% the 1980s, 23% the 1970s, 13% the 1960s, 6% the 1950s, and 2% before the 1950s (8% did not know). Not surprisingly, the results were strongly age-related: for example, 45% of those aged 18-24 chose the 1990s, but only 29% of those 25-34, 20% of those 35-49 and 17% of those 50 and over.

There was a good fit between the responses to the two questions. For example, 51% of those who choose the 1990s as the best decade also thought life was getting better, while among those who choose the 1980s as the best decade, 47% thought QoL was staying about the same. In contrast, 50% or more of those who thought the 1970s or earlier were the best time thought QoL is declining.

It would appear, then, that such broad questions are tapping public sentiments about long-term trends in social QoL, but that, as one would expect, these sentiments are influenced by personal attributes and circumstances and relatively short-term shifts in social conditions and public mood. However, the results require further research to assess their validity.

State differences in perceptions of social QoL are intriguing and may – and I stress 'may' – offer some insight into the relationships between objective and subjective measures. The State differences were as marked as any of those between income, age or other demographic groupings. However, the reasons for the differences are not self-evident.

Victorians stood out as the most positive Australians, with 37% saying they thought life is getting better, compared with 14-23% for the other States. Victorians were also the most positive when the same question was asked in 1997. All States reflected the general lift in mood which occurred between 1997 and 1999, but the extent of the rise varied. The proportion of Victorians believing life is getting better doubled, increasing the State's lead. NSW also almost doubled its percentage, moving from fourth to second place. The Tasmanian figure tripled, but comes off a low base and could be influenced by the small sample size for that State. On the other hand, Queensland and Western Australia recorded much smaller changes.

Victorians were also the most positive when it came to the decade of highest QoL, with 32% choosing the 1990s as the best decade, compared with 9-25% for the other States. State differences across decades show that Victorians showed a clear liking for the 1990s and were less likely to choose the 1960s. Queenslanders, South Australians and Tasmanians preferred the 1980s, with about 30% choosing this decade as having had the highest QoL. People in NSW spread their preferences evenly over the 1990s, 1980s and 1970s, while West Australians shared their preferences across the four decades from the 1960s to the 1990s.

While many of the state differences are statistically significant (at the 95% confidence level), this does not necessarily mean there is a causal link between the people's attitudes and the State they live in. However, it is plausible that differences between the States do explain the results. If so, what might they be?

Victorians do not stand out as the richest, best-educated, healthiest or most personally satisfied of Australians. Indeed, in the 1999 edition of *The State of the States* report, published by the Evatt Foundation and the Public Sector Research Centre at the University of NSW, Victoria ranked last! It had dropped from fourth in 1998. The report is based on the performance of the States on 15 social, environmental and economic indicators. Overall, Victoria scored 16 percentage points less than the all-State average, and 26 points below first-place getter, NSW. Victoria did particularly badly on environmental indicators, where it scored 33 points below the average. On social measures it scored 8 points below the average. It did best on the economic indicators, but even here it only managed fourth place, 5 points below the average.

Journalists speculated that Victoria's good showing on the quality-of-life poll was due to the 'Jeff factor'. Jeff Kennett seems to have succeeded in making Victorians feel better about themselves, but his style of government, his critics argue, is secretive and undemocratic. He encourages people to enjoy themselves - at the casino, the footy or the grand prix - and leave the running of the State to him. Social Researcher, Hugh Mackay, has linked the recent lifting of the public mood in Australia, in part, to a disengagement from the political agenda, a focus on 'tending our own patch' and a determination to have more fun. Perhaps with Kennett's encouragement, Victorians are excelling at this shift in lifestyle.

Chris Sheil, the author of *The State of the States* report, says that the contrast between Kennett's popularity and Victoria's performance might be because the Premier 'has jumped social categories'. Opinions about Victoria no longer turn on services and outcomes, he says, but on Kennett's status as a celebrity. If the 'Jeff factor' does explain the Victorian result, it demonstrates that the personal popularity of a leader does influence broader perceptions of QoL.

A comparison between the Australia Institute poll results and *The State of the States* audit shows that, Victoria aside, there is a striking concordance between the State rankings on both measures. Victoria is the State of anomaly. It is clearly on the move, but to where? Public mood and State performance tell contradictory stories. Is this a good thing, or bad? Victorians may well have answered that question in the recent state election.

However, the State differences in the shifts in attitudes between 1997 and 1999 and in the decade-by-decade patterns suggest that, even excluding Victoria, there is more to public perceptions than objective differences in State performance. If the differences mean anything at all, it is that perceptions of QoL may reflect social, environmental and economic realities, but they also have their own rhyme and reason. Either way, when it comes to measuring QoL, perceptions clearly matter.

More fundamentally, the surveys about QoL appear to be about values, priorities and goals - both personal and national - and the degree of tension between these.

Pusey's 1996 survey, The Middle Australia Project, which produced similar findings to those of the 1997 poll on QoL, study found that the most common ways in which QoL was perceived to be falling were: too much greed and consumerism; the breakdown in community and social life; too much pressure on families, parents and marriages; falling living standards; and employers demanding too much. The study suggests Australians are experiencing economic change as harmful pressure on the family. Over 90% of people believed family life was changing, with 54% saying it was changing a lot). Of all those who said family life was changing, two thirds said the negative aspects of these changes stood out most. These included: the breakdown of traditional values; too much consumerism and pressure to get more money and buy things; a breakdown of communication between family members; and greater isolation of families from extended family networks and the community. (The third that saw the changes as positive cited the more equal relationship between men and women, the sharing of housework and more freedom.)

Perceptions of moral decay and decline emerge repeatedly in US surveys. At the time Gallup recorded high levels of satisfaction with 'the way things are going in the US', other surveys were confirming these findings of deep disquiet about the values driving American society. Conducted in July/August 1998 by *The Washington Post*, Harvard University and the Henry J. Kaiser Family Foundation (1998), the surveys (N=2,025, 1,200) found that 76% of Americans thought the country was 'pretty seriously off on the wrong track' when it came to values and moral beliefs. Over half (55%) believed 'people and groups that hold values similar to yours' were losing influence in American life in general, while 66% said Americans were 'greatly divided' over the most important values.

Gallup surveys in 1998 and 1999 found that 49% of Americans believed there was a moral crisis in the US, while 41% believed there were major moral problems. A third (34%) said the state of moral values was very weak, and 41% somewhat weak. Asked about the changes in moral and cultural values since the 1960s, 32% thought that on the whole the changes had been good because the country had become more tolerant, while 64% thought they were bad because it had become too permissive. Only 23% admitted to being optimistic about future moral and ethical standards in the US, while 43% were pessimistic.

Still these moral qualms may not be new. The Gallup data suggest that moral pessimists have always outnumbered optimists, at least as far back as the 1970s, although the gap between them has widened. And while, in another question, only 32% professed to be satisfied with the honesty and standards of behaviour of Americans, and 63% were dissatisfied, the results do not reveal a marked shift in sentiment between the early 1960s and late 1990s.

