STIRLING UNIVERSITY

Subjective Evaluation of Quality of Life after Brain Injury

Measuring quality of life and the impact of response shift

(Volume 2: Appendices)

Hannah Blair

Contents

Appendix 2.1 – Hadorn’s scale as used in Chapter 3

Overall Quality of Life

Participant no:……………………………..

Date:…………………………………………

Please rate on this scale, how you feel your overall Quality of Life was before your injury, if 0 is the worst possible way your life could be and 10 if there is no way that life could be any better.

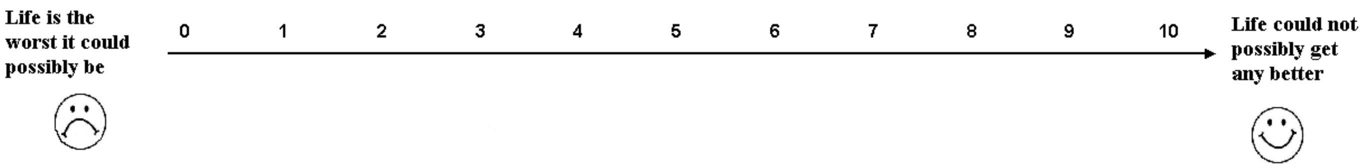
Life is the worst it could possibly be.	**0**	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**	**Life could not possibly get any better**

Appendix 2.2 – QOLIBRI as presented in Chapter 5

Appendix 2.2: Qolibri overall scale as presented in questionnaire pack for study reported in Chapter 5 (including Hadorn’s scale)

Your life now:

How would you rate your life as it is at the moment?



	Not at all	Slightly	Moderately	Quite	Very
Overall, how satisfied are you with your physical condition?					
Overall, how satisfied are you with how your brain is working, in terms of your concentration, memory, thinking?					
Overall, how satisfied are you with your feelings and emotions?					
Overall, how satisfied are you with your ability to carry out day to day activities?					
Overall, how satisfied are you with your personal and social life?					
Overall, how satisfied are you with your current situation and future prospects?					

Your life before your injury:

How would you rate your life as it was <u>before your injury</u>?

Life was the worst it could possibly have been ☹

0 1 2 3 4 5 6 7 8 9 10 →

Life could not possibly have been any better ☺

Before your injury:	Not at all	Slightly	Moderately	Quite	Very
Overall, how satisfied were you with your physical condition?					
Overall, how satisfied were you with how your brain was working, in terms of your concentration, memory, thinking?					
Overall, how satisfied were you with your feelings and emotions?					
Overall, how satisfied were you with your ability to carry out day to day activities?					
Overall, how satisfied were you with your personal and social life?					
Overall, how satisfied were you with your current situation and future prospects?					

Appendix 2.3 – GOSE interview format

Glasgow Outcome Scale - Extended

Patient's name: ____________________________________ Date of interview: ___________

Date of Birth: _____________ Date of injury ______________ Gender: M / F

Age at injury: ___________ Interval post-injury: _____________

Respondent: Patient alone ___ Relative/ friend/ carer alone ___ Patient + relative/ friend/ carer ___

Interviewer: _______________________________

CONSCIOUSNESS

1.	Is the head injured person able to obey simple commands, or say any words?	☐	1 = No (VS) 2 = Yes

Anyone who shows ability to obey even simple commands, or utter any word or communicate specifically in any other way is no longer considered to be in the vegetative state. Eye movements are not reliable evidence of meaningful responsiveness. Corroborate with nursing staff. Confirmation of VS requires full assessment as in the Royal College of Physician Guidelines.

INDEPENDENCE IN THE HOME

2a	Is the assistance of another person at home essential every day for some activities of daily living?	☐	1 = No 2 = Yes If "No" go to question 3a.

For a 'No' answer they should be able to look after themselves at home for 24 hours if necessary, though they need not actually look after themselves. Independence includes the ability to plan for and carry out the following activities: getting washed, putting on clean clothes without prompting, preparing food for themselves, dealing with callers, and handling minor domestic crises. The person should be able to carry out activities without needing prompting or reminding, and should be capable of being left alone overnight.

2b	Do they need frequent help or someone to be around at home most of the time?	☐	1 = No (Upper SD) 2 = Yes (Lower SD)

For a 'No' answer they should be able to look after themselves at home for up to 8 hours during the day if necessary, though they need not actually look after themselves.

2c	Was assistance at home essential before the injury?	☐	1 = No 2 = Yes

INDEPENDENCE OUTSIDE THE HOME

3a	Are they able to shop without assistance?	☐	1 = No (Upper SD) 2 = Yes

This includes being able to plan what to buy, take care of money themselves, and behave appropriately in public. They need not normally shop, but must be able to do so.

3b	Were they able to shop without assistance before the injury?	☐	1 = No 2 = Yes

4a	Are they able to travel locally without assistance?	☐	1 = No (Upper SD) 2 = Yes

They may drive or use public transport to get around. Ability to use a taxi is sufficient, provided the person can phone for it themselves and instruct the driver.

4b	Were they able to travel without assistance before the injury?	☐	1 = No 2 = Yes

WORK

5a	Are they currently able to work to their previous capacity?	☐	1 = No 2 = Yes

If they were working before, then their current capacity for work should be at the same level. If they were seeking work before, then the injury should not have adversely affected their chances of obtaining work or the level of work for which they are eligible. If the patient was a student before injury then their capacity for study should not have been adversely affected.

5b	How restricted are they?	☐	
	a) Reduced work capacity.		1 = a (Upper MD)
	b) Able to work only in a sheltered workshop or non-competitive job, or currently unable to work.		2 = b (Lower MD)
5c	Were they either working or seeking employment before the injury (answer ‘yes’) or were they doing neither (answer ‘no’)?	☐	1 = No 2 = Yes

SOCIAL & LEISURE ACTIVITIES

6a	Are they able to resume regular social and leisure activities outside home?	☐	1 = No 2 = Yes

They need not have resumed all their previous leisure activities, but should not be prevented by physical or mental impairment. If they have stopped the majority of activities because of loss of interest or motivation then this is also considered a disability.

6b	What is the extent of restriction on their social and leisure activities?	☐	
	a) Participate a bit less: at least half as often as before injury.		1 = a (Lower GR)
	b) Participate much less: less than half as often.		2 = b (Upper MD)
	c) Unable to participate: rarely, if ever, take part.		3 = c (Lower MD)
6c	Did they engage in regular social and leisure activities outside home before the injury?	☐	1 = No 2 = Yes

FAMILY & FRIENDSHIPS

7a	Have there been psychological problems which have resulted in ongoing family disruption or disruption to friendships?	☐	1 = No 2 = Yes

Typical post-traumatic personality changes: quick temper, irritability, anxiety, insensitivity to others, mood swings, depression, and unreasonable or childish behaviour.

7b	What has been the extent of disruption or strain?	☐	
	a) Occasional - less than weekly		1 = a (Lower GR)
	b) Frequent - once a week or more, but tolerable.		2 = b (Upper MD)
	c) Constant - daily and intolerable.		3 = c (Lower MD)
7c	Were there problems with family or friends before the injury?	☐	1 = No 2 = Yes

If there were some problems before injury, but these have become markedly worse since injury then answer ‘No’ to Q7c.

RETURN TO NORMAL LIFE

8a	Are there any other current problems relating to the injury which affect daily life?	☐	1 = No (Upper GR) 2 = Yes (Lower GR)

Other typical problems reported after head injury: headaches, dizziness, tiredness, sensitivity to noise or light, slowness, memory failures, and concentration problems.

8b	Were similar problems present before the injury?	☐	1 = No 2 = Yes

If there were some problems before injury, but these have become markedly worse since injury then answer ‘No’ to Q8b.

Epilepsy:
Since the injury has the head injured person had any epileptic fits? No / Yes
Have they been told that they are currently at risk of developing epilepsy? No / Yes

What is the most important factor in outcome?
Effects of head injury ___ Effects of illness or injury to another part of the body ___ A mixture of these ___

Scoring: The patient's overall rating is based on the lowest outcome category indicated on the scale. Refer to Guidelines for further information concerning administration and scoring

1	Dead
2	Vegetative State (VS)
3	Lower Severe Disability (Lower SD)
4	Upper Severe Disability (Upper SD)
5	Lower Moderate Disability (Lower MD)
6	Upper Moderate Disability (Upper MD)
7	Lower Good Recovery (Lower GR)
8	Upper Good Recovery (Upper GR)

☐

Appendix 2.4 – GOSE self-report questionnaire

Glasgow Outcome Scale Questionnaire

These questions are to do with changes in your lifestyle since your injury. There are also some questions about how things were before the injury. The questions can be answered by you, or by a close relative or friend, or by you both together. We are interested in the recovery you have made up to now.

Injured person's name: ___________________________________ Today's date: ___________

Person who filled out this form:

Patient alone☐ Relative or friend or carer alone☐ Patient and relative, friend or carer together ☐

The injured person is:

Out of hospital☐ In hospital or residential care☐

Please answer each question by ticking one box ☑ which is true for you.

---

1. Before the injury were you able to look after yourself at home? Yes ☐ No ☐
2. As a result of your injury do you now need someone to help look after you at home?

(please tick ☑ one box)

I do not need help or supervision in the home ☐

I need some help in the home, but not every day ☐

I need help in the home every day, but I could look after myself for at least 8 hours if necessary ☐

I could not look after myself for 8 hours during the day ☐

I need help in the home, but not because of the injury ☐

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3. Before the injury were you able to buy things at shops without help? Yes ☐ No ☐
4. As a result of your injury do you now need help to buy things at shops?

(please tick ☑ one box)

I do not need help to shop ☐

I need some help, but I can go to local shops on my own ☐

I need help to shop even locally, or I cannot shop at all ☐

I need help to shop, but not because of the injury ☐

---

5. Before the injury were you able to travel without help? Yes ☐ No ☐

6. As a result of your injury do you now need help to travel? **(please tick ☑ one box)**

I do not need help to travel ☐

I need some help, but can travel locally on my own ☐
(e.g. by arranging a taxi)

I need help to travel even locally, or I cannot travel at all ☐

I need help to travel but not because of the injury ☐

---

7. Employment before the injury: **(please tick ☑ one box)**

Working ☐ Looking for work ☐

Looking after family ☐ Studying as a student ☐

Retired ☐ None of these (e.g. unfit for work) ☐

8. As a result of your injury has there been a change in your ability to work? (or to study if you were a student; or to look after your family) **(please tick ☑ one box)**

I still do the same work ☐

I still do the same work, but have some problems (e.g. tiredness, lack of concentration). ☐

I still work, but at a reduced level (e.g. change from full-time to part-time, or change in level of responsibility) ☐

I am unable to work, or only able to work in sheltered workshop ☐

My ability to work has changed, but not because of the injury ☐

---

9. Before the injury did you take part in regular social and leisure activities outside home (at least once a week)? Yes ☐ No ☐

Social and leisure activities include: going out to a pub or club, visiting friends, going to the cinema or bingo, going out for a walk, attending a football match, taking part in sport.

10. As a result of your injury has there been a change in your ability to take part in social and leisure activities outside home? **(please tick ☑ one box)**

I take part about as often as before ☐
(the activities may be different from before)

I take part a bit less, but at least half as often ☐

I take part much less, less than half as often ☐

I do not take part at all ☐

My ability to take part has changed for some other reason, not because of the injury ☐

---

11. Before the injury did you have any problems in getting on with friends or relatives?

Yes ☐ No ☐

12. As a result of your injury are there now problems in how you get on with friends or relatives? **(please tick ☑ one box)**

Things are still much the same ☐

There are occasional problems (less than once a week) ☐

There are frequent problems (once a week or more) ☐

There are constant problems (problems every day) ☐

There are problems for some other reason, not because of the injury ☐

---

13. Are there any other problems resulting from your injury which have interfered with your daily life over the past week? (Problems sometimes reported after head injury: **headaches, dizziness, tiredness, sensitivity to noise or light, slowness, memory failures, and concentration problems**.)

(please tick ☑ one box)

I have no current problems ☐

I have some problems, but these do not interfere with my daily life ☐

I have some problems, and these have affected my daily life ☐

I have some problems for other reasons, not because of the head injury ☐

14. Before the injury were similar problems present? **(please tick ☑ one box)**

I had no problems before, I had minor problems ☐

I had similar problems before ☐

Are there any other comments that you would like to make?

(Please continue overleaf if you wish)

Appendix 2.5 – Silver lining questionnaire

The Silver Lining Questionnaire

What is this questionnaire all about?

Although illness can be a distressing experience, some people who have or have had an illness talk about its positive aspects. This questionnaire asks you to think about this positive side of illness.

How do I complete this questionnaire?

On the next two pages, there are 38 statements about the experience of being ill. Please indicate the extent to which you agree or disagree with each statement by circling a number between 5 "strongly agree" and 1 "strongly disagree". There are no right or wrong answers, your own personal views are important.

An example to help you:

	strongly agree	agree	not sure	disagree	strongly disagree
I appreciate other people more because of my illness	[✓ 5]	4	3	2	1

If you strongly feel that you appreciate other people more now as a result of your illness, you would circle the number five.

Please complete: **Age** ………………….

Sex (tick) Male ☐

Female ☐

Please write any illnesses you have

…………………………………………………………..

…………………………………………………………..

…………………………………………………………..

Please circle *one* number for *each* statement

	strongly agree	**agree**	**not sure**	**disagree**	**strongly disagree**
1. I appreciate life more because of my illness	5	4	3	2	1
2. My illness gave me a new start in life	5	4	3	2	1
3. My life is much better now than it was before	5	4	3	2	1
4. My illness has made me live life to its fullest	5	4	3	2	1
5. Because of my illness I find it easier to accept what life has in store	5	4	3	2	1
6. My illness made me think about the true purpose of life	5	4	3	2	1
7. My religious/spiritual beliefs deepened because of my illness	5	4	3	2	1
8. I am now more open to other religions because of my illness	5	4	3	2	1
9. My illness made me a better person	5	4	3	2	1
10. I became a happier person because of my illness	5	4	3	2	1
11. I am a calmer person because of my illness	5	4	3	2	1
12. My illness made me more mature	5	4	3	2	1
13. My illness made me a more tolerant person	5	4	3	2	1
14. My illness made me realise that I matter as a person	5	4	3	2	1
15. My illness gave me more confidence	5	4	3	2	1
16. I am less concerned about failure because of my illness	5	4	3	2	1
17. My illness gave me permission to do things for myself	5	4	3	2	1
18. My illness made me a more determined person	5	4	3	2	1
19. My illness helped me find myself	5	4	3	2	1
20. My illness made me more aware of my strengths	5	4	3	2	1
21. Through my illness I discovered a talent I didn't know I had	5	4	3	2	1
22. I can face whatever is around the corner because of my illness	5	4	3	2	1

Please turn over

Please circle *one* number for *each* statement

	strongly agree	**agree**	**not sure**	**disagree**	**strongly disagree**
23. My illness encouraged me to reflect on how I feel about myself.	5	4	3	2	1
24. My illness made me face up to problem areas of my life	5	4	3	2	1
25. My illness strengthened my relationships with others	5	4	3	2	1
26. My illness made me less concerned with the approval of others	5	4	3	2	1
27. Because of my illness I have more to offer other people	5	4	3	2	1
28. My illness made me more at ease with others	5	4	3	2	1
29. I see others in their true colours because of my illness	5	4	3	2	1
30. My illness gave me the opportunity to meet new people	5	4	3	2	1
31. My illness taught me how to stand up for myself	5	4	3	2	1
32. My illness made me put an end to troublesome relationships	5	4	3	2	1
33. My illness made me less judgmental of others	5	4	3	2	1
34. I have been an inspiration to others	5	4	3	2	1
35. People can be more open with me since my illness	5	4	3	2	1
36. My illness changed other people for the better	5	4	3	2	1
37. My illness changed other people's perception of me for better	5	4	3	2	1
38. Other people appreciate me more because of my illness	5	4	3	2	1

Thank you for completing this questionnaire

Appendix 2.6 – BIGI

The Brain Injury Grief Inventory

Coetzer ©, Vaughan & Ruddle, 2003.