On the other hand, of the period from the 1920s to 1990s, the 1950s easily top scored as the decade in which people thought American values and morals were particularly good, being chosen by 28%, with the vote declining on either side (only 3% nominated the 1990s). And, asked if young people today have as strong a sense of right and wrong as they did, say 50 years ago, 78% of Americans said 'no' in 1998, compared to only 34% in 1952.

So if QoL is closely linked to perceptions about morality and ethics, and while survey results indicate a widespread dismay about moral standards today, the evidence about whether this dismay is increasing, and so suggests declining QoL, is mixed. We also have to remember that being subjective assessments, the benchmarks are also likely to change over time (as has happened with ideal weight). What is considered 'moral' today is not necessarily what was

considered 'moral' in the past (think, for example, of the status of women and ethnic minorities).

## **Conclusion**

QoL studies are highly relevant to our times. To date, public interest is focused on well-being as the goal of personal growth and development strategies – witness the proliferation of books on how to become happier or more satisfied.

But QoL research is also intensely and inherently political in that it concerns the question of what goals political effort should be directed towards. This is especially pertinent when political power is being so closely focused on achieving and maintaining high rates of economic growth as the prime determinant of improving QoL.

We should not be intimidated by this, but rather ensure that our research findings inform political debate and policy directions. The process of making life better will remain highly political in that it involves choices between different views of the world and competing goals. We should not kid ourselves that scientific research will come up with clear, unequivocal answers.

I am yet to be convinced that there is a simple, easy way of measuring QoL in a way that allows us to say whether, on the whole or all things considered, life is getting better or worse. GDP doesn't do it. Or life expectancy. I'm not convinced that 'life satisfaction' or 'happiness' measures what we need to know. Asking about overall social QoL, as distinct from personal QoL, may be useful, but that remains to be established.

Measuring factors such as mastery or optimism, which are closely related to personal QoL but may be less subject to homeostatic or equilibrium influences, may also be useful. Qualitative research suggests Australians perceive a loss of control over their lives. Jones's QoL surveys show mean satisfaction with life as a whole has been relatively constant over the past two decades – 5.32 (on a scale of 1-7) in 1981, 5.35 in 1988 and 5.31 in 1998 – but mean satisfaction in his 'freedom' domain declined from 4.87 in 1981 to 4.75 in 1988 to 4.63 in 1998.

Beyond that, there are more philosophical issues – whether, for example, maximised satisfaction or happiness (like maximised wealth) should be the bottom line - for individuals or societies. Happiness is so closely related to extroversion that you have to wonder why its converse, neuroticism, was not weeded out of human nature by natural selection long ago. Clearly the more cautious, questioning, doubting aspects of neuroticism have survival value. The bi-polar depressive in his manic phase over-estimates his abilities and qualities to the detriment of himself and his family.

Similarly, self-esteem, optimism and mastery can also become counter-productive or dysfunctional when taken too far, and so need to be kept in check. For example, if mastery reflects an individual's freedom of choice and control over his life, its maximisation can actually be harmful by tending to detach him from the web of personal and social relationships and attachments which promote well-being and through which he influences the people and social environment around him. Individual freedoms, rights and privileges need to be balanced by social ties, obligations and responsibilities.

As I mentioned, Headey and Wearing say a sense of relative superiority appears to be normal and an important aspect of human psychology. However, they note that a sense of relative superiority can have costs as well as benefits in that people might filter our information about poor performance and consequently fail to take corrective action. They point out that research has found that depressed people are more realistic in assessing their own performance than people who are not depressed. Successful life, then, may be about maintaining a balance between a realistic and fantastic view of ourselves!

To sum up: QoL studies will deliver most, scientifically, if they take a very broad approach, embracing many disciplines and exploring many perspectives. They will deliver most, socially, if QoL researchers are active participants in the political debate about the sort of society we want to live in and how to create it.

## Notes

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This paper is a 'text' version of Richard's keynote address, which was accompanied by about 40 overheads, most of them PowerPoint graphs of the survey results and trends cited in the paper. People interested in obtaining any of these should contact Richard.

Much of the material is taken from the following papers, which also include the full references:

Eckersley, R. (in preparation), The mixed blessings of progress, *Journal of Happiness Studies* (invited paper).

Eckersley, R. (in press), The state and fate of nations: Implications of subjective measures of personal and social quality of life, *Social Indicators Research* (invited paper).

Eckersley, R. 1999, *Quality of Life in Australia: An analysis of public perceptions*, the Australia Institute, Canberra, discussion paper no. 23, September.

Eckersley, R. 1998, Perspectives on progress: Economic growth, quality of life and ecological sustainability. In Eckersley, R. (ed), *Measuring Progress: Is life getting better?*, CSIRO Publishing, Collingwood, Victoria.

# **The subjective well-being of people caring for a severely disabled family member at home: A review.**

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This review concerns the life quality of people caring for a severely disabled relative within their family. Contemporary reviews tend to concentrate on the advantages this brings to the care recipient and to give little attention to the costs born by the family. The analysis presented here attempts to redress this balance. A brief history indicates that the forces that encourage family care are not concerned with family welfare. Moreover, an analysis of both qualitative and quantitative data indicates that primary caregivers are at considerable risk of high stress, clinical depression, and abnormally low subjective quality of life. It is concluded that increased public expenditure directed to the care of severely disabled people within families is urgently required.

The topic of family care for severely disabled people is an emotion-laden topic. Perhaps that is why so few reviewers of this literature are willing to place themselves on the line and provide a straight-forward opinion, that there is now overwhelming evidence that this process is harmful for the well-being of other family members, most especially mothers. So the major aim of this review is to provide such opinion, which will be presented through the following progression of ideas. First, the stage will be set in historical terms and caveats concerning the content and nature of the review will be stated. This will be followed by an analysis of empirical data acquired for this review, and finally a section comprising the conclusions that can be drawn and the challenges that such conclusions poses for our society. So let me begin with some history.

## **Background**

The historical context of family care has been presented elsewhere (Cummins & Baxter, 1997). Essentially, there have been three major phases of public opinion on this matter. The first, prior to 1900, simply involved the assumption that such care would be provided. After all, there were no public institutions to offer a reasonable alternative and then, as now, few families had the resources to support a disabled family member beyond the home environment. But over the next half-century this was to radically change.

Around the turn of the last century, a major fear was promulgated through Western society based on Mr Darwin's new ideas concerning 'Natural Selection'. This involved the belief that, in order for a society to avoid future degeneration, attention must be paid to who was making the babies. The 'fittest' families, not the low-class families, should be dominant in this endeavor. And yet a look at the basic demographics suggested that the precise opposite was happening. The poorer 'unfitter' sections of society had the most children. Something had to be done.