This questionnaire is designed to help your clinician to know how you feel. Read each item below and underline the response which comes closest to how you have been feeling in the past week.

If you find it difficult reading and filling in the items, you can ask someone else to read each question out to you.

Don't take too long over your replies; your immediate reaction to each item will probably be more accurate than a long, thought-out response.

Name: ________________________________ Date: _____________

Please rate each statement below as 'never', 'sometimes' or 'mostly'.
Please underline one only.

1. I try to avoid thinking and reminding myself about having had a brain injury ☐
   Never Sometimes Mostly

2. I am able now to think through what the brain injury means to my life ☐
   Never Sometimes Mostly

3. I feel angry that I had a brain injury ☐
   Never Sometimes Mostly

4. Although life has changed for me, I feel able to get on with my life now ☐
   Never Sometimes Mostly

5. I am upset by things that remind me about my injury, e.g. the anniversary ☐
   Never Sometimes Mostly

6. I have stopped comparing how things were before my brain injury ☐
   Never Sometimes Mostly

7. I have found myself longing for the time before my injury occurred ☐
   Never Sometimes Mostly

8. I am less preoccupied with the effects of my brain injury now than I was before ☐
   Never Sometimes Mostly

F1☐ F2☐

9. I have a strong desire to talk about my injury and the effects it had on me ☐
   Never Sometimes Mostly

10. I feel I can reach out to people ☐
    Never Sometimes Mostly

11. I miss the things I cannot do since I had my injury ☐
    Never Sometimes Mostly

12. I think I have overcome the losses resulting from my brain injury ☐
    Never Sometimes Mostly

13. I have been feeling low since my injury ☐
    Never Sometimes Mostly

14. I feel it is unfair that I had a brain injury ☐
    Never Sometimes Mostly

15. I think I understand what has happened to me ☐
    Never Sometimes Mostly

16. I think about my brain injury so much that I find it difficult to do other things ☐
    Never Sometimes Mostly

17. I do not feel sad or depressed ☐
    Never Sometimes Mostly

18. I feel less able to care for other people since my injury ☐
    Never Sometimes Mostly

19. I have accepted the fact that I have a brain injury ☐
    Never Sometimes Mostly

20. Life is empty since my injury ☐
    Never Sometimes Mostly

F1☐ F2☐

Thank you for completing this questionnaire.

Appendix 2.7 – INCOM

SCALE FOR SOCIAL COMPARISON ORIENTATION (INCOM, Iowa-Netherlands Comparison Orientation Scale)
English version

Primary references:

Gibbons, F.X. & Buunk, B.P. (1999). Individual differences in social comparison: The development of a scale of social comparison orientation. *Journal of Personality and Social Psychology, 76*, 129-142.

Buunk, B.P., Belmonte, J., Peiró, J.M., Zurriaga, R., & Gibbons, F.X. (2005). Diferencias individuales en la comparación social: Propiedades de la escala española de orientación hacia la comparación social. *Revista Latinoamericana de Psicología, 37*, 561-581.

Buunk, A.P., & Gibbons, F.X. (2006). Social comparison orientation: a new perspective on those who do and those who don't compare with others. In Guimond, S. (Ed.) *Social Comparison and Social Psychology: Understanding cognition, intergroup relations and culture* (pp. 15-33). Cambridge: Cambridge University Press.

Response scale for all items:

1. I disagree strongly
2. I disagree
3. I neither agree nor disagree
4. I agree
5. I agree strongly

Recode: items 6 en 10
Short version: items 1, 3, 4, 6, 7, 11

Most people compare themselves from time to time with others. For example, they may compare the way they feel, their opinions, their abilities, and/or their situation with those of other people. There is nothing particularly 'good' or 'bad' about this type of comparison, and some people do it more than others. We would like to find out how often you compare yourself with other people. To do that we would like to ask you to indicate how much you agree with each statement below.

1. I often compare myself with others with respect to what I have accomplished in life

2. If I want to learn more about something, I try to find out what others think about it

3. I always pay a lot of attention to how I do things compared with how others do things

4. I often compare how my loved ones (boy or girlfriend, family members, etc.) are doing with how others are doing

5. I always like to know what others in a similar situation would do

6. I am not the type of person who compares often with others

7. If I want to find out how well I have done something, I compare what I have done with how others have done

8. I often try to find out what others think who face similar problems as I face

9. I often like to talk with others about mutual opinions and experiences

10. I never consider my situation in life relative to that of other people

11. I often compare how I am doing socially (e.g., social skills, popularity) with other people

Appendix 2.8 – PCRS

Patient Competency Rating
(Clinician's Form)

Identifying Information

Patient's Name: ____

Clinician's Name: ____

Date: _______________

How well is clinician acquainted with patient's behavior?

1. Hardly at all
2. Not so well
3. Fairly well
4. Pretty well
5. Very well

Instructions

The following is a questionnaire that asks you to judge this person's ability to do a variety of very practical skills. Some of the questions may not apply directly to things they often do, but you are asked to complete each question as if it were something they "had to do." On each question, you should judge how easy or difficult a particular activity is for them and mark the appropriate space.

Source: Prigatano, G. P. and Others (1986). Neuropsychological Rehabilitation After Brain Injury. Baltimore: Johns Hopkins University Press.

Competency Rating

1	2	3	4	5
Can't do	Very difficult to do	Can do with some difficulty	Fairly easy to do	Can do with ease

_____ 1. How much of a problem do they have in preparing their own meals?

_____ 2. How much of a problem do they have in dressing themselves?

_____ 3. How much of a problem do they have in taking care of their personal hygiene?

_____ 4. How much of a problem do they have in washing the dishes?

_____ 5. How much of a problem do they have in doing the laundry?

_____ 6. How much of a problem do they have in taking care of their finances?

_____ 7. How much of a problem do they have in keeping appointments on time?

_____ 8. How much of a problem do they have in starting conversation in a group?

_____ 9. How much of a problem do they have in staying involved in work activities even when bored or tired?

_____ 10. How much of a problem do they have in remembering what they had for dinner last night?

_____ 11. How much of a problem do they have in remembering names of people they see often?

_____ 12. How much of a problem do they have in remembering their daily schedule?

_____ 13. How much of a problem do they have in remembering important things they must do?

_____ 14. How much of a problem would they have driving a car if they had to?

_____ 15. How much of a problem do they have in getting help when they are confused?

_____ 16. How much of a problem do they have in adjusting to unexpected changes?

1	2	3	4	5
Can't do	Very difficult to do	Can do with some difficulty	Fairly easy to do	Can do with ease

_____ 17. How much of a problem do they have in handling arguments with people they know well?

______ 18. How much of a problem do they have in accepting criticism from other people?

______ 19. How much of a problem do they have in controlling crying?

_____ 20. How much of a problem do they have in acting appropriately when they are around friends?

_____ 21. How much of a problem do they have in showing affection to people?

_____ 22. How much of a problem do they have in participating in group activities?

_____ 23. How much of a problem do they have in recognizing when something they say or do has upset someone else?

_____ 24. How much of a problem do they have in scheduling daily activities?

_____ 25. How much of a problem do they have in understanding new instructions?

_____ 26. How much of a problem do they have in consistently meeting their daily responsibilities?

_____ 27. How much of a problem do they have in controlling their temper when something upsets them?

_____ 28. How much of a problem do they have in keeping from being depressed?

_____ 29. How much of a problem do they have in keeping their emotions from affecting their ability to go about the day's activities?

_____ 30. How much of a problem do they have in controlling their laughter?

Patient Competency Rating
(Patient's Form)

Source: Prigatano, G. P. and Others (1986). Neuropsychological Rehabilitation After Brain Injury. Baltimore: Johns Hopkins University Press.

Identifying Information

Patient's Name: ____

Date: _______________

Instructions

The following is a questionnaire that asks you to judge your ability to do a variety of very practical skills. Some of the questions may not apply directly to things you often do, but you are asked to complete each question as if it were something you "had to do." On each question, you should judge how easy or difficult a particular activity is for you and mark the appropriate space.

Competency Rating

1	2	3	4	5
Can't do	Very difficult to do	Can do with some difficulty	Fairly easy to do	Can do with ease

_____ 1. How much of a problem do I have in preparing my own meals?

_____ 2. How much of a problem do I have in dressing myself?

_____ 3. How much of a problem do I have in taking care of my personal hygiene?

_____ 4. How much of a problem do I have in washing the dishes?

_____ 5. How much of a problem do I have in doing the laundry?

_____ 6. How much of a problem do I have in taking care of my finances?

_____ 7. How much of a problem do I have in keeping appointments on time?

1	2	3	4	5
Can't do	Very difficult to do	Can do with some difficulty	Fairly easy to do	Can do with ease

_____ 8. How much of a problem do I have in starting conversation in a group?

_____ 9. How much of a problem do I have in staying involved in work activities even when bored or tired?

_____ 10. How much of a problem do I have in remembering what I had for dinner last night?

_____ 11. How much of a problem do I have in remembering names of people I see often?

_____ 12. How much of a problem do I have in remembering my daily schedule?

_____ 13. How much of a problem do I have in remembering important things I must do?

_____ 14. How much of a problem would I have driving a car if I had to?

_____ 15. How much of a problem do I have in getting help when I'm confused?

_____ 16. How much of a problem do I have in adjusting to unexpected changes?

_____ 17. How much of a problem do I have in handling arguments with people I know well?

______ 18. How much of a problem do I have in accepting criticism from other people?

______ 19. How much of a problem do I have in controlling crying?

_____ 20. How much of a problem do I have in acting appropriately when I'm around friends?

_____ 21. How much of a problem do I have in showing affection to people?

_____ 22. How much of a problem do I have in participating in group activities?

1	2	3	4	5
Can't do	Very difficult to do	Can do with some difficulty	Fairly easy to do	Can do with ease

_____ 23. How much of a problem do I have in recognizing when something I say or do has upset someone else?

_____ 24. How much of a problem do I have in scheduling daily activities?

_____ 25. How much of a problem do I have in understanding new instructions?

_____ 26. How much of a problem do I have in consistently meeting my daily responsibilities?

_____ 27. How much of a problem do I have in controlling my temper when something upsets me?

_____ 28. How much of a problem do I have in keeping from being depressed?

_____ 29. How much of a problem do I have in keeping my emotions from affecting my ability to go about the day's activities?

_____ 30. How much of a problem do I have in controlling my laughter?

Patient Competency Rating
(Relative's Form)

Source: Prigatano, G. P. and Others (1986). Neuropsychological Rehabilitation After Brain Injury. Baltimore: Johns Hopkins University Press.

Identifying Information

Patient's Name: ____

Date: _______________

Informant's relationship to patient (circle one):

1. Mother
2. Father
3. Spouse
4. Child
5. Sibling
6. Grandparent
7. Aunt or uncle
8. Niece or nephew
9. Cousin
10. Friend
11. In-law
12. Ward attendant
13. Other ___________________

Sex of informant:

Male _______
Female _____

How well is informant acquainted with patient's behavior?

1. Hardly at all
2. Not so well
3. Fairly well
4. Pretty well
5. Very well

Instructions

The following is a questionnaire that asks you to judge this person's ability to do a variety of very practical skills. Some of the questions may not apply directly to things they often do, but you are asked to complete each question as if it were something they "had to do." On each question, you should judge how easy or difficult a particular activity is for them and mark the appropriate space.

Competency Rating

1	2	3	4	5
Can't do	Very difficult to do	Can do with some difficulty	Fairly easy to do	Can do with ease

_____ 1. How much of a problem do they have in preparing their own meals?

_____ 2. How much of a problem do they have in dressing themselves?

_____ 3. How much of a problem do they have in taking care of their personal hygiene?

_____ 4. How much of a problem do they have in washing the dishes?

_____ 5. How much of a problem do they have in doing the laundry?

_____ 6. How much of a problem do they have in taking care of their finances?

_____ 7. How much of a problem do they have in keeping appointments on time?

_____ 8. How much of a problem do they have in starting conversation in a group?

_____ 9. How much of a problem do they have in staying involved in work activities even when bored or tired?

_____ 10. How much of a problem do they have in remembering what they had for dinner last night?

_____ 11. How much of a problem do they have in remembering names of people they see often?

_____ 12. How much of a problem do they have in remembering their daily schedule?

_____ 13. How much of a problem do they have in remembering important things they must do?

_____ 14. How much of a problem would they have driving a car if they had to?

_____ 15. How much of a problem do they have in getting help when they are confused?

_____ 16. How much of a problem do they have in adjusting to unexpected changes?

1	2	3	4	5
Can't do	Very difficult to do	Can do with some difficulty	Fairly easy to do	Can do with ease

_____ 17. How much of a problem do they have in handling arguments with people they know well?

______ 18. How much of a problem do they have in accepting criticism from other people?

______ 19. How much of a problem do they have in controlling crying?

_____ 20. How much of a problem do they have in acting appropriately when they are around friends?

_____ 21. How much of a problem do they have in showing affection to people?

_____ 22. How much of a problem do they have in participating in group activities?

_____ 23. How much of a problem do they have in recognizing when something they say or do has upset someone else?

_____ 24. How much of a problem do they have in scheduling daily activities?

_____ 25. How much of a problem do they have in understanding new instructions?

_____ 26. How much of a problem do they have in consistently meeting their daily responsibilities?

_____ 27. How much of a problem do they have in controlling their temper when something upsets them?

_____ 28. How much of a problem do they have in keeping from being depressed?

_____ 29. How much of a problem do they have in keeping their emotions from affecting their ability to go about the day's activities?

_____ 30. How much of a problem do they have in controlling their laughter?

Appendix 2.9 – MSPSS

Multidimensional Scale of Perceived Social Support (Zimet, Dahlem, Zimet & Farley, 1988)

Instructions: We are interested in how you feel about the following statements. Read each statement carefully. Indicate how you feel about each statement.

Circle the "1" if you **Very Strongly Disagree**
Circle the "2" if you **Strongly Disagree**
Circle the "3" if you **Mildly Disagree**
Circle the "4" if you are **Neutral**
Circle the "5" if you **Mildly Agree**
Circle the "6" if you **Strongly Agree**
Circle the "7" if you **Very Strongly Agree**

1.	There is a special person who is around when I am in need.	1	2	3	4	5	6	7	SO
2.	There is a special person with whom I can share my joys and sorrows.	1	2	3	4	5	6	7	SO
3.	My family really tries to help me.	1	2	3	4	5	6	7	Fam
4.	I get the emotional help and support I need from my family.	1	2	3	4	5	6	7	Fam
5.	I have a special person who is a real source of comfort to me.	1	2	3	4	5	6	7	SO
6.	My friends really try to help me.	1	2	3	4	5	6	7	Fri
7.	I can count on my friends when things go wrong.	1	2	3	4	5	6	7	Fri
8.	I can talk about my problems with my family.	1	2	3	4	5	6	7	Fam
9.	I have friends with whom I can share my joys and sorrows.	1	2	3	4	5	6	7	Fri
10.	There is a special person in my life who cares about my feelings.	1	2	3	4	5	6	7	SO
11.	My family is willing to help me make decisions.	1	2	3	4	5	6	7	Fam
12.	I can talk about my problems with my friends.	1	2	3	4	5	6	7	Fri

The items tended to divide into factor groups relating to the source of the social support, namely family (Fam), friends (Fri) or significant other (SO).