What, precisely, could be done posed something of a problem. Poverty and a lack of education did not make good targets for a campaign of limited procreation because such criteria involved too many people and, anyway, it could be argued that opportunity, not genetics, was the cause of such people's station. So the target group chosen were those who, in addition to their poverty and illiteracy, had an intellectual disability. But even so, due to the sensitivities of a civilized society, this group could not be simply be prevented from breeding on the grounds that their genes would degrade the population gene pool. Some other reason had to be found, and it was.

“Every feeble-minded person, especially the high grade imbecile, is a potential criminal, needing only the proper environment and opportunity for the development and expression of his criminal tendencies. The unrecognized imbecile is a most dangerous element in the community.” (Fernald, 1912, pp.90-91).

And so it came about that the most disadvantaged group in society came under attack from the most advantaged. The reason for preventing their contribution to the gene pool had been found. Society had to be protected against this tendency to criminality and it was not long before the law reflected popular opinion. Thus Craft (1984) quotes Justice Oliver Homes (1927) of the USA Supreme court:

“It is better for the entire world if, instead of waiting to execute degenerate offspring for crimes, or to let them starve for their imbecility, society can prevent those who are manifestly unfit from continuing their kind. The principle that sustains compulsory vaccination is broad enough to cover cutting the fallopian tubes ... three generations of imbeciles are enough.” (p.177).

While sterilization was certainly practiced, another technique to prevent people breeding was to place them in to institutions. This had other advantages. It not only removed people with an intellectual or psychiatric disability from the community, but the institutions became valued economic resources within communities, and their numbers grew and grew.

By 1969 there were 214,000 people, the majority under 25 years of age, living in ‘institutions for the retarded’ in the USA, and a proportional number in Australia, Canada and England. It had become an industry offering secure employment to the chief bureaucrats, who were usually psychiatrists, and a legion of direct-care and support staff. Mothers were advised to institutionalize their child as soon as the disability was diagnosed. They were assured that this was best for all concerned, most particularly the child, since the specialized forms of medical care, presumed necessary for their survival, would be most readily available. And then came Winnie Halderman.

Mrs Halderman had placed her daughter Terri Lee in an institution called Penhurst. Subsequently, however, she became convinced that, while living in the institution, Terri Lee had been abused and injured (see Feinstein, 1986, for a detailed account). She thus initiated an action against the Center and in 1977, following 13 weeks of trial, Judge Broderick ruled that Penhurst was violating the rights of the residents as guaranteed by Federal Law. This, in turn, resulted in a class action by other parents against the institution, and also a government-funded study of the subsequent deinstitutionalization.

And so the wheel of public opinion began to turn once more. The report of the Penhurst Study and the findings of numerous derivative research projects, emphasized the benefits of returning institutional residents to their community. Moreover, the timing of these reports meshed with two other forces for social change to bring the wheel full-cycle. The first was the ideological movements of Normalization promulgated by Wolfensberger (1972) and Nirje (1976). They advocated objective living conditions that conformed to general population standards. Clearly this was anti-institutional and their views dominated service delivery ideology in the Western world for the next two decades. The second force was economic rationalism, with its emphasis on ‘user pays’ and the consequential withdrawal of government expenditure on human services. This force is very compelling. For example, Johnson (1999) states that unpaid work by voluntary carers makes up 74 percent of the aged

and disability services in Australia “saving the community about \$16 billion a year.” (p.11). And so it was that as the twentieth century drew to a close families, once again, cared for their severely disabled members.

But an important perspective onto the family care-giving role is that Western families in 2000 are, on average, very different from families a century earlier. They are generally much smaller, containing fewer children and fewer adults. It is quite rare for families to contain grandparents or other adults with a non-parental role. This is highly significant because it means that the responsibility for family maintenance rests with far fewer people than it ever has before. Even worse in this regard, an increasing number of families contain just one parent, contain two parents who both have paid employment outside the home, or are ‘blended’ involving two adults with children from previous relationships. Each of these conditions adds a level of difficulty to the task of family management. In sum, contemporary families are supported by a smaller number of adults, fewer children to offer assistance, and often in more complex social circumstances than has ever previously been the case.

It is also notable that the social forces that have deemed families responsible for the care of their own disabled members have not been shaped by considerations of life quality for the families concerned. Normalization had a single focus on the objective living conditions of the disabled person, while economic rationalism has a focus on the reduction of public expenditure on human services. So it is surely not surprising that the life quality of families performing a caregiving role may be severely compromised. This side of the equation requires exploration. But let me state a caveat before proceeding.

The data to be presented will demonstrate that the life quality of families caring for a severely disabled person is very low. However, this does not mean that all families have a life quality compromised by caring for a disabled member. There are two reasons. The first is due to differences in the nature of the disability. For example, a person who has high dependence needs, who is unpredictably violent and non-verbal will reduce the life quality of almost any family. On the other hand, a responsible adolescent with diabetes who self-administers insulin will be unlikely to have any negative impact. So the degree and type of disability is a major factor.

The second reason is statistical. The evidence to be presented deals with statistical differences and relationships. These refer to a ‘majority condition’ in the sample under study. They do not imply that each individual in the sample conforms to the discovered difference or relationship. Thus, even when, for example, the statistical evidence is unequivocal that caring for a certain type of person under some particular conditions causes stress, some people in these circumstances may experience little or no stress.

Both of these understandings are important if the following account is to be read in its correct context, which is a concern to describe the implications of care-giving as experienced by the majority of caregivers.

A final word of caution in interpreting the conclusions that follow concerns the nature of the studies forming this review. Given that the literature in this area is too vast for any review to be totally inclusive, it is important to know how the reviewed materials were selected. The answer in this case is through ‘Current Contents’, library-held journals, and through bibliographic tracking. So the coverage is likely to be representative of the contemporary

literature, but may also omit some older key publications. So, with these caveats in place the review will commence with an analysis of previous reviewer conclusions on this issue.

### **Previous reviews**

About one dozen reviews have been located for this article, and opinion seems to be fairly evenly divided. First I will present the case for the positive, which seems to rest on three foundations. These are economic rationalism, the fact that not all caregiver families are overly stressed, and rewards delivered by the caregiving experience.

The economic rationalists have a straight forward view, that the availability of family care makes it possible for 'bedfast persons' (Shanas, 1979) to live outside institutions thereby saving money for the state. From this perspective the only real concern in relation to family stress is that, if the levels of stress become intolerable, the recipients of such care may be 'prematurely institutionalized' (Berg-Weger, 1996). This author even puts a positive spin on family stress, suggesting it can promote family cohesion and solidarity, which indicates a very strange interpretation of the stress construct (see later). While it seems likely that this case is valid economically, the related economic costs of stressed families also needs to be taken into consideration. While no data are known that could enlighten such an equation, in any event, it clearly ignores the deeper humanitarian considerations of family well-being.