References

Canty-Mitchell, J. & Zimet, G.D. (2000). Psychometric properties of the Multidimensional Scale of Perceived Social Support in urban adolescents. *American Journal of Community Psychology*, *28*, 391-400.

Zimet, G.D., Dahlem, N.W., Zimet, S.G. & Farley, G.K. (1988). The Multidimensional Scale of Perceived Social Support. *Journal of Personality Assessment*, *52*, 30-41.

Zimet, G.D., Powell, S.S., Farley, G.K., Werkman, S. & Berkoff, K.A. (1990). Psychometric characteristics of the Multidimensional Scale of Perceived Social Support. *Journal of Personality Assessment*, *55*, 610-17.

Appendix 2.10 – MOS-SS

MOS Social Support Survey

People sometimes look to others for companionship, assistance, or other types of support. How often is each of the following kinds of support available to you if you need it? Circle one number on each line.

	None of the time	A little of the time	Some of the time	Most of the time	All of the time
Emotional/informational support					
Someone you can count on to listen to you when you need to talk	1	2	3	4	5
Someone to give you information to help you understand a situation	1	2	3	4	5
Someone to give you good advice about a crisis	1	2	3	4	5
Someone to confide in or talk to about yourself or your problems	1	2	3	4	5
Some whose advice you really want	1	2	3	4	5
Someone to share your most private worries and fears with	1	2	3	4	5
Someone to turn to for suggestions about how to deal with a personal problem	1	2	3	4	5
Someone who understands your problems	1	2	3	4	5
Tangible support					
Someone to help you if you were confined to bed	1	2	3	4	5
Someone to take you to the doctor if you needed it	1	2	3	4	5
Someone to prepare your meals if you were unable to do it yourself	1	2	3	4	5
Someone to help with daily chores if you were sick	1	2	3	4	5
Affectionate support					
Someone who shows you love and affection	1	2	3	4	5
Someone to love and make you feel wanted	1	2	3	4	5
Someone who hugs you	1	2	3	4	5

	None of the time	A little of the time	Some of the time	Most of the time	All of the time
Positive social interaction					
Someone to have a good time with	1	2	3	4	5
Someone to get together with for relaxation	1	2	3	4	5
Someone to do something enjoyable with	1	2	3	4	5
Additional item					
Someone to do things with to help you get your mind off things	1	2	3	4	5

Appendix 2.11 – Brief COPE

Brief COPE

These items deal with ways you've been coping with the stress in your life. There are many ways to try to deal with problems. These items ask what you've been doing to cope with this one. Obviously different people deal with things in different ways, but I'm interested in how you've tried to deal with it. Each item says something about a particular way of coping. I want to know to what extent you've been doing what the item says. Don't answer on the basis of whether it seems to be working or not – just whether or not you're doing it. Use the response choices. Try to rate each item separately in your mind from the others. Make your answers as true FOR YOU as you can.

	I haven't been doing this at all	**I've been doing this a little bit**	**I've been doing this a medium amount**	**I've been doing this a lot**
1. I've been turning to work or other activities to take my mind off things				
2. I've been concentrating my efforts on doing something about the situation I'm in				
3. I've been saying to myself 'this isn't real'				
4. I've been using alcohol or other drugs to make myself feel better				
5. I've been getting emotional support from others				
6. I've been giving up trying to deal with it				
7. I've been taking action to try to make the situation better				
8. I've been refusing to believe that it has happened				
9. I've been saying things to let my unpleasant feelings escape				
10. I've been getting help and advice from other people				
11. I've been using alcohol or other drugs to help me get through it				
12. I've been trying to see it in a different light to make it seem more positive				
13. I've been criticizing myself				
14. I've been trying to come up with a strategy to do something about it				
15. I've been getting comfort and understanding from someone				
16. I've been giving up the attempt to cope				
17. I've been looking for something good in what is happening				
18. I've been making jokes about it				
19. I've been doing something to think about it				

less; such as going to movies, watching TV, reading, daydreaming, sleeping, or shopping				
20. I’ve been accepting the reality of the fact it has happened				
21. I’ve been expressing my negative feelings				
22. I’ve been trying to find comfort in my religion or spiritual beliefs				
23. I’ve been trying to get advice or help from other people about what to do				
24. I’ve been learning to live with it				
25. I’ve been thinking hard about what steps to take				
26. I’ve been blaming myself for things that happened				
27. I’ve been praying or meditating				
28. I’ve been making fun of the situation				

Computed as follows (no reversals of coding)
Self-distraction – 1 & 19
Active Coping – 2 & 7
Denial – 3 & 8
Substance Use – 4 & 11
Use of emotional support – 5 & 15
Use of instrumental support – 10 & 23
Behavioural Disengagement – 6 & 16
Venting – 9 & 21
Positive Re-framing – 12 & 17
Planning – 14 & 25
Humor – 18 & 28
Acceptance – 20 & 24
Religion – 22 & 27
Self-blame – 13 & 26

Appendix 2.12 – LOT-R

LOT-R

	I agree a lot	I agree a little	I neither agree or disagree	I DISagree a little	I DISagree a lot
In uncertain times, I usually expect the best.					
It's easy for me to relax					
If something can go wrong for me, it will.					
I'm always optimistic about my future.					
I enjoy my friends a lot.					
It's important for me to keep busy.					
I hardly ever expect things to go my way.					
I don't get upset too easily					
I rarely count on good things happening to me.					
Overall, I expect more good things to happen to me than bad.					

Appendix 3.1: Participant Information Sheet; Chapter 3.

PATIENT INFORMATION SHEET

Study: Quality of Life after Brain Injury

ed to take part in a research study. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take the time to read the following information carefully. Discuss it with friends, relatives and your GP if you wish.

- **Part 1** tells you the purpose of the study and what will happen to you if you take part.
- **Part 2** gives you more detailed information about the conduct of the study.

Please ask if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

What is this research? This study looks at traumatic brain injury and the impact that this has had on your life. In particular we are interested in finding out whether things you consider to be important to your 'quality of life' have changed as a consequence of your injury.

There is a phenomenon known as *'response shift'* described in the literature. This suggests that your perception of quality of life will change to accommodate any changes that occur in your life.

We hope to find out how true this is by asking people who have suffered a traumatic brain injury in the past and those who have not what areas they feel are important to their quality of life and how well they feel that these areas are for them at the moment. By comparing this information we hope that it will be possible to identify if there are differences in what is important to life as a consequence of brain injury.

Why would this information be useful? Measures of quality of life are increasingly being used as an outcome measure in health care and research settings. If there is a difference in how quality of life will be perceived and rated due to injury, illness or other life events these might not always be accurate. The information from this study may help to find out how useful these measures are.

More specific to traumatic brain injury – if specific aspects of life are consistently identified as being important it might be possible to use this information in developing rehabilitation for people who have recently sustained a brain injury. If certain aspects of life are more important than others rehabilitation programmes could be focused to ensure the best possible outcome from injury. Additionally; if no specific areas of life emerge in general, it will help to highlight the need for rehabilitation programmes to be tailored to individual needs.

Why have I been chosen? We are contacting as many patients as possible who, like yourself, have received treatment at the Centre for Brain Injury Rehabilitation following a traumatic brain injury. This is to find out what is important to a variety of people.

Do I have to take part? No. It is up to you to decide whether or not to take part. If you do, you will be given this information sheet to keep and will be asked to sign a consent form. You are still free to withdraw at any time and without giving a reason. A decision to withdraw at any time or a decision not to take part will not affect the standard of care you receive.

What will taking part involve? Taking part in this study will involve an interview taking around 50 minutes in total. This will take place at the CBIR, or if it is more convenient for you a time may be arranged for the researcher to visit you at home. The interview is based around questionnaires that are commonly used in both clinical and research settings. The answers you will be asked for will be essentially straightforward in nature, although you might have to put a bit of thought into what areas are important to your quality of life. The questions will relate to your health and well-being at the moment, although you will also be asked about whether things are different now from how they were before your injury.

With your consent, we will access your medical records solely to obtain information about the severity and clinical features of your head injury.

Are there any possible disadvantages or risks of taking part? There are no physical risks, but it will take some effort on your part to answer the questions. We recognise that this may be tiring and the researcher will be more than happy for you to take rest breaks as needed if this is the case. The questions are all about your own experience, and while it is not expected that you will find them particularly upsetting you are free not too answer any that you do not wish to.

What are the possible benefits of taking part? There are no immediate benefits to you personally, but we hope that the information that we gather will allow a better understanding of the consequences of traumatic brain injury.

Expenses: If you come to the hospital to meet the researcher we will reimburse you with your travel expenses.

What if there is a problem? Any complaint about the way you have been dealt with during the study or any possible harm you might suffer will be addressed. The detailed information on this is given in Part 2. If you do have a complaint, you may refer this to the researcher or to the hospital.

Will my taking part on the study be kept confidential? Yes. All the information about your participation in this study will be kept confidential. The details are included in Part 2.

Contact Details:

If you would like any further information about the study, or if you have any concerns about it, please contact Hannah Blair:

01786 466860
07748 171864
hcb00001@students.stir.ac.uk

This completes Part 1 of the Information Sheet. If the information in Part 1 has interested you and you are considering participation, please continue to read the additional information in Part 2 before making any decision.

PART 2

What will happen if I don’t want to carry on with the study? You may withdraw from the study either before or during the completion of questionnaires. In this case we will destroy any forms you have already completed.

What if there is a problem? If you have a concern about any aspect of the study, you should ask to speak with the researcher who will do their best to answer your questions (01786 466860). If you remain unhappy and wish to complain formally, you can do this through the NHS Complaints Procedure. Details can be obtained from the hospital.

In the event that something does go wrong and you are harmed during the research study there are no special compensation arrangements. If you are harmed and this is due to someone’s negligence then you may have grounds for legal action for compensation against the Tayside NHS Trust or the University of Stirling but you may have to pay your legal costs. The normal National Health Service complaints mechanisms will still be available to you.

Will my taking part in the study be kept confidential? Our procedures for handling, processing, storing, and eventually destroying these data are compliant with the 1998 Data Protection Act. In particular please note that:

- All information which is collected about you during the course of the research will be kept strictly confidential so that identifiable information will be accessible only to the research team and to authorised regulatory authorities who are responsible for monitoring the quality of the research.
- Any information about you which leaves the researcher’s office will have your name and address removed so that you cannot be recognised from it. The questionnaires you have completed will be stored securely in the offices of the principle investigator with your participant code but not your name on them; the research team but nobody else will have access to a separate list of which code corresponds to which participant.
- You have the right to check the accuracy of the data held about you and to correct any errors. Please ask the researcher if you would like to do this.
- The data will be used only for the purposes described in Part 1; should we want to use it in any future research addressing different questions than those explained here we would seek approval from the Research Ethics Committee to do so.
- We will retain the questionnaires in secure conditions for at least 10 years, to comply with good scientific practice, and they will then be shredded. Electronic data (that is, a computerised record of your information and scores) will be archived in a suitable format (e.g. on CD) indefinitely but will not include any personal identifiers such as your name.

Will my GP be notified of my participation? As the study does not involve you receiving any treatment and does not affect any treatment you may already be receiving we will not routinely let him/her know of your involvement unless you ask us to do so.

What will happen to the results of the research study? The data will be analysed for the purpose of Hannah Blair’s MSc dissertation. This is being completed under the supervision of Professor Lindsay Wilson at the University of Stirling.

It is also envisioned that the results will be published in scientific journals.

Please note that you will not be identified in any report or publication unless we have expressly sought your written consent.

Who is involved in the research? The research involves the Centre for Brain Injury Rehabilitation at the Royal Victoria Hospital and the Department of Psychology at the University of Stirling.

Who has reviewed the study? This study has been reviewed by the Tayside Research Ethics Committee and received approval on the 2nd August 2007. Reference number: 07/S1401/89.

Thank you for having read this sheet and taken the time to consider participating in this study. If you do decide to participate you will be given copies of both this information sheet and the signed consent form to keep.

Appendix 3.2: Participant Consent Form; Chapter 3.

Centre Number:
Study Number:
Patient Identification Number:

NHS
Tayside

CONSENT FORM

Title of Project: **Quality of Life after Brain Injury**

Name of researcher:…………………………………..

Please Initial Box

1. I confirm that I have read and understood the information sheet dated ……………………………………….for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐

2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving a reason and without my medical care or legal rights being affected. ☐

3. I understand that relevant sections of my medical notes and data collected during the study may be looked at by responsible individuals from regulatory authorities or from the NHS Trust where it is relevant to my taking part in this research. I give my permission for these individuals to have access to my records. ☐

4. I consent to the researcher accessing my medical records to extract information relating to the severity and clinical aspects of my head injury. ☐

5. I agree to take part in the above study. ☐

……………………………………	…………………………	……………………………
Name of Patient	Date	Signature
……………………………………	…………………………	……………………………
Researcher	Date	Signature

Appendix 3.3: Data Distribution; Chapter 3.

Distribution Data for Measures Used in this study

	Min	Max	Mean	Std. Deviation	Skewness	Kurtosis
GOSE	3.00	8.00	6.1071	1.64067	-.564	-.997
TICS	26	38	32.64	3.832	-.058	-1.265
PCS	31.20	59.70	51.3269	7.43320	-1.200	.744
MCS	28.90	63.10	49.8192	10.18155	-.680	-.699
HADS - Anxiety	1.00	20.00	5.5357	4.55812	1.932	4.207
HADS - Depression	.00	16.00	4.6786	3.83023	1.275	1.594
Overall SEIQoL - Current	15.28	98.86	72.3864	21.86940	-1.370	1.516
Hadorn - Current	3.00	10.00	7.3125	1.79328	-.860	.341

Appendix 4.1: Participant Information Sheet; Chapter 4.

PARTICIPANT INFORMATION SHEET

Study: Changes in Quality of Life after Head Injury

You are being invited to take part in a research study. This is being conducted as part of a PhD in Psychology. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take the time to read the following information carefully. Discuss it with friends, relatives and your GP if you wish.

- **Part 1** tells you the purpose of the study and what will happen to you if you take part.
- **Part 2** gives you more detailed information about the conduct of the study.

Please ask if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

What is this research? This study looks at head injury and the impact that this has had on your life. In particular we are interested in finding out whether your quality of life changes.

We hope to find out what might impact on quality of life after a head injury. We aim to find this out by asking you about your quality of life now and in 6-12 months time and to look at ways in which you might have adjusted to your injury.

Why have I been chosen? We are contacting as many patients as possible who have recently had a head injury. This is to get information from a wide range of people.

Do I have to take part? No. It is up to you to decide whether or not to take part. If you do, you will be given this information sheet to keep and will be asked to sign a consent form. You are still free to withdraw at any time and without giving a reason. A decision to withdraw at any time or a decision not to take part will not affect the standard of care you receive.

What will taking part involve? Taking part in this study will involve an interview taking around 2 hours, although you will have the opportunity to take a break. This will take place at the hospital, or if it is more convenient for you, a time may be arranged for the researcher to visit you at home. The questions will relate to your health and well-being at the moment, although you will also be asked about whether things are different now from how they were before your injury.

With your consent, we will access your medical records solely to obtain information about the severity and clinical features of your head injury.

Are there any possible disadvantages or risks of taking part? There are no physical risks, but it will take some effort on your part to answer the questions. We recognise that this may be tiring and the researcher will be more than happy for you to take rest breaks as needed if this is the case. The questions are all about your own experience, and while it is not expected that you will find them particularly upsetting you are free not too answer any that you do not wish to.

What are the possible benefits of taking part? There are no immediate benefits to you personally, but we hope that the information that we gather will allow a better understanding of the consequences of head injury.

Expenses: If you come to the hospital to meet the researcher we will reimburse you with reasonable expenses.

What if there is a problem? Any complaint about the way you have been dealt with during the study or any possible harm you might suffer will be addressed. The detailed information on this is given in Part 2. If you do have a complaint, you may refer this to the researcher or to the hospital.

Will my taking part on the study be kept confidential? Yes. All the information about your participation in this study will be kept confidential. The details are included in Part 2.

Contact Details:

If you would like any further information about the study, or if you have any concerns about it, please contact Hannah Blair:
01786 466365
h.c.blair@stir.ac.uk

For queries not related directly to the study you may also contact Linda Cullen:
01786 467640
linda.cullen@stir.ac.uk

This completes Part 1 of the Information Sheet. If the information in Part 1 has interested you and you are considering participation, please continue to read the additional information in Part 2 before making any decision.

INFORMATION SHEET (Changes in Quality of Life after Head Injury): PART 2

What will happen if I don't want to carry on with the study? You may withdraw from the study before or during the completion of questionnaires. In this case we will destroy any forms you have already completed.

What if there is a problem? If you believe that you have been harmed in any way by taking part in this study, you have the right to pursue a complaint and seek any resulting compensation through the University of Stirling who are acting as research sponsor. Details about this are available from the research team. Also as a patient of the NHS you have the right to pursue a complaint through the usual NHS process. To do so, you can submit a written complaint to the Greater Glasgow and Clyde NHS Board**,** Complaints Office, Dalian House, 350 St Vincent Street, Glasgow G3 8YZ, (Phone: 0141 201 4477). Note that the NHS has no legal liability for non-negligent harm. However, if you are harmed and this is due to someone's negligence, you may have grounds for a legal action against NHS Greater Glasgow and Clyde but you may have to pay your legal costs.

Will my taking part in the study be kept confidential? Our procedures for handling, processing, storing, and eventually destroying these data are compliant with the 1998 Data Protection Act. In particular please note that:

- All information which is collected about you during the course of the research will be kept strictly confidential so that identifiable information will be accessible only to the research team and to authorised regulatory authorities who are responsible for monitoring the quality of the research.
- Any information about you which leaves the researcher's office will have your name and address removed so that you cannot be recognised from it. The questionnaires you have completed will be stored securely in the offices of the principle investigator with your participant code but not your name on them; the research team but nobody else will have access to a separate list of which code corresponds to which participant.
- You have the right to check the accuracy of the data held about you and to correct any errors. Please ask the researcher if you would like to do this.
- The data will be used only for the purposes described in Part 1; should we want to use it in any future research addressing different questions than those explained here we would seek approval from the Research Ethics Committee to do so.
- We will retain the questionnaires in secure conditions for at least 10 years, to comply with good scientific practice, and they will then be shredded. Electronic data (that is, a computerised record of your information and scores) will be archived in a suitable format (e.g. on CD) indefinitely but will not include any personal identifiers such as your name.

Will my GP be notified of my participation? As the study does not involve you receiving any treatment and does not affect any treatment you may already be receiving we will not routinely advise him/her of your involvement unless you ask us to do so.

What will happen to the results of the research study? The data will be analysed for the purpose of Hannah Blair's PhD. This is being completed under the supervision of Professor Lindsay Wilson at the University of Stirling.

It is also envisioned that the results will be published in scientific journals.

Please note that you will not be identified in any report or publication unless we have expressly sought your written consent.

Who is involved in the research? The research involves acute and rehabilitation services for people with brain injury in the NHS regions of Fife, Forth Valley, Greater Glasgow, Lothian, and Tayside, and the Department of Psychology at the University of Stirling.

Who has reviewed the study?

This study has been reviewed by The Tayside Committee on Medical Research Ethics A, and was given approval on the 27th April 2009. REC reference number 09/S1401/19.

Thank you for having read this sheet and taken the time to consider participating in this study. If you do decide to participate you will be given copies of both this information sheet and the signed consent form to keep.

Appendix 4.2: Participant Consent Form; Chapter 4.

UNIVERSITY OF STIRLING

NHS SCOTLAND

CONSENT FORM

Title of Project: **Changes in Quality of Life after Head Injury**

Name of researcher:…………………………………….
Participant number:……………………………………..

Please Initial Box

1. I confirm that I have read and understood the information sheet dated ……………………………………….for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving a reason and without my medical care or legal rights being affected. ☐
3. I understand that relevant sections of my medical notes and data collected during the study may be looked at by responsible individuals from regulatory authorities or from the NHS Trust where it is relevant to my taking part in this research. I give my permission for these individuals to have access to my records. ☐
4. I consent to the researcher accessing my medical records to extract information relating to the severity and clinical aspects of my head injury. ☐
5. I agree to my family member/ significant other …………………………… being asked about the effects of my injury. ☐
6. I agree to my clinician …………………………………. being asked about the effects of my injury. ☐
7. I agree to my anonymous data being used in future research ☐
8. I agree to take part in the above study. ☐

……………………………………	…………………………	……………………………
Name of Patient	Date	Signature
……………………………………	…………………………	……………………………
Researcher	Date	Signature

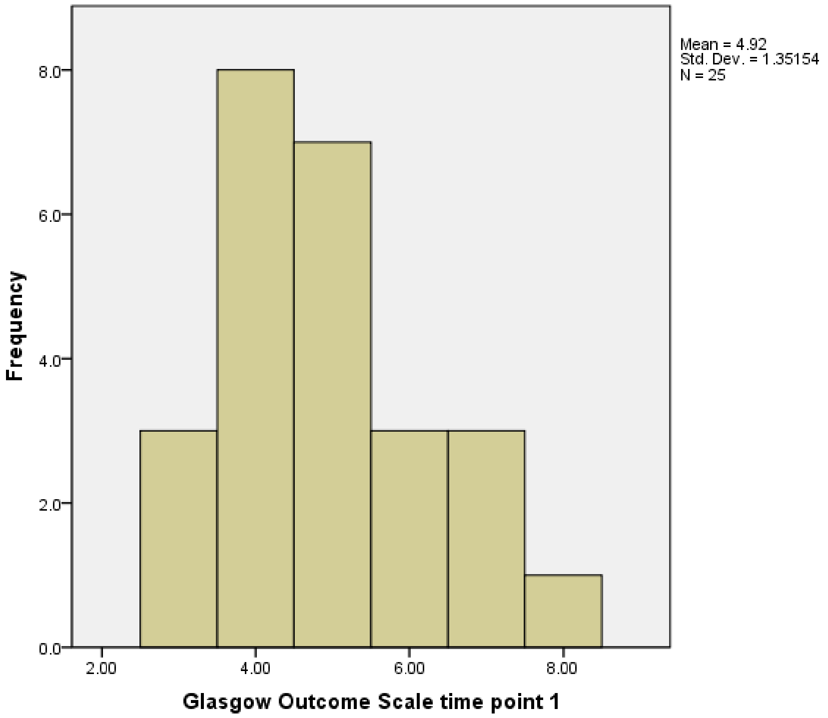
Version: consent09/03; Updated 24.03.09

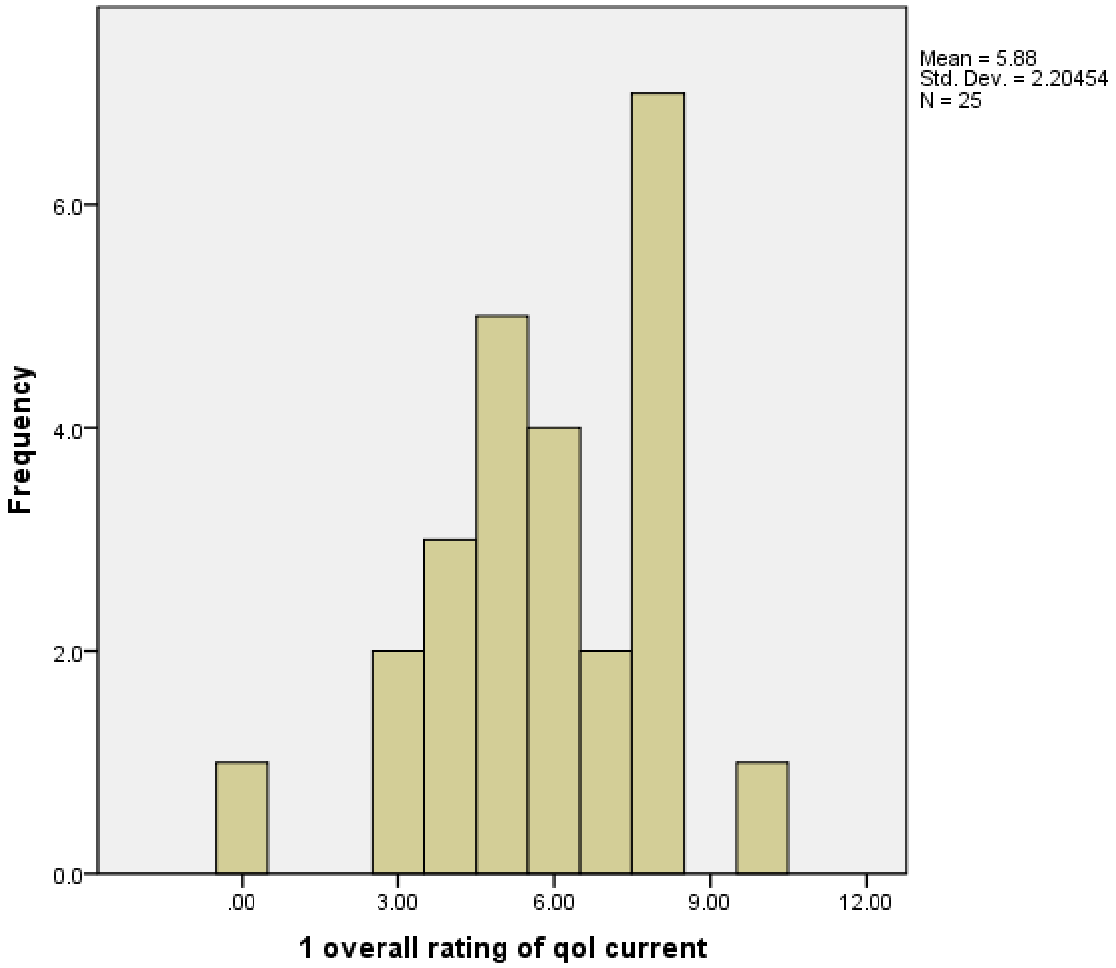
Appendix 4.3: Data Distribution; Chapter 4.

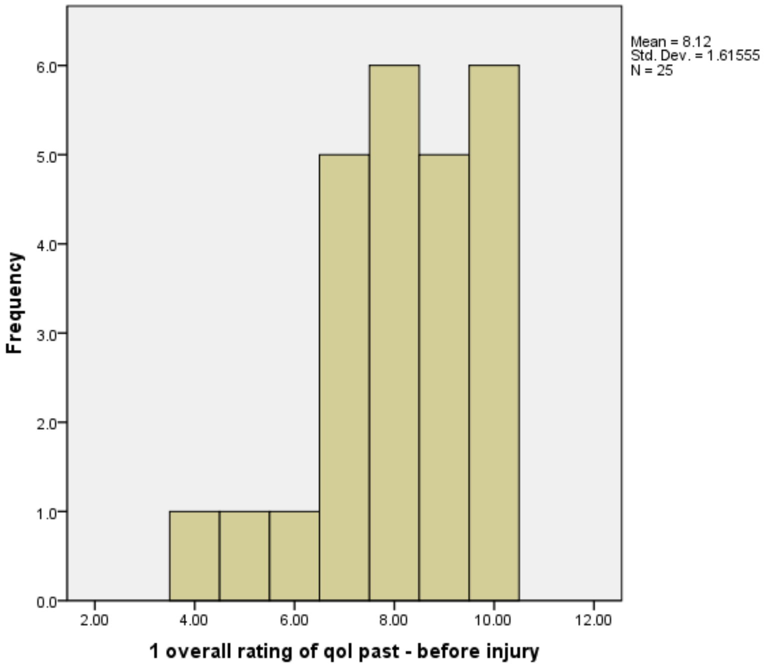
	Minimum	Maximum	Mean	SD	Skew	Kurtosis
Glasgow Outcome Scale baseline	3.00	8.00	4.9200	1.35154	.597	-.259
Glasgow Outcome Scale follow up	3.00	8.00	5.5000	1.63836	.199	-1.171
T1 overall rating of qol current	.00	10.00	5.8800	2.20454	-.571	.678
T1 overall rating of qol past - before injury	4.00	10.00	8.1200	1.61555	-.790	.426
T2 overall rating of qol current	3.00	9.00	6.5882	1.41681	-.651	1.378
T2 overall rating of qol before injury	4.00	10.00	8.0588	1.51948	-1.323	2.146
T2 overall rating of baseline qol	2.00	9.00	5.5294	2.06512	-.337	-.544
T1 PCS	-4.62	.30	-1.3242	1.23669	-.769	.353
T1 MCS	-3.62	1.74	-.6777	1.65914	-.331	-.817
T1 HADS - Anxiety	.00	17.00	8.0000	5.50000	.271	-1.271
T1 HADS - Depression	.00	17.00	6.8400	4.70532	.743	-.499
T1 RBANS - TOTAL SCALE	61	112	84.46	14.685	.199	-.794
T1 PCRS - difference	-40.00	42.00	1.0000	19.93322	-.010	.321
T1 INCOM - comparison in general	20.00	44.00	36.2381	6.07375	-1.237	1.733
T1 BIGI - loss	11.00	31.00	19.9600	6.71118	.356	-1.335
T1 BIGI - adjustment	13.00	27.00	21.0400	3.51757	-.448	-.200
T1 MSPSS total	54.00	84.00	70.5600	9.20634	-.166	-1.206
T1 Silver lining questionnaire	82.00	145.00	114.6000	20.59935	-.284	-1.208
T1 NART	5.00	45.00	21.2083	10.72575	.391	-.052
T2 PCS	-3.97	1.07	-1.3118	1.71747	-.211	-1.494
T2 MCS	-3.60	1.78	-.4972	1.61158	-.471	-.791
T2 HADS - Anxiety	.00	16.00	7.0000	4.51897	.091	-.865
T2 HADS - Depression	.00	12.00	4.2000	3.88790	.776	-.351