The second line of argument in favor of family care rests on the truism that not all families are stressed by the care-giving process (Moroney, 1983) and that "an overview of controlled studies suggests that many families of children with disabilities adapt quite successfully ... [that] those studies ... do not necessarily suggest debilitating stresses ... [and] there is also evidence of considerable positive impact for families" (Weisz & Tomkins, 1996; p.1241). These are surely chilling sentiments. Leaving aside the claim for positive impact which will be dealt with later, by what criterion is stress considered to be 'non-debilitating'? Is it that the family, however stressed and dysfunctional, is still managing to supply care? That family, rather than institutional care, is better no matter what? Surely such views are those of administrators and professionals rather than those of the family members involved in primary care.

This view is reinforced by Moroney (1983) who states "Professionals now seem to feel that community care, including family care, is superior to institutional care ... The current thinking among professionals is that institutional care is not in the best interests of the child or family as a whole." (p.210). So the second line of argument boils down to this. Family care is good because it is better for the care-recipient than institutional care, it is consistent with professionals' views on caregiving, and relatively few families will be so stressed by the process that they will find the task impossible. Notably absent from this list is concern for the impact of caregiving on the lives of the care-recipient's family.

This theme continues in one of the most recent and most upbeat reviews of family caregiving (Yau & Li-Tsang, 1999) reported in the *British Journal of Developmental Disabilities*. These authors state "parents of children with a disability, who currently show 'maladjustment' or inability to cope with stress, may be just at the early stage of a developmental process of coping and adaptation [They cite a text-book, Winzer, 1990]. They have still not reached a stage of mature adaptation at which they can accept the child, the disability and themselves." (p.45). Then, in complete negation of this proposition they state " ... current literature suggests resistance to the idea that parents of disabled children go through an ordered

sequence or discrete 'stages of adjustment', or that they do indeed attain a 'final stage' of acceptance." (p.45).

Other sections of this paper deal with the evidence for positive family experience and the conditions that promote this experience. They state "Current studies indicate that families of children with disability, including those whose disabilities are severe, often believe their lives have been enriched by their children's presence" (p.39). They then cite a series of personal accounts, and an unpublished manuscript as evidence that "... in some instances – where the parents are competent and supportive – siblings may also benefit from association with brothers and sisters with developmental disability because of increased opportunity to enact teaching, helping and caregiving roles" (p.39). In fact, their cited data are quite insufficient to support this view.

Finally, they cite the conditions under which such positive outcomes can be expected to occur as involving "quality of personal resources, a strong marital relationship, ... the availability of a small, intense social support network, a two parent family with two children, high socio-economic status, adequate crisis-meeting resources, and living in a supporting community." (p.47). In other words, all of the conditions least likely to be found within families caring for a severely disabled person.

So the case for the positive can be summarised as follows: (a) From the perspective of the economic rationalist and the professional work-force, family care is preferable to institutional care because it is more cost-effective for the State and better for the well-being of the care recipient. Both of these reasons seem valid. (b) From the perspective of the families, there is rather grudging acknowledgement from reviewers that caregiving is stressful, but much is made of the claim that some families are minimally stressed by the process and the caregiving role has significant positive outcomes for the family members. Both of these are partially valid. The first has been discussed as a 'caveat' in the first section. While there is no doubt that some families are less stressed than others, the statement of this obvious fact distracts from what should be the main focus. That is whether the 'average' family is stressed to a level that reduces well-being. The second point, claiming generalised positive outcomes, seems much more doubtful. Certainly the majority of families will endorse positive statements if they are asked leading questions on such issues, such as whether they gain personal rewards from knowing that the disabled person is being well cared for (Stephens & Franks, 1999). However, this kind of questioning can produce a false impression that the respondents are gaining an overall positive experience from the caregiving situation. (c) Finally, a set of conditions have been stated that are likely to result in the positive family experience that everybody desires. The fact that almost no real-life families would enjoy this set of conditions is perhaps the most damning statement on the case that home-care is a positive experience for the family as a whole.

The case for the negative is really quite simple. Essentially reviewers have compiled a list of negative states experienced more frequently by family carers compared with normative data. Thus, for example, Fadden et al. (1987) conclude that carers experience reduced social and leisure activities, financial problems, difficulty in getting relatives to accept the situation, and coping with the care recipients behavior. Other reviewers have noted that caregiving engenders stress (e.g. Singer & Irvin, 1989), a pervasive negative impact on family functioning (Conoley & Sheridan, 1996) and caregiver depression (Mohide & Streiner, 1993). Moreover, a review by Ammeman et al. (1988) concludes that disabled children, across disability types, have a higher risk than normal for carer abuse. This is a serious

consideration for those who regard home-care as inevitably a superior experience for the care-recipient and it is a logical outcome of an environment containing highly stressed people. So the conclusion here is straightforward. The data indicate that, on average, the impact of a disabled person on family caregivers is predominately negative.

In attempting to come to a balanced opinion derived from these reviews, assistance is provided by Sherwood (1975). Even a quarter of a century ago this author realised the tensions between personal advantage and family disadvantage inherent in the provision of family-based care, and offered the following perspective:

“An important issue then concerns the question of the perspectives from which the needs of the long-term care person are being viewed. Even in the criterion as simple as ‘preserving life’, someone must decide that it is good to preserve life. There are times when values and therefore goals are in conflict. ... The goal of the professional called upon to help the chronically ill person may be to keep him in the community; but the goal of his family may be to end the conflict caused by having him in the home. Indeed, they may prefer for him to be in the protected environment of an institution.” (p.57).

This, then, identifies the nature of the problem. The care-recipient is probably, on balance, better off being cared for in their family, while their family, on balance, is worse off through the provision of such care. Where should society as a whole regard such a point of balance to lie? This complex question can be answered at various levels such as from the viewpoints of ethics, legal and moral responsibility, social and economic costs, and the well-being of the individuals concerned. This review acknowledges these viewpoints but the data to be presented in subsequent sections attempts to explore just one of them. This is the cost of such care provision to those family members involved.

## **Qualitative Data**

Of the seven qualitative studies located for this review just one came down on the positive side. Grant et al. (1998) interviewed the carers of young disabled adults and concluded that their data:

“support the view that the vast majority of family caregivers obtain rewards and satisfactions from caregiving ... Satisfactions were mentioned much more often than stressors. Moreover, it appeared that many of the satisfactions were linked to, or outcomes of, successful strategies for coping with potentially challenging situations. This would seem to reinforce the view that pathological views of the caregiving process are unlikely to reflect the realities that the vast majority of families with intellectually disabled children and relatives face in their daily lives.” (p.68).

There is no doubt that carers experience ‘rewards and satisfactions from caregiving’ or that many of these will be linked to successful coping strategies. The reasons for this have already been discussed. But the claim that the caregiver role does not induce psychological damage at the same time, and that the ‘vast majority’ of families are spared such pathology is unfounded. This is so even when measured against the other qualitative reports, let alone the quantitative data presented later, of which the authors seem unaware.