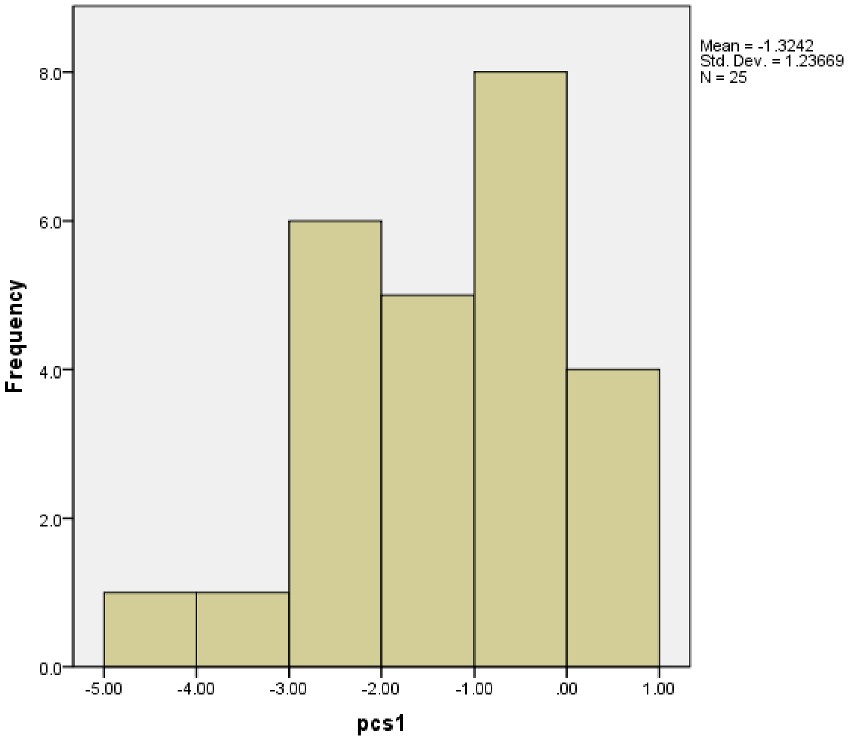
T2 RBANS - TOTAL SCALE	68	117	88.47	14.454	.759	-.430
T2 PCRS - difference	-13.00	31.00	3.9286	14.09563	.634	-.693
T2 INCOM - comparison in general	22.00	45.00	34.3684	5.88039	-.014	.322
T2 BIGI – loss	12.00	31.00	19.3000	6.45715	.343	-1.485
T2 BIGI - adjustment	16.00	27.00	22.3000	3.61430	-.448	-.665
T2 MSPSS total	57.00	84.00	70.3500	8.59176	.073	-.953
T2 Silver lining questionnaire	80.00	153.00	118.6500	22.41540	-.324	-.925

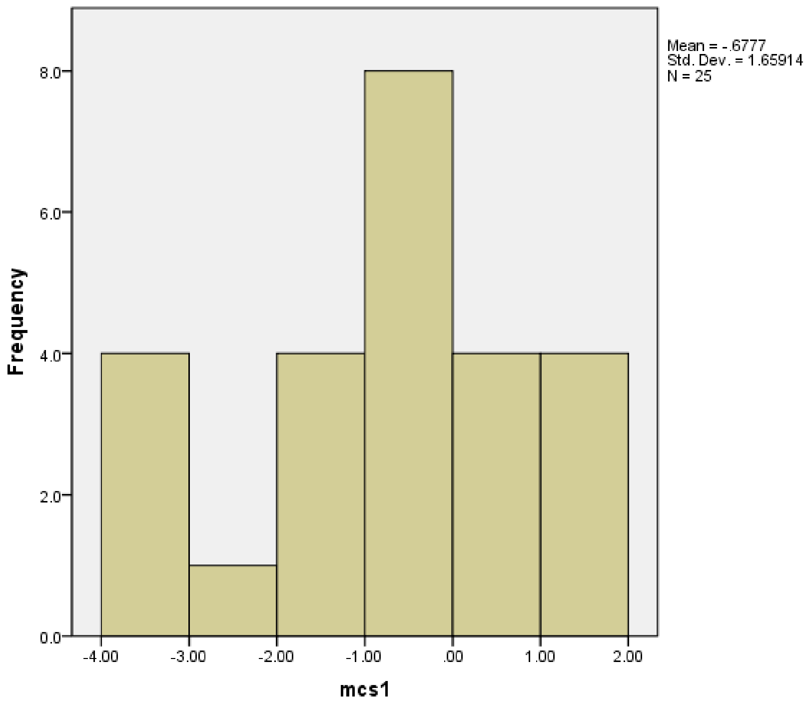
After winsorisation of the most extreme outlier in both T2 rating of pre-injury QoL, and T1 INCOM levels of skew and kurtosis reached acceptable levels (T2 pre-injury QoL: skew=-.602, kurtosis=-.085. INCOM general: skew=-.929, and kurtosis=.709).

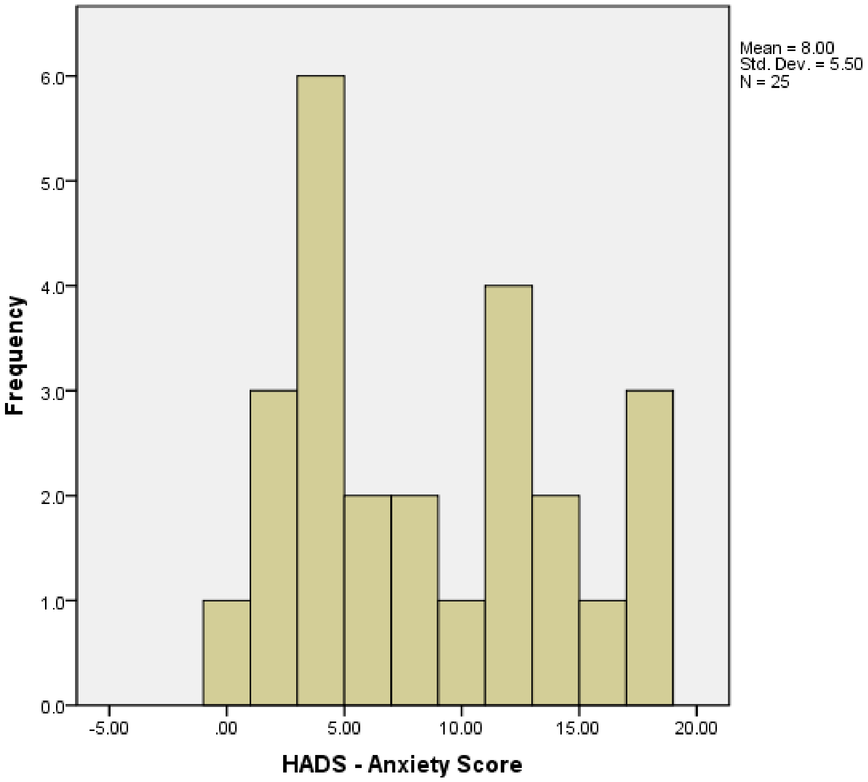

Mean = 4.92
Std. Dev. = 1.35154
N = 25
Frequency
8.0
6.0
4.0
2.0
0.0
2.00
4.00
6.00
8.00
Glasgow Outcome Scale time point 1

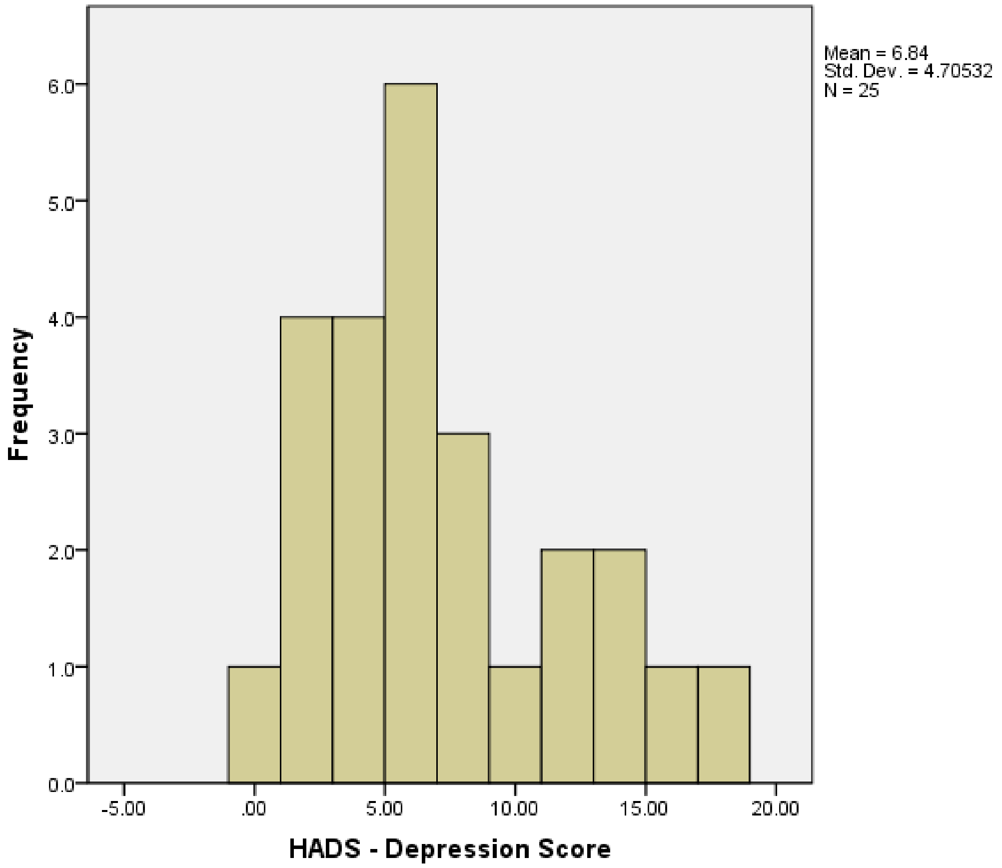

Mean = 5.88
Std. Dev. = 2.20454
N = 25
Frequency
6.0
4.0
2.0
0.0
.00
3.00
6.00
9.00
12.00
1 overall rating of qol current

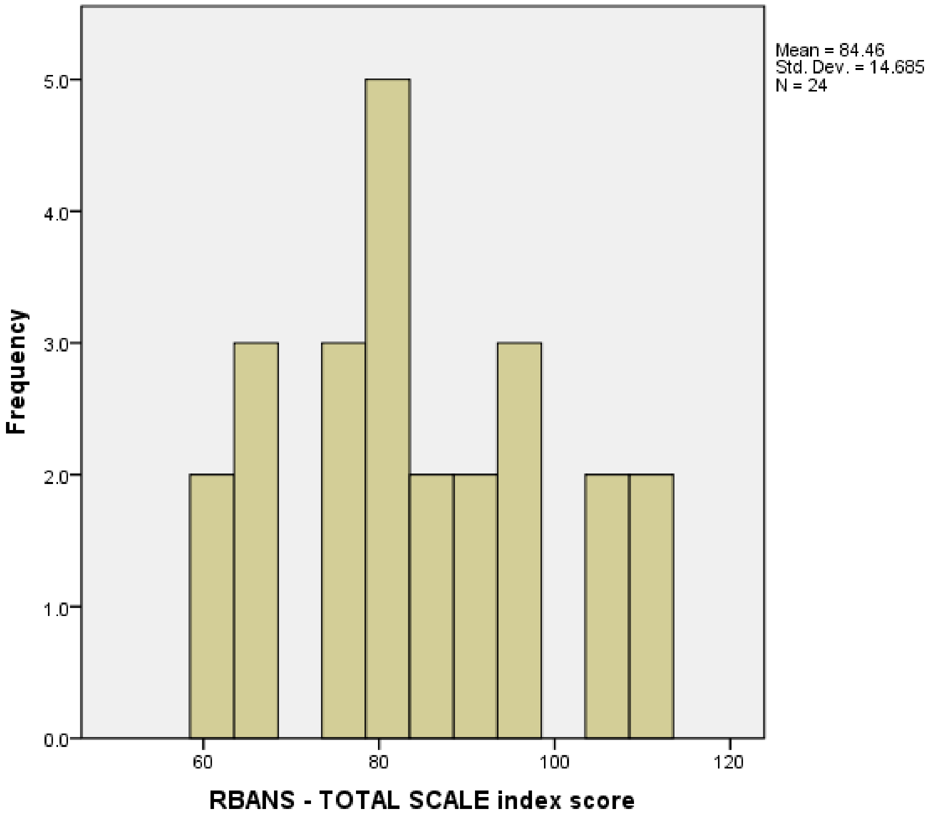

Mean = 8.12
Std. Dev. = 1.61555
N = 25
Frequency
6.0
5.0
4.0
3.0
2.0
1.0
0.0
2.00
4.00
6.00
8.00
10.00
12.00
1 overall rating of qol past - before injury

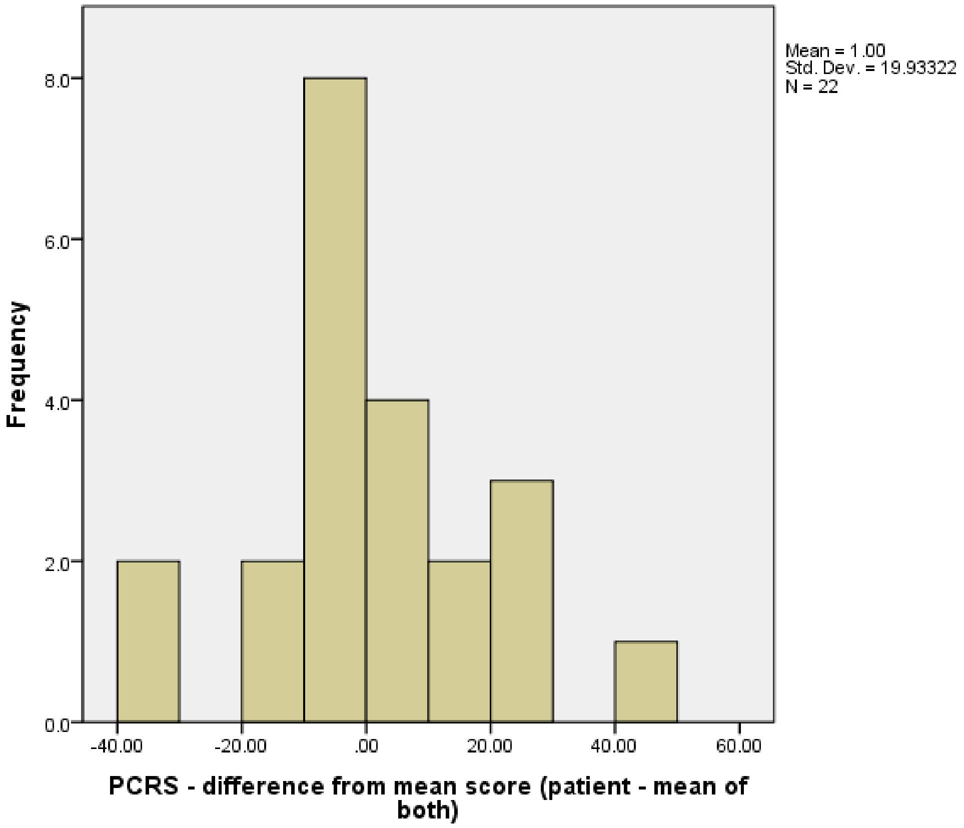

Mean = -1.3242
Std. Dev. = 1.23669
N = 25
Frequency
8.0
6.0
4.0
2.0
0.0
-5.00
-4.00
-3.00
-2.00
-1.00
.00
1.00
pcs1

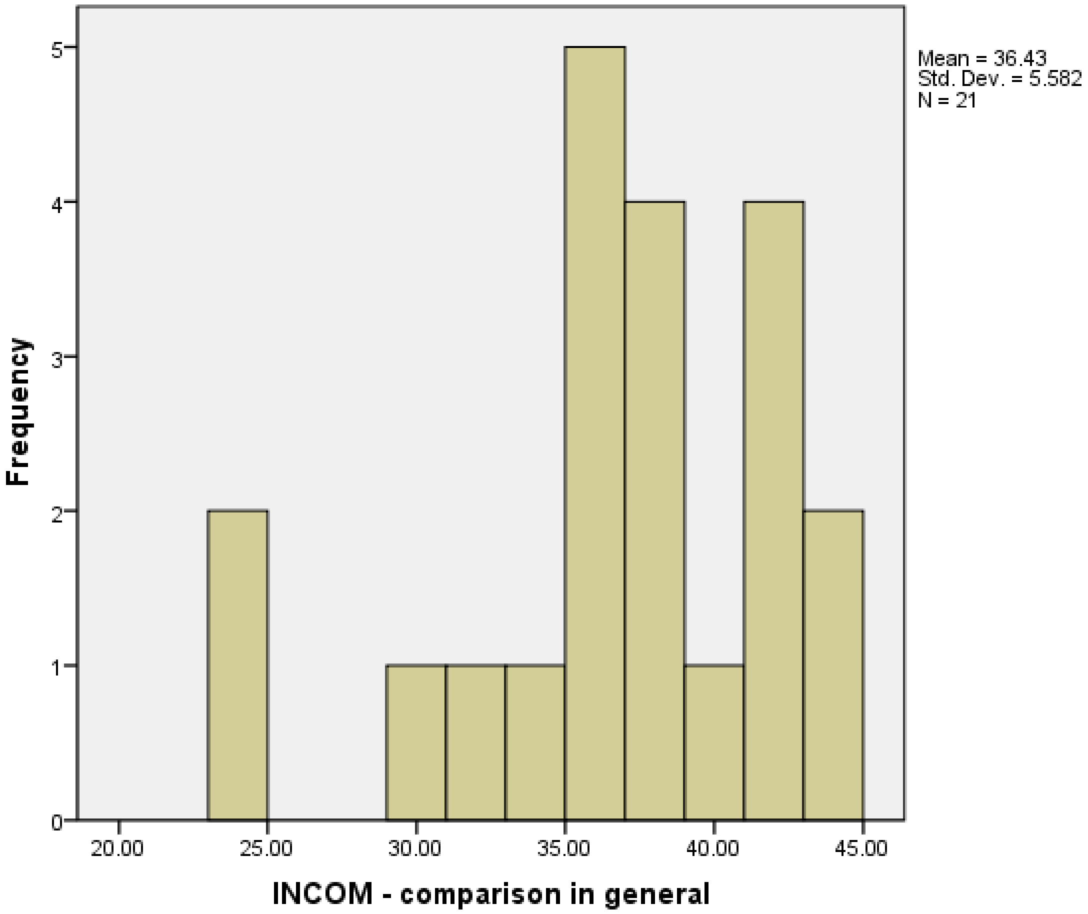

Mean = -.6777
Std. Dev. = 1.65914
N = 25
Frequency
8.0
6.0
4.0
2.0
0.0
-4.00
-3.00
-2.00
-1.00
.00
1.00
2.00
mcs1


Mean = 8.00
Std. Dev. = 5.50
N = 25
Frequency
6.0
5.0
4.0
3.0
2.0
1.0
0.0
-5.00
.00
5.00
10.00
15.00
20.00
HADS - Anxiety Score

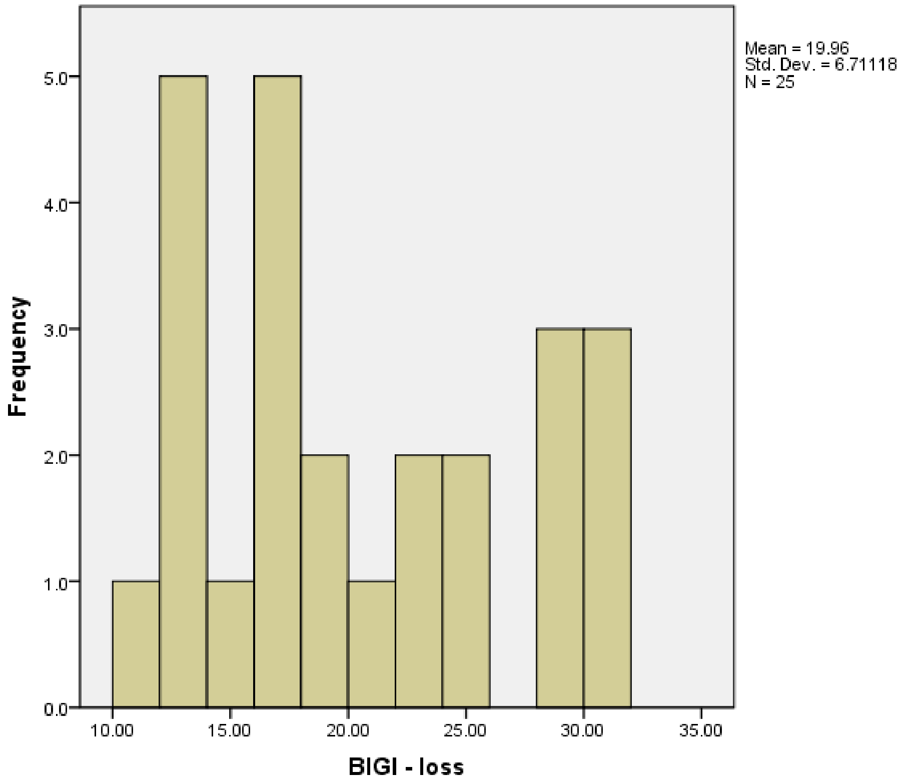

Mean = 6.84
Std. Dev. = 4.70532
N = 25
Frequency
6.0
5.0
4.0
3.0
2.0
1.0
0.0
-5.00
.00
5.00
10.00
15.00
20.00
HADS - Depression Score

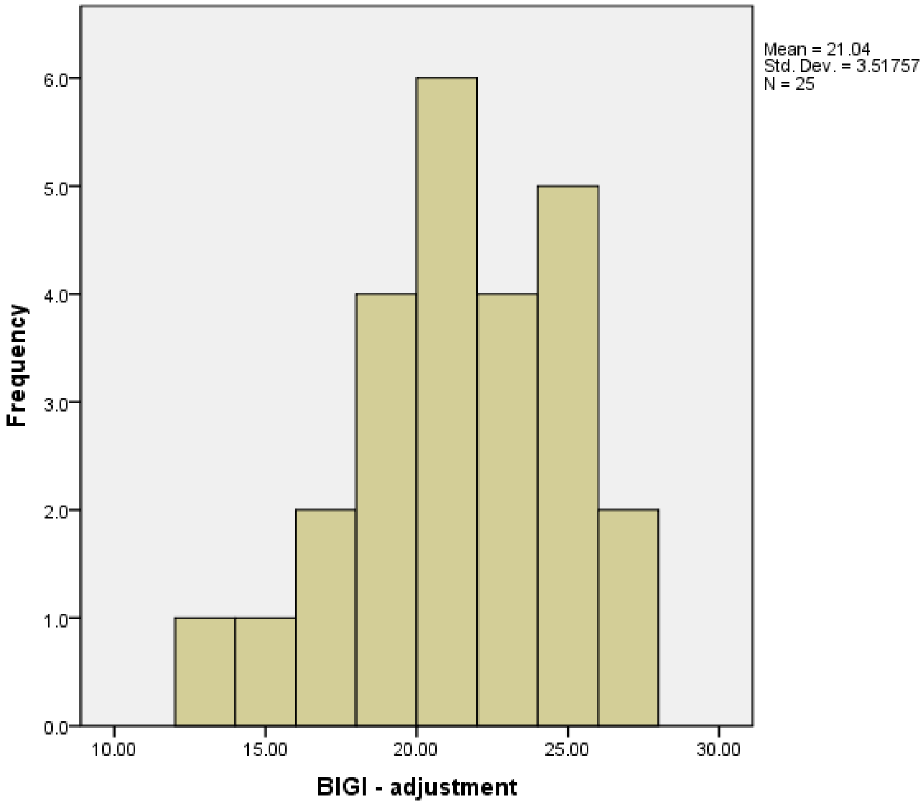

Mean = 84.46
Std. Dev. = 14.685
N = 24
Frequency
5.0
4.0
3.0
2.0
1.0
0.0
60
80
100
120
RBANS - TOTAL SCALE index score

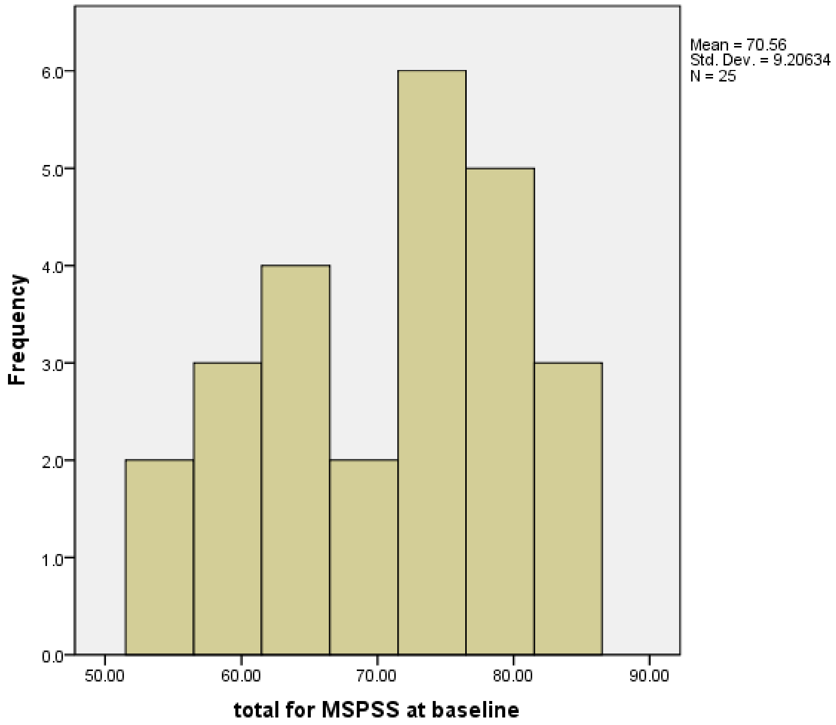

Mean = 1.00
Std. Dev. = 19.93322
N = 22
Frequency
8.0
6.0
4.0
2.0
0.0
-40.00
-20.00
.00
20.00
40.00
60.00
PCRS - difference from mean score (patient - mean of both)

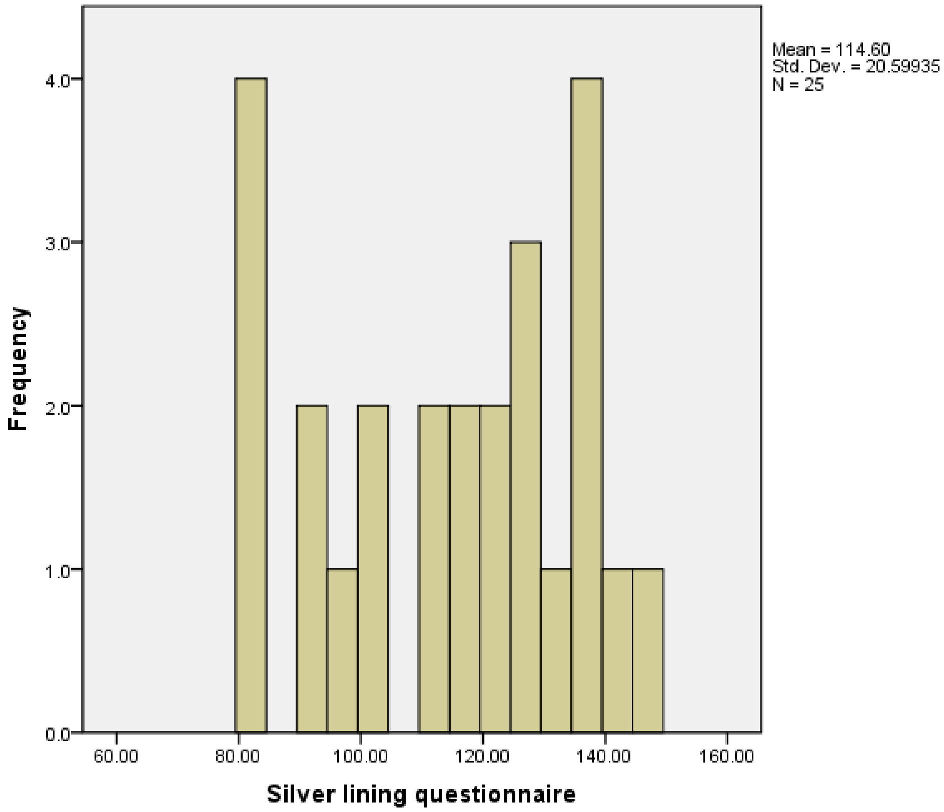

Mean = 36.43
Std. Dev. = 5.582
N = 21
Frequency
5
4
3
2
1
0
20.00
25.00
30.00
35.00
40.00
45.00
INCOM - comparison in general

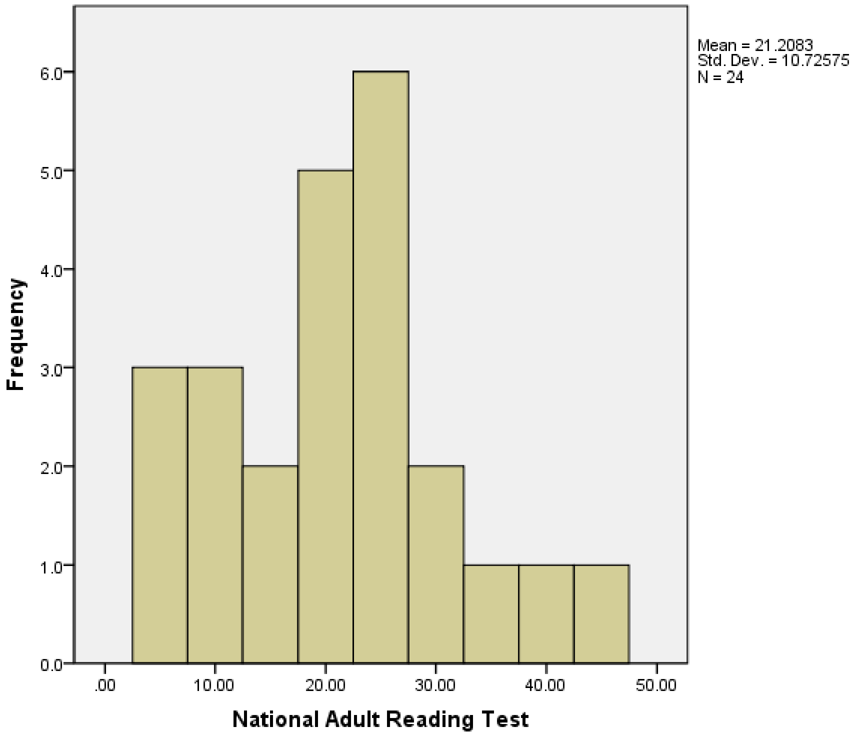
(INCOM chart after winsorisation)






Mean = 70.56
Std. Dev. = 9.20634
N = 25
Frequency
6.0
5.0
4.0
3.0
2.0
1.0
0.0
50.00
60.00
70.00
80.00
90.00
total for MSPSS at baseline


Mean = 114.60
Std. Dev. = 20.59935
N = 25
Frequency
4.0
3.0
2.0
1.0
0.0
60.00
80.00
100.00
120.00
140.00
160.00
Silver lining questionnaire


Mean = 21.2083
Std. Dev. = 10.72575
N = 24
Frequency
6.0
5.0
4.0
3.0
2.0
1.0
0.0
.00
10.00
20.00
30.00
40.00
50.00
National Adult Reading Test

Appendix 5.1: Questionnaire Pack; Chapter 5.