The other qualitative reports all indicated a dominating negative experience (Kropf & Greene, 1993; Thompson & Doll, 1982). Case histories detail the huge emotional and financial cost of caring for a child with severe behaviour problems (Lubetsky, et al., 1995) and the very considerable difficulties imposed by the care of an elderly relative who suffered

a stroke (Archbold, 1980). Marsh et al. (1996) record how 40% of carers volunteered negative experiences even though the interviewer had asked them to describe the positive influences of caregiving, while Baumanis (1970) in describing her own experience states “How does the average family cope with such a volatile, hyperactive, immature child? According to the literature, it is difficult but nevertheless he can be ‘included in all family activities’. At what cost to the rest of the family is he included?” (p.25).

This, then, seems to end on a note that is similar to that of the previous section. Families, of course, will be able to describe some positive aspects of their caregiver role and, were they not able to do this, the burden of the role would likely be intolerable. But this can not be interpreted as the caring process imparting an overall positive experience to the family. It is all a question of balance and the evidence for a negative balance has clearly come through in these qualitative reports. As Baumanis asks, ‘At what cost’ to the family as a whole are severely disabled family members cared for? Further light on this question will now be sought from empirical data.

### **Comparing different forms of disability**

The data to be cited are derived from a very heterogeneous set of studies in relation to the actual circumstances of caregiving. This is justified on the grounds that the differences in caregiving between the types of disability and ages of the care recipient are relatively trivial. Essentially, the medical description of the condition is far less important than the degree of burden it imposes due to such parameters as the extent of behaviour disturbance, communication ability, and specialist care involvement. So, for example, Bouma and Schmeitzer (1990) found parental stress to be higher within those families caring for a child with autism and severe intellectual disability than within families caring for children with cystic fibrosis, Mohide and Streiner (1993) found caregiver depression to be higher among those caring for a demented than a non-demented elderly relative, while Wade et al. (1996) found more family stress associated with children who had suffered severe traumatic brain injury than those with milder brain injury or orthopedic injuries not involving the brain.

It seems obvious that the more severe the condition, the more family burden it creates (see also Deimling & Bass, 1986). But it is also true that once the level of care required is substantial, individual differences between families start to exceed the differences in caregiving intensity and, as a consequence, the conditions become indistinguishable in terms of their overall impact on family functioning. So, for example, Bindoff et al. (1997) found no differences in measures of carer outcome between those caring of severely disabled adults with either a physical or intellectual disability or dementia, Jenkins and Schumacher (1999) found no difference in this regard between schizophrenia or severe depression, while Breslau et al (1982) found no differences in parental distress due to the type of severe childhood disability. Interestingly, these latter authors also found no differences in impact between Euro-American or Latino (Spanish speaking) families, but this obviously cannot be generalized to other cultural groups. So, the conclusion drawn for this section, that family burden is a consequence of condition severity rather than specific diagnosis, must be seen in the framework of Western families. Whether and to what extent cross-cultural differences exist cannot be answered here.

In relation to age-related differences, caregivers obviously experience some different kinds of stressors when caring for children as opposed to elderly people. The former group are associated with concerns regarding community engagement and future life while the latter are associated with concerns regarding independence and dignity. These issues have been

discussed by Moroney (1983) who indicates agreement with the line to be taken here. That despite these differences, the intensity of the stress and the nature of the caregiving demands are much more similar than different between types of care recipient.

So, in summary, since this review is concerned with the broad picture of caregiver well-being, differences between care-recipient age or medical condition will be ignored.

### **Differences from normative standards**

Within the research literature, family members acting as primary caregivers have been measured on a variety of instruments and their scores compared either with scale norms or scores from other families without a disabled member. By far the most common measures have been those related to psychopathology, so these will be presented first, followed by data on measures of well-being.

It is interesting to note first, that the only comparative measure of physical health (George & Gwyther, 1986) found no effect due to caregiving, which probably indicates the insensitivity of the measure they employed. Not only did these authors also find relatively high levels of psychopathology among the same caregivers (see later), but other authors have found both perceived health (e.g. Bindoff et al., 1997) and general mental health (e.g. Burgener, 1994) to be negatively affected by family caregiving. All of these measures are, however, relatively uninformative due to their general nature. Of more interest are the specific measures of stress/distress and anxiety/depression.

Of the 17 studies that measured stress or distress located for this review, every one reported higher than normal levels among caregivers (Bentelspacher et al., 1994; Bouma & Schmeitzer, 1990; Dyson, 1996; George & Gwyther, 1986; Hatton et al., 1998; Hodapp et al., 1998; Holroyd & Guthrie, 1986; Rosenvinge et al., 1998; Sharpley et al., 1997; Singhi et al., 1990; Stengård & Salokangas, 1997; Wade et al., 1996; Warfield et al., 1999; Winefield & Harvey, 1994). Moreover, Winefield and Harvey (1993) determined higher levels of stress even after controlling for caregiver age, sex, and degree of social support, while Breslau et al. (1982) found more distress after controlling for caregiver education level, income, and race.

So the conclusion that caregiving a disabled family member is stressful seems to be beyond doubt. As, also, is the fact that this is linked to higher than normal levels of anxiety and depression. Of the 12 studies that measured these parameters all except one confirmed this view. The odd one out is Knight et al. (1998) who report in their abstract "Carers did not differ on measures of depression or subjective health ratings from persons not involved in care". Curiously, however, the study to which this abstract refers makes no such comparisons, so this statement can be dismissed. Other studies that have found abnormally high anxiety or depression among primary caregivers are Bethoux et al. (1996), Sharpley et al. (1997), Spangenberg and Theron (1999), Trute (1995), and Whitlatch et al. (1997). More specifically, both Baumgarten et al. (1992) and Stuckey et al. (1996) found the average level of depression to approximate the cut-off points for clinical depression. In a similar vein, the proportion of each sample determined to actually have clinical depression was estimated at 38% (Smith et al., 1993), 40% (Tymchuk, 1994), and 54% (Spangenberg & Theron, 1999). The degree of convergence between these studies is extraordinary and leads to the inescapable conclusion that somewhat less than half of the caregiver population have clinical levels of depression. It seems hardly surprising this population are also major consumers of psychotropic drugs (e.g. George & Gwyther, 1986).

So what about the positive side of the affective coin. Do caregivers also have low levels of subjective well-being? Of the seven studies that provide generally relevant data three have answered in the negative. The first of these, by Townsend et al. (1989) states “predominately positive affect was reported” (p.398). However, this result is an artifact of their methodology and has also been misinterpreted. The methodological problems are twofold. First that the ‘caregivers’ were not co-habiting with the care-recipient and only 36% nominated themselves as the primary caregiver. Second, that the respondents represented only 50% of those who were involved in a previous study some 14 months earlier, so these ‘study survivors’ were probably biased towards having a positive outlook. Their misinterpretation comes from the fact that they interpreted an average positive affect score slightly above the scale mid-point (61% of the scale maximum score) as indicative of good mental health. In fact, had they known that such data are quite strongly negatively skewed, to the extent of a normal score being around 75% of the scale maximum, they would have drawn the opposite conclusion. This measurement perspective will be elaborated later.