How does life change after a head injury?

UNIVERSITY OF STIRLING

E·S·R·C ECONOMIC & SOCIAL RESEARCH COUNCIL

Questionnaire Pack

The aim of this research is to find out how your life has changed since your injury, and how you may have adjusted to any changes that might have occurred.

This pack includes a number of questions which we hope will help us to understand how your life has changed since your injury. Please take breaks if you feel you need to.

All your answers will be kept confidential.

If you have any questions please contact Hannah Blair:

Department of Psychology
University of Stirling
Stirling
FK9 4LA
hcb3@stir.ac.uk
01786 466365

This study can also be completed online: http://www.survey.bris.ac.uk/stirling/tbi

Thank you

Participant Information Sheet and Consent Form

The purpose of this study: This study is investigating the impact that head injury has had on your life. We hope to gain a better understanding of how quality of life is affected and how people adjust to the consequences of head injury.

Who will be taking part? We are asking as many people as possible who have had a head injury in the past to complete this survey.

Do I have to answer all the questions? We hope that you will be able to answer as many questions as possible, but if there are any questions that you do not wish to answer you do not have too, just skip them and move on.

What will happen to the information I provide? All data will be kept confidential, and will be used for the purposes outlined above. This is being done as part of a PhD in psychology.

What if I have any questions? If you have any questions contact Hannah Blair. You will find contact details on the cover sheet to this pack.

As an informed participant, I understand that:

1. My participation is voluntary.
2. There are no risks involved in the participation of this study.
3. I have been given the opportunity to ask questions and these have been satisfactorily answered.

I have read and understood the above, and consent to my anonymous data being used

Please tick here ☐

About yourself:

- What is today's date?

…………………………………….

- Where did you hear about this research?

Headway website/facebook ☐
Headway groups ☐
Received a letter through the post ☐
Saw a poster ☐
Other *(Please specify)* ☐

……………………………………………………….

- What is your <u>date of birth</u>? …………………………………….
- Your <u>postcode</u>? *(if you know it)* …………………………………….

- Are you *(Please tick box)* Male ☐ Female ☐

- What is your <u>Marital Status</u>? *(Please tick box)*

Single ☐
Married ☐
Co-habiting ☐
Separated ☐
Divorced ☐
Widowed ☐

- How would you describe your <u>Ethnic Origin</u>? *(Please tick box)*

White ☐
Mixed ☐
Asian / Asian British ☐
Black or Black British ☐
Chinese ☐
Other *(Please Specify)*

…………………………………………………………………

- What educational qualifications do you have? *(Please tick box)*

No formal qualifications	☐
School Qualifications	☐
College/ vocational qualifications	☐
Degree level	☐

- What is your employment status?

  (Please tick box)

- Employed Full Time	☐
- Employed Part Time	☐
- Looking after family	☐
- Student	☐
- Unable to work due to health/disability	☐
- Retired	☐
- Looking for work	☐
- Not working, but not looking for work	☐
- Other *(Please specify)*	☐

……………………………………………………………………………………

- Are you completing this form alone *(Please tick box)* Yes ☐ No ☐

If you are receiving assistance, who is it from?

(Please tick box)

Relative	☐
Friend	☐
Carer	☐
Other *(Please specify)*	☐

………………………………………………………………

About your injury:

- **When did your injury happen?** *(approximately if you're not sure)*

  Month? Year? ……………………………………………………………………………

- **What happened to you?** *(Please tick box)*

  - Accident while driving a car ☐
  - Accident while passenger in a car ☐
  - Motorcycle accident ☐
  - Hit by a car while walking ☐
  - Hit by a car while cycling ☐
  - Fall while cycling ☐
  - Fall ☐
  - Assault ☐
  - Sporting accident (e.g. whilst skiing, mountain biking, horse riding etc; *please specify*) ☐

    …………………………………………
  - Other *(Please specify)* ☐

    ……………………………………………………………………………………………

- **Were you unconscious after your injury?** *(Please tick box)*

  Yes ☐ No ☐

- **As a result of your injury was there a period when you can not remember what was going on around you?**

  No memory loss ☐
  Less than 5 minutes ☐
  5 - 60 minutes ☐
  More than 1 but less than 24 <u>hours</u> ☐
  More than 1 but less than 7 <u>days</u> ☐
  More than 1 and up to 4 <u>weeks</u> ☐
  More than 4 weeks ☐

- **Were you admitted to hospital?** Yes ☐ No ☐
- **Did you receive inpatient rehabilitation?** Yes ☐ No ☐

These questions are to do with changes in your lifestyle since your injury. There are also some questions about how things were before the injury. The questions can be answered by you, or by a close relative or friend, or by you both together. We are interested in the recovery you have made up to now.

1. Before the injury were you able to look after yourself at home? *(Please tick box)*

Yes ☐ No ☐

2. As a result of your injury do you now need someone to help look after you at home? *(Please tick box)*

- I do not need help or supervision in the home ☐
- I need some help in the home, but not every day ☐
- I need help in the home every day, but I could look after myself for at least 8 hours if necessary ☐
- I could not look after myself for 8 hours during the day ☐
- I need help at home, but not because of my injury ☐

---

3. Before the injury were you able to buy things at shops without help?

(Please tick box) Yes ☐ No ☐

4. As a result of your injury do you now need help to buy things at shops?

(Please tick box)

- I do not need help to shop ☐
- I need some help, but I can go to local shops on my own ☐
- I need help to shop even locally, or I cannot shop at all ☐
- I need help to shop, but not because of my injury ☐

---

5. Before the injury were you able to travel without help? *(Please tick box)*

Yes ☐ No ☐

6. As a result of your injury do you now need help to travel? *(Please tick box)*

- I do not need help to travel ☐
- I need some help, but can travel locally on my own (e.g. by arranging a taxi) ☐
- I need help to travel even locally, or I cannot travel at all ☐
- I need help to travel, but not because of my injury ☐

---

7. Employment before injury: *(Please tick box)*

Working ☐
Looking after family ☐
Retired ☐
Looking for work ☐
Studying as a student ☐
None of these (e.g. unfit to work ☐

8. As a result of your injury has there been any change in your ability to work? (or to study if you were a student; or to look after your family) *(Please tick box)*

- I still do the same work ☐
- I still do the same work, but have some problems (e.g. tiredness, lack of concentration) ☐
- I still work, but at a reduced level (e.g. change from full-time to part-time, or change in level of responsibility) ☐
- I am unable to work, or only able to work in sheltered workshop ☐
- My ability to work has changed, but not because of my injury ☐

---

9. Before the injury did you take part in regular social and leisure activities outside home (at least once a week)? *(Please tick box)*

Yes ☐ No ☐

Social activities include: going out to a pub or club, visiting friends, going to the cinema or bingo, going out for a walk, attending a football match, taking part in sport.

10. As a result of your injury has there been a change in your ability to take part in social and leisure activities outside home? *(Please tick box)*

- I take part about as often as before ☐
  (the activities may be different from before)
- I take part a bit less, but at least half as often ☐
- I take part much less, less than half as often ☐
- I do not take part at all ☐
- My ability to take part has changed for some other reason, not because of my injury ☐

---

11. Before the injury did you have any problems in getting on with friends or relatives? *(Please tick box)*

Yes ☐ No ☐

12. As a result of your injury are there now problems in how you get on with friends or relatives? *(Please tick box)*

- Things are still much the same ☐
- There are occasional problems (less than once a week) ☐
- There are frequent problems (once a week or more) ☐
- There are constant problems (problems every day) ☐
- There are problems for some other reason, not because of my injury ☐

---

13. Are there any problems resulting from your injury which have interfered with your daily life over the past week? (Problems sometimes reported after head injury: *headaches, dizziness, tiredness, sensitivity to noise or light, slowness, memory failures, and concentration problems*.) *(Please tick box)*

- I have no current problems ☐
- I have some problems, but these do not interfere with my daily life ☐
- I have some problems, and these have affected my daily life ☐
- I have some problems for other reasons, not because of the head injury ☐

14. Before the injury were similar problems present? *(Please tick box)*

- I had no problems before, I had minor problems ☐
- I had similar problems before ☐

Are there any other comments you would like to make?

What is important to your quality of life?

How important are the following areas to your quality of life now?

i.e. how much do they impact on your overall quality of life

	Not important	Slightly Important	Moderately important	Very Important	Extremely important
Your physical condition					
How your brain works (e.g. concentration, memory, thinking)					
Your feeling and emotions					
Your ability to carry out day to day activities					
Your personal and social life					
Your current situation and future prospects					

	Not important	Slightly Important	Moderately important	Very Important	Extremely important
Work					
Close relationships					
Social and Leisure Activities					

How important were the following areas to your quality of life <u>before your injury</u>?

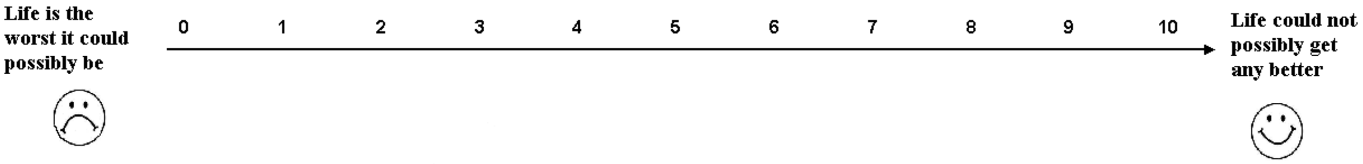
i.e. how much did they impact on your overall quality of life

	Not important	Slightly Important	Moderately important	Very Important	Extremely important
Your physical condition					
How your brain works (e.g. concentration, memory, thinking)					
Your feeling and emotions					
Your ability to carry out day to day activities					
Your personal and social life					
Your current situation and future prospects					

	Not important	Slightly Important	Moderately important	Very Important	Extremely important
Work					
Close relationships					
Social and Leisure Activities					

Your life now:

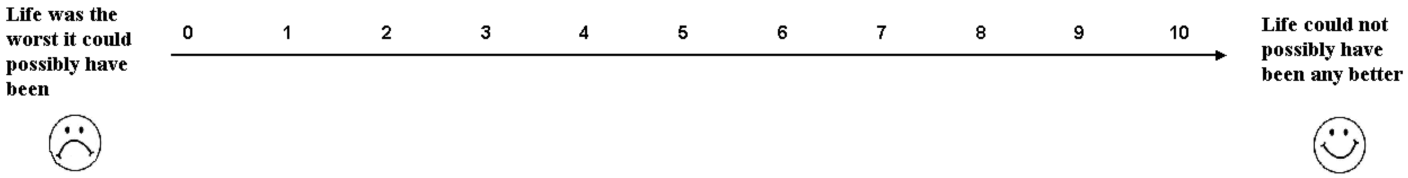
How would you rate your life as it is at the moment?



	Not at all	Slightly	Moderately	Quite	Very
Overall, how satisfied are you with your physical condition?					
Overall, how satisfied are you with how your brain is working, in terms of your concentration, memory, thinking?					
Overall, how satisfied are you with your feelings and emotions?					
Overall, how satisfied are you with your ability to carry out day to day activities?					
Overall, how satisfied are you with your personal and social life?					
Overall, how satisfied are you with your current situation and future prospects?					

Your life before your injury:

How would you rate your life as it was <u>before your injury</u>?



Before your injury:	Not at all	Slightly	Moderately	Quite	Very
Overall, how satisfied were you with your physical condition?					
Overall, how satisfied were you with how your brain was working, in terms of your concentration, memory, thinking?					
Overall, how satisfied were you with your feelings and emotions?					
Overall, how satisfied were you with your ability to carry out day to day activities?					
Overall, how satisfied were you with your personal and social life?					
Overall, how satisfied were you with your current situation and future prospects?					

Do you compare your own life with that of others?

Please tick the option that best describes how much you agree with each statement

(Iowa-Netherlands Social Comparison Scale)	**Strongly disagree**	**Disagree**	**Neither agree or disagree**	**Agree**	**Strongly agree**
1. I often compare how my loved ones are doing with how others are doing					
2. I always pay attention to how I do things compared with how others do things					
3. If I want to find out how well I have done at something, I compare with how others do things					
4. I often compare how I am doing socially (e.g. social skills, popularity) with other people					
5. I am not the type of person who compares often with others					
6. I often compare myself with others with respect to what I have accomplished in life					
7. I often like to talk to others about mutual opinions and experiences					
8. I often try to find out what others think who face similar problems as I face					
9. I always like to know what others in a similar situation would do					
10. If I want to learn more about something, I try to find out what others think about it					
11. I *never* consider my situation in life relative to that of other people					
12. When it comes to my personal life, I sometimes compare myself with others who have it better than I do					
13. When I consider how I am doing socially (e.g. social skills, popularity), I prefer to compare with others who are more socially skilled than I am					

	Strongly disagree	Disagree	Neither agree or disagree	Agree	Strongly agree
14. When evaluating my current performance (e.g. how I am doing at home, work, school , or wherever), I often compare with others who are doing better at it than I am					
15. When I wonder how good I am at something, I sometimes compare myself with others who have accomplished more in life than I have					
16. When things are going poorly, I think of others who have it better than I do					
17. I sometimes compare myself with others who have accomplished more in life than I have.					
18. When it comes to my personal life, I sometimes compare myself with others who have it worse than I do					
19. When I consider how I am doing socially (e.g. social skills, popularity), I prefer to compare with others who are less socially skilled than I am					
20. When evaluating my current performance (e.g. how I am doing at home, work, school , or wherever), I often compare with others who are doing worse than I am					
21. When I wonder how good I am at something, I sometimes compare myself with others who are worse at it than I am					
22. When things are going poorly, I think of others who have it worse than I do					
23. I sometimes compare myself with others who accomplished less in life than I have					

How you cope with things:

These items deal with ways you've been coping with the stress in your life. There are many ways to try to deal with problems. These items ask what you've been doing to cope with this one. Obviously different people deal with things in different ways, but I'm interested in how you've tried to deal with it. Each item says something about a particular way of coping. I want to know to what extent you've been doing what the item says. Don't answer on the basis of whether it seems to be working or not – just whether or not you're doing it. Use the response choices. Try to rate each item separately in your mind from the others. Make your answers as true FOR YOU as you can.

(Brief-COPE)	I haven't been doing this at all	I've been doing this a little bit	I've been doing this a medium amount	I've been doing this a lot
1. I've been turning to work or other activities to take my mind off things				
2. I've been concentrating my efforts on doing something about the situation I'm in				
3. I've been saying to myself 'this isn't real'				
4. I've been using alcohol or other drugs to make myself feel better				
5. I've been getting emotional support from others				
6. I've been giving up trying to deal with it				
7. I've been taking action to try to make the situation better				
8. I've been refusing to believe that it has happened				
9. I've been saying things to let my unpleasant feelings escape				
10. I've been getting help and advice from other people				
11. I've been using alcohol or other drugs to help me get through it				

	I haven't been doing this at all	I've been doing this a little bit	I've been doing this a medium amount	I've been doing this a lot
12. I've been trying to see it in a different light to make it seem more positive				
13. I've been criticizing myself				
14. I've been trying to come up with a strategy to do something about it				
15. I've been getting comfort and understanding from someone				
16. I've been giving up the attempt to cope				
17. I've been looking for something good in what is happening				
18. I've been making jokes about it				
19. I've been doing something to think about it less; such as going to movies, watching TV, reading, daydreaming, sleeping, or shopping				
20. I've been accepting the reality of the fact it has happened				
21. I've been expressing my negative feelings				
22. I've been trying to find comfort in my religion or spiritual beliefs				
23. I've been trying to get advice or help from other people about what to do				
24. I've been learning to live with it				
25. I've been thinking hard about what steps to take				
26. I've been blaming myself for things that happened				
27. I've been praying or meditating				
28. I've been making fun of the situation				

Social Support

People sometimes look to others for companionship, assistance, or other types of support. How often is each of the following kinds of support available to you if you need it?