The other two studies are more interesting. Bränholm and Degerman (1992) found no differences in subjective quality of life (subjective QOL: defined as aggregate satisfaction over a number of life domains), and Lawenius and Veisson (1996) found no differences in self-esteem, between parents of Down Syndrome children and parents of non-disabled children. There are a number of factors that may have contributed to this result. First that these nuclear families were intact. Second that Down Syndrome children do not typically have a high level of behaviour problems and constitute a distinct group in terms of parent support groups. Third, both studies were conducted in Sweden. This is relevant since the Nordic countries are well known for their high level of expenditure on human welfare and for the fact that, on a population basis, their people experience a higher level of life satisfaction than any other nation (Cummins, 1995, 1998). This differential level of life satisfaction may well reflect differences generated between the lower ends of the distributions. That is, the high welfare expenditure in the Nordic countries elevates the life satisfaction of those people most at risk and, as a consequence, raises the level of life satisfaction measured across the population as a whole. It seems plausible, therefore, that this could also be happening to people caring for a disabled person in the home, and that the relatively high level of welfare support has helped to negate the negative experiences of caregiving.

Other than these studies, however, the remainder of the reports show a significant reduction in subjective well-being consistent with the earlier data on stress and depression (Burgener, 1994; Fengler & Goodrich, 1979; George & Gwyther, 1986; Herrman et al., 1994; Stuckey et al., 1996).

### **Subjective quality of life**

Over the past few years a great deal has been learned about the variable referred to as life satisfaction, measured by a single question concerning ‘life as a whole’, and subjective quality of life (QOL), measured as an aggregate of satisfaction across a number of life domains. Most importantly, the life satisfaction of general Western population samples averages 75 percentage of the measurement scale maximum score (%SM). Moreover, when the mean scores of general population samples are combined as data, their standard deviation is just 2.5%SM. Therefore, using two standard deviations as the criterion for a normal range, general population sample means can be predicted to fall between 70-80%SM (Cummins, 1995, 1998).

Within-sample variance is also highly predictable at  $18 \pm 1\%SM$  (Cummins, 2000), such that normative range for individual life satisfaction lies within the range 40-100%SM. Moreover, measures of subjective QOL also approximate these standards. The population mean derived from the seven domains of the Comprehensive Quality of Life Scale (Cummins, 1997) approximates 75%SM (Cummins, 1996) but the within-sample standard deviation is smaller at about 12%SM, providing an approximate normal range for individuals of 50-100%SM (Cummins, 1997).

The consistency of these data have led to the proposition that both life satisfaction and subjective QOL are held under homeostatic control (Cummins, 1995, 2000). This is consistent with the idea that each person has a 'set-point' for subjective QOL lying within the range 50-100%SM, and that the sum of these set-points yields the 75%SM population mean. Thus, studies that have utilized these variables can now be interpreted not just against comparative within-study data, but also against this broader understanding of normative data distributions.

The data presented in Table 1 can be interpreted within both of these contexts. All six studies have used items requesting participants to rate their level of satisfaction with either 'life as a whole' or across a number of life domains, and all studies have involved primary caregivers. In most other respects, however, the studies are very different from one another. They involve different research teams, operating in four different countries, and a host of other variations in demographic variables. Despite these differences, the data are remarkably similar, and when the eight mean scores are combined as data they yield  $61.0 \pm 5.9\%SM$ .

Table 1 Subjective quality of life of caregivers

Study and Instrument	Country	N	Care Recipient	Caregivers		Non-Caregivers	
				8	SD	8	SD
Browne & Bramston (1996) ComQol	Aust	102	A	67.8	(30.9)	74.3	(16.4)
Burgener (1994) LS-1	USA	84	B	61.5	(14.2)	70.0	(15.1)
Christensen et al. (1998) LS-5	USA	296	C	54.5	(11.3)		
Haley et al. (1987) LSI	USA	54	D	62.6	(21.7)		
Herrman et al. (1994) LS-8	Aust	96	E	64.5	(10.3)	70.0	(7.7)
Seltzer et al. (1995) PGCMS	N. Ireland S. Ireland USA	151 131 462	F F F	68.2 53.5 55.3			
MEAN				61.0	(5.9)	71.4	(2.5)

Key

ComQol: Comprehensive quality of life Scale (Cummins, 1997)

LS-1: Satisfaction with 'Life as a whole'

LS-5: 5-item Satisfaction Scale

LSI: Life Satisfaction Index (Wood et al., 1969)

LS-8: 8-item Satisfaction Scale

PGCMS: Philadelphia Geriatric Center Morale Scale (Lawton, 1975)

A: Intellectually disabled child aged 15-26y

B: Elderly people with Alzheimer's disease

C: Disabled parent

D: Elderly parents with dementia

E: Disabled elderly people

F: Adult child with an intellectual disability

As has been stated, these data can be viewed in terms of two types of comparison. The first is against the three measures of subjective QOL derived from non-carers. These three means average to  $71.4 \pm 2.5\%SM$  and they are significantly higher than the caregiver data despite the small N values ( $t(9)=2.694$ ,  $p<0.05$ ). The second kind of comparisons is against the standard score of  $75 \pm 2.5\%SM$  and the associated normal range for sample means of 70-80%SM that has been previously discussed. There it can be seen that while all of the non-caregiver means fall within this range, all of the caregiver means fall below this range. Indeed, the average of 61.0%SM is over three standard deviations below the base score (70%SM) of the normative range.

While it is obvious that the caregiver groups, on average, have a severely diminished level of subjective QOL, three additional insights can be gained by examining these and related studies more closely. First, the people sampled by Christensen et al. (1998) had one of the lowest mean scores (54.5%SM) and yet these caregivers were not co-habiting with the care recipients. The explanation comes from learning that the criteria for caregiver selection involved the following: an elderly care-recipient who had at least one activity of daily living that required assistance or supervision, for the caregiver to be a mother to children living at home, to be currently married and living with her husband, and to have at least half-time paid employment. This indicates clearly that diminished well-being is a function of overall life burden of which the caregiving role is a part.

The second and third points of interest involve comparisons concerning the top end of the subjective QOL scale. Voepel-Lewis et al. (1990) report life satisfaction scores among caregivers of  $73.3 \pm 12.2\%SM$  while Bränholm and Degerman (1992) report scores of  $74.6 \pm 7.0\%SM$ . The former group were caregivers to people who had received a kidney transplant between 3 weeks to 6 months prior to the study. Presumably, therefore, their normal range subjective QOL reflects the decreased burden of caregiving associated with successful treatment of the care recipient. It is also interesting to note that these caregivers were also asked to rate 'their life as a whole before the family member's transplant' and rated this  $58.3 \pm 16.8\%SM$ . Even though such retrospective data are often regarded by researchers as unreliable, this estimate is remarkably consistent with the contemporaneous evaluations recorded in Table 1.

The Bränholm and Degerman (1992) study has already been mentioned, as involving the parents of Down Syndrome children in Sweden. This study also involved a comparison group of random parents who did not have care of a disabled child, and the comparative scores were as follows: Male parent (disabled child 81.6%SM; non-disabled child 81.6%SM) and female parent (80.4 and 81.0%SM respectively). As before, the most ready explanation for such data is the level of assistance provided by the welfare system in this country.

## **Summary**

Over the past 20 years or so there has been the coincidence of a perfect match between the ideology of normalization and the emergence of economic rationalism. This social environment has caused whole-scale institutional closure, the return or retention of severely disabled people within the community, and the provision of care within the family environment. The benefits for disabled people and for governments are pretty obvious. The former have a generally improved life-style and quality of care, certainly in comparison with conditions in some of the institutions that have closed. Governments, on the other hand, have saved billions of dollars through the utilization of free care and lodging provided by families.

But what has been forgotten or ignored in all this is the cost to the families most particularly, of course, the mother or wife who dominates as the primary caregiver in such circumstances. The following quotation is from Golodetz et al. (1969):

“She is not trained to do her job, a priori. She may have little choice about doing the job. She belongs to no union or guild, works no fixed maximum of hours. She lacks formal compensation, job advancement and even the possibility of being fired. She has no job mobility. In her work situation, she bears a heavy emotional load, but has no colleagues or supervisor or education to help her handle this. Her own life and its needs compete constantly with her work requirements. She may be limited in her performance by her own ailments.” (p.390).

This quotation poignantly presents a side of the caregiving equation that must no longer be ignored. It is surely impossible to absorb the strength and consistency of the data that have been presented and not come to the conclusion that families, most especially mothers, are paying a very high price for providing care. Caregivers of severely disabled people are at extreme risk of being highly stressed, clinically depressed, and with a subjective QOL that is way below normal. So given this information, can the assumptions underpinning the demise of public care facilities be sustained?

It has already been noted that disabled children have a higher risk of abuse than non-disabled children. It would not be surprising to find that the risk of such abuse bore a relationship to the degree of family stress. Consequently, the assumption that severely disabled people are better-off living within their families than elsewhere needs to be tested. As does also the assumption that such care is cheaper for the State. If the family is rendered dysfunctional through the stress of caregiving this will have obvious consequences for the public economy through, for example, increased use of prescription medication for the caregivers and decreased possibilities of them engaging in paid employment. Thus, not only are the assumptions of ‘cheaper-better’ care in need of careful analysis but the costs to family wellbeing must be taken into consideration in any balanced view of this vexed topic. When it is also understood that there are about 2.3 million such caregivers in Australia (Johnson, 1999), the magnitude of the problem is apparent.

To end this review on a cautionary note is important. This review is not advocating a return to large-scale public institutions for the care of severely disabled people. It is advocating the allocation of increased public resources for the purpose of their care. Whether this involves support for care inside or outside the family is an issue that requires careful attention, but the requirement for such an allocation seems indisputable. The issues at stake are more than providing quality care. They involve the balance of such provision against the costs in life quality born by family caregivers.

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# **Subjective Quality of Life, Perceived Control and Dispositional Optimism among Older People**

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There are 2 million Australians aged over 65 years, with that figure expected to exceed 6 million by the year 2051 (22% of males, and 26% of females) (Year Book Australia, 1999). Australian older people, defined as those aged 65 years and over, are engaging in healthier, more independent and more active lives than previous generations (Year Book Australia, 1999). Although older people are increasingly challenging the stereotypical perceptions of aging as a period of inevitable decline in subjective Quality of Life (QOL), researchers still tend to focus on the pathology of aging as the normative reference point for subjective QOL (Browne et al., 1998).

## **Older Peoples' Subjective QOL**

QOL is both objective and subjective, each axis being the aggregate of 7 domains: material well-being, health, productivity, intimacy, safety, community and emotional well-being. Objective dimensions comprise culturally relevant Measures of objective well-being. Subjective dimensions comprise domain satisfaction weighted by their importance to the individual (Cummins, 1997, p.5). Empirical studies investigating the relationship between subjective QOL and age are inconsistent with researchers demonstrating that subjective QOL can increase (Horley & Lavery, 1995), remain stable (Stock, Okun, Haring & Witter, 1983), or decrease from younger (18-25 years) to older (65+ years) age groups (Edwards & Klemmack, 1973). Older people may maintain their level of subjective QOL through lowering their expectations (Shmotkin, 1998). The Multiple Discrepancies Theory explicates this, proposing that "reported net satisfaction is a function of perceived discrepancies between what one has and wants" (Michalos, 1985, p.347). Older people may maintain their level of subjective QOL through utilising downward comparisons. Older people may accept the stereotypical perceptions that older people are poor, frail and socially isolated, and enhance their self-esteem and emotional well-being in a stressful situation by comparing themselves with those stereotypical disadvantaged others.

## **Primary control and Secondary control**

Perceptions of control are intimately interrelated with Subjective QOL (Abeles, 1991). Primary control involves the perception of altering the environment to equate with the self (e.g. taking medication), whereas secondary control involves altering the self to equate with the environment (e.g. believing everything will be okay). In older age, the Life Span Theory of Control proposes that the probability of primary control failure increases with increasing physical deterioration. Repeated primary control failure generates pessimistic expectations of control and reduces the motivational resources required for primary control. Secondary control strategies enable people to move from experiencing a loss of control to maintaining perceptions of primary control by providing the motivational resources required for primary control (Heckhausen & Schulz, 1995).

## **Dispositional Optimism**

Optimism, defined as a "generalised expectancy for positive outcomes" is positively related to subjective QOL (Scheier & Carver, 1985). The type of control strategies selected by older

people may be influenced by an individual's level of dispositional optimism. Optimistic people tend to implement the preferred primary control strategies, whereas pessimistic people tend to implement secondary control strategies.

### Daily Hassles and Daily Uplifts

Daily hassles are the “irritating, frustrating demands that are, to some extent, characteristic of everyday transactions with the environment.” (Kanner, Coyne, Schaefer & Lazarus, 1981, p.3). Daily hassles directly reduce subjective QOL, particularly if positive experiences are lacking. Uplifts may act as an emotional buffer against stress by acting as a breather from stressful situations.

### Hypotheses

- 1) Older people will report a higher subjective QOL than younger people
- 2) Secondary control strategies will be more positively related to Subjective QOL for older people than for younger people
- 3) Low optimism will reduce subjective QOL for both the younger and older age groups
- 4) Daily uplifts will influence subjective QOL beyond the influence of daily hassles

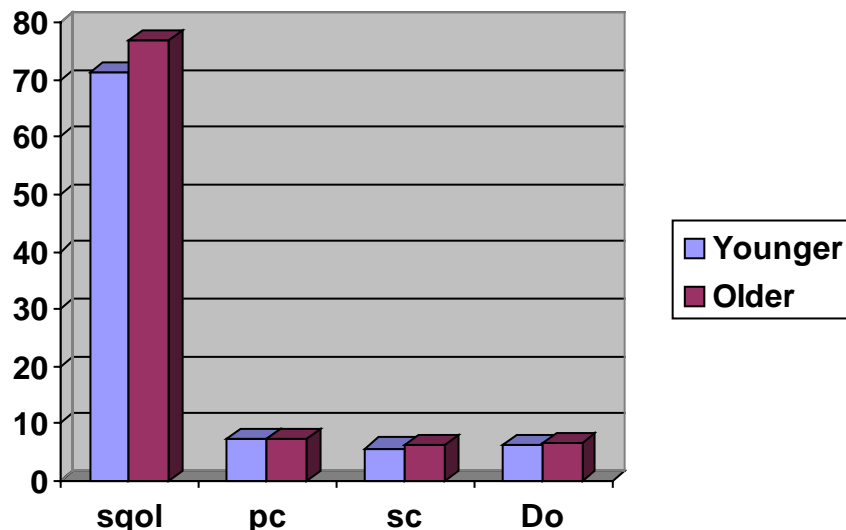
### Method

- 107 younger people (18-25 years,  $M = 20.1$  years), obtained from Deakin University
- 100 older people (65+ years,  $M = 75.6$  years), obtained from 6 retirement villages, a senior citizens club, and convenience sampling.
- Subjective QOL : Comprehensive Quality of Life Scale (Com-QOL; Cummins, 1997)
- Primary and Secondary control : Cognitive-Behavioural Control Questionnaire (CBCQ; Heaps, 1998)
- Hassles and Uplifts : List top 5 hassles and uplifts and rate their severity/intensity
- Dispositional Optimism : Life Orientation Test (LOT; Scheier & Carver, 1985).

### Results

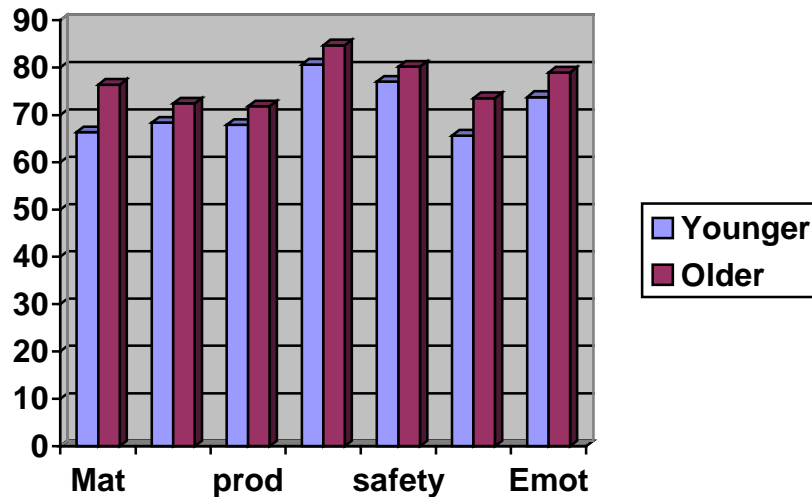
#### Age Differences in Subjective QOL, Primary control, Secondary control and Dispositional Optimism

Older people reported a significantly higher level of subjective QOL, more Secondary control strategies, a higher level of dispositional optimism, and equal perceptions of Primary control.



### Age Differences in the 7 domains of Subjective QOL

Older people reported significantly higher material well-being, emotional well-being and community.



### Predicting Subjective QOL from Primary control, Secondary control and Dispositional Optimism for the Younger and Older Groups

In the younger group, primary control and secondary control were positively related to subjective QOL, accounting for 3 and 4 % of the variance, respectively. In the older group, only primary control was positively related to subjective QOL, accounting for almost 5% of the variance. Hence, the 2<sup>nd</sup> hypothesis proposing that secondary control strategies will be more positively related to subjective QOL for older than younger people was not supported.

Dispositional optimism accounted for 13% of the variance in Subjective QOL for both the younger and older groups. When dispositional optimism was included in the equation however, primary control and secondary control were no longer significant. This suggests that dispositional optimism subsumes primary control and secondary control, and that the effects of dispositional optimism on subjective QOL may be mediated by primary control and secondary control.

### Age Differences in Subjective QOL, Primary control and Secondary control strategies of people low in Dispositional Optimism

Consistent with the 3<sup>rd</sup> hypothesis, low levels of dispositional optimism reduced subjective QOL for both the younger and older groups. Although younger and older people low in dispositional optimism reported similar levels of dispositional optimism, older people reported a higher subjective QOL than the younger people.

### Predicting Subjective QOL from Daily Hassles and Daily Uplifts

2% of the variance in subjective QOL was predicted by daily hassles and 8% was predicted by daily uplifts.

## **Implications**

These findings challenge the stereotypical perceptions of aging as a period of inevitable decline in subjective QOL and control. The differences in younger and older peoples' subjective QOL may be explained in part, by the Multiple Discrepancies Theory, and the Social Comparison Theory. In terms of the former, the older group perceives a smaller discrepancy between what they have and what they expect, than younger people. In terms of the latter, older people reported more downward comparisons than younger people. Disadvantaged others may be more accessible for older people.

Older people tend to have a higher subjective QOL when they have higher perceptions of primary control rather than secondary control. How can they maintain their perceptions of primary control when the probability of actual primary control failure increases? It is speculated that they maintain their perceptions of primary control through avoiding experiencing or thinking about primary control failure, and through selectively focussing on areas where they have actual primary control (i.e. secondary control strategies). This was partially supported as older people reported significantly more secondary control strategies than younger people.

Dispositional optimism exerts its influence on subjective QOL through primary control and secondary control strategies.

Interventions aiming to increase older peoples' subjective QOL may benefit from increasing the intensity of their uplifts rather than attempting to decrease the severity of daily hassles. Daily hassles account for less of the variance in subjective QOL, and are often uncontrollable situations such as health problems, that are not as amenable to change as uplifts.

## **Conclusions**

Contrary to the stereotypical perceptions of aging, older peoples' level of subjective QOL and control may not necessarily deteriorate. Older people who report a higher subjective QOL tend to have high perceptions of primary control, and dispositional optimism, and experience intense uplifts. Although secondary control strategies do not increase older peoples' subjective QOL, interventions aiming to increase perceptions of primary control may do so through increasing secondary control strategies.