MOS social support survey	**None of the time**	**A little of the time**	**Some of the time**	**Most of the time**	**All of the time**
(Emotional/informational support)					
Someone you can count on to listen to you when you need to talk					
Someone to give you information to help you understand a situation					
Someone to give you good advice about a crisis					
Someone to confide in or talk to about yourself or your problems					
Someone whose advice you really want					
Someone to share your most private worries and fears with					
Someone to turn to for suggestions about how to deal with a personal problem					
Someone who understands your problems					
(Tangible support)					
Someone to help you if you were confined to bed					
Someone to take you to the doctor if you needed it					
Someone to prepare your meals if you were unable to do it yourself					
Someone to help with daily chores if you were sick					
(Affectionate support)					
Someone who shows you love and affection					
Someone to love and make you feel wanted					
Someone who hugs you					
(Positive social interaction)					
Someone to have a good time with					
Someone to get together with for relaxation					
Someone to do something enjoyable with					
(Additional item)					
Someone to do things with to help you get your mind off things					

(LOT-R)	I agree a lot	I agree a little	I neither agree or disagree	I DISagree a little	I DISagree a lot
In uncertain times, I usually expect the best.					
It's easy for me to relax					
If something can go wrong for me, it will.					
I'm always optimistic about my future.					
I enjoy my friends a lot.					
It's important for me to keep busy.					
I hardly ever expect things to go my way.					
I don't get upset too easily					
I rarely count on good things happening to me.					
Overall, I expect more good things to happen to me than bad.					

If there is anything else you feel would be useful for us to know, or would like to add please use this page to do so.

Appendix 5.2: Narrowing down factors in the Brief COPE: Principle components analysis

Appendix 5.2: Narrowing down factors in order to conduct a regression analysis: Brief COPE

The Brief COPE provides scores on 14 different subscales, and thus principal component analysis was conducted to narrow down the number of factors. Principal component analysis using varimax rotation was used. This technique of extracting 'second order factors' has been employed previously (e.g. Kallasmaa and Pulver, 2000; Finset and Andersson, 2000).

Kaiser-Meyer-Olkin Measure of Sampling Adequacy (KMO) for all 14 variables was 0.73, indicating that the available sample is suitable for factor analysis. However, as the variable 'substance use' did not individually meet the minimum value of 0.5 (at 0.32) this was removed and the analysis repeated. This increased the KMO statistic for multiple variables to 0.78.

Principal component analysis was conducted on 13 items of the Brief COPE (self-distraction, active coping, denial, use of emotional support, use of instrumental support, behavioural disengagement, venting, positive reframing, planning, humour, acceptance, religion and self-blame). The KMO for multiple variables was 0.78 indicating an adequate sample for analysis, with all individuals also all >0.54 (above cut off of 0.5). Bartlett's test of sphericity (χ^2 (78) =294.35, p<0.001) indicates that correlations between items are large enough for principal component analysis to be conducted. Initial analysis was run to obtain eigenvalues for each component of the data. The point of inflexion on the scree plot suggests that the first 4 components should be retained, which explain 67.47% of the variance. The factor loadings after rotation are shown in the table 5.9.

Loading (with factor loadings above 0.4) on the first component are; self-distraction, active coping, emotional support, instrumental support, behavioural disengagement, positive reframing, planning, and acceptance. As the subscales loading most highly on this component are active coping (.89), positive reframing (.71), planning (.62), and acceptance (.81) it is suggested that this component represents positive coping strategies. On the second component are emotional support, instrumental support, behavioural disengagement, planning, humour, and self-blame. The highest factor loadings on this are behavioural disengagement (-.60) and humour (.83), and so it is though that this component may represent avoidant coping; while planning does not obviously fit into this, it has a relatively low factor loading at (.42), which is roughly equivalent to those of use of emotional support (.42) and instrumental support (.40), which also cross-load between this and component 1. On the third, are; denial, emotional support and venting. These are thought to represent emotional coping strategies. On the fourth is religion.

Scores for each factor were calculated using the factor loadings to weight the item scores. This provided each participant with a score for each the four components that could then be entered into a regression analysis.

Table 5.9: Summary of exploratory factor analysis of the Brief-COPE subscales (principal component with varimax rotation)

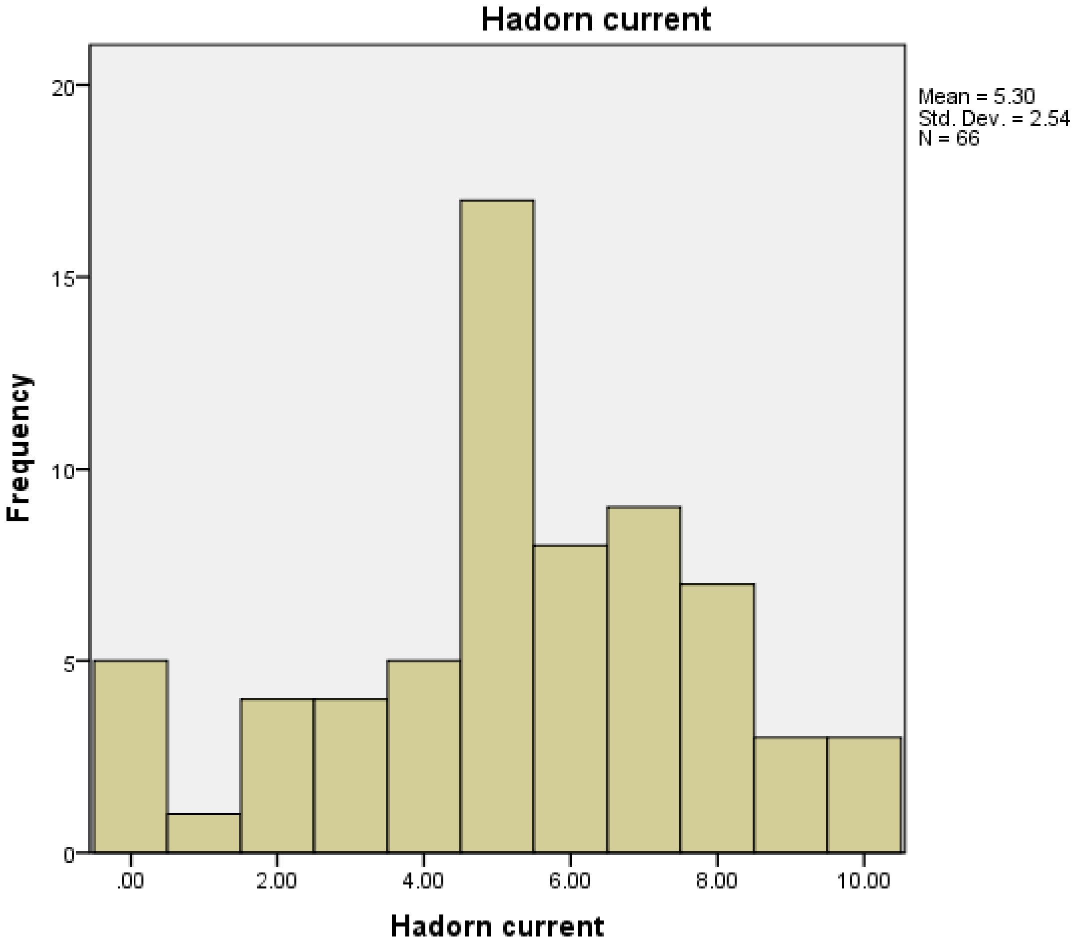
	Component			
	1	2	3	4
Self –distraction	**.49**	.16	.08	.04
Active Coping	**.89**	-.03	-.11	-.02
Denial	.07	-.11	**.79**	-.03
Use of emotional support	**.43**	**.42**	**.54**	-.01
Use of instrumental support	**.57**	**.40**	.34	.13
Behavioural disengagement	**.43**	**-.60**	.32	-.34
Venting	-.16	.07	**.84**	.02
Positive Reframing	**.71**	.33	.07	.32
Planning	**.62**	**.42**	.19	.19
Humor	.21	**.83**	-.06	.07
Acceptance	**.81**	.02	-.11	-.10
Religion	.11	.01	-.00	**.94**
Self-blame	.25	**.73**	.14	-.12
Eigenvalues	**3.42**	**2.25**	**1.93**	**1.18**
% of variance	**26.27**	**17.27**	**14.82**	**9.10**

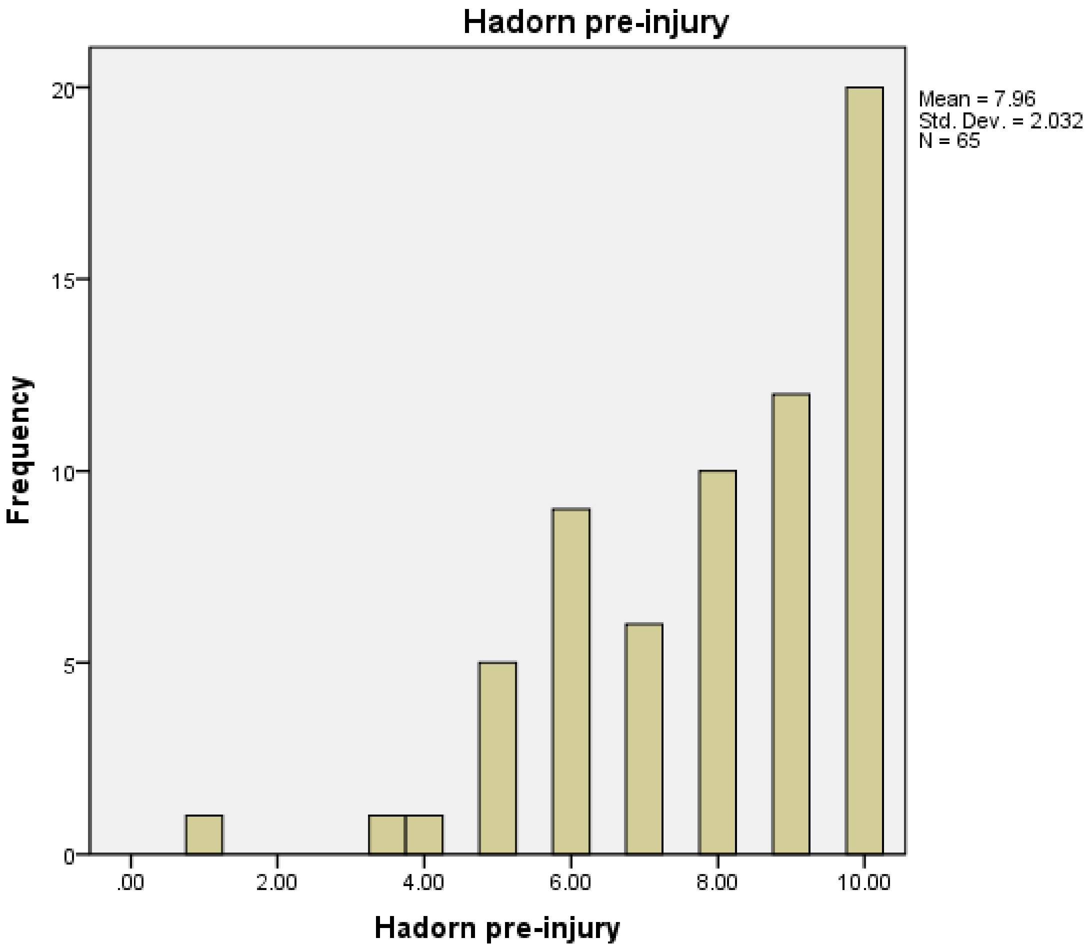
Factor loadings above 0.40 are given in bold

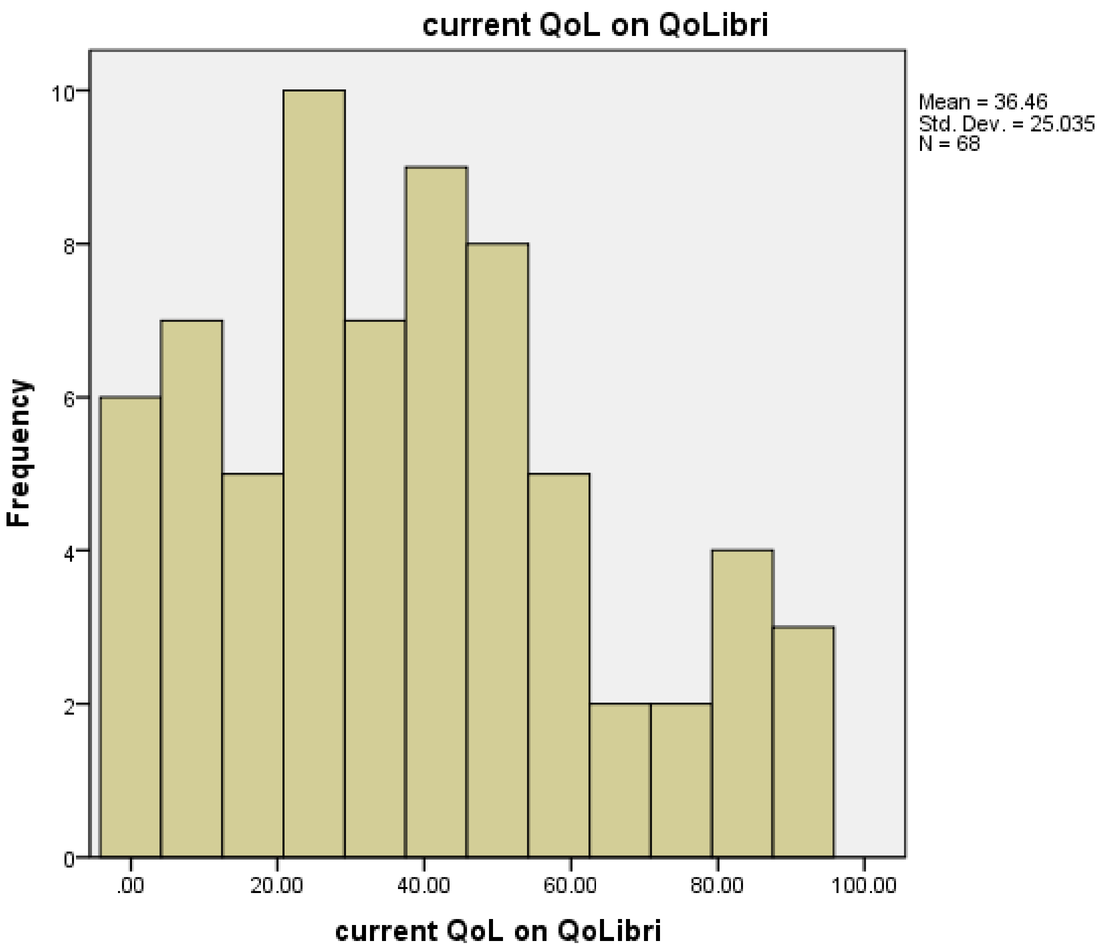
Appendix 5.3: Distribution Data; Chapter 5.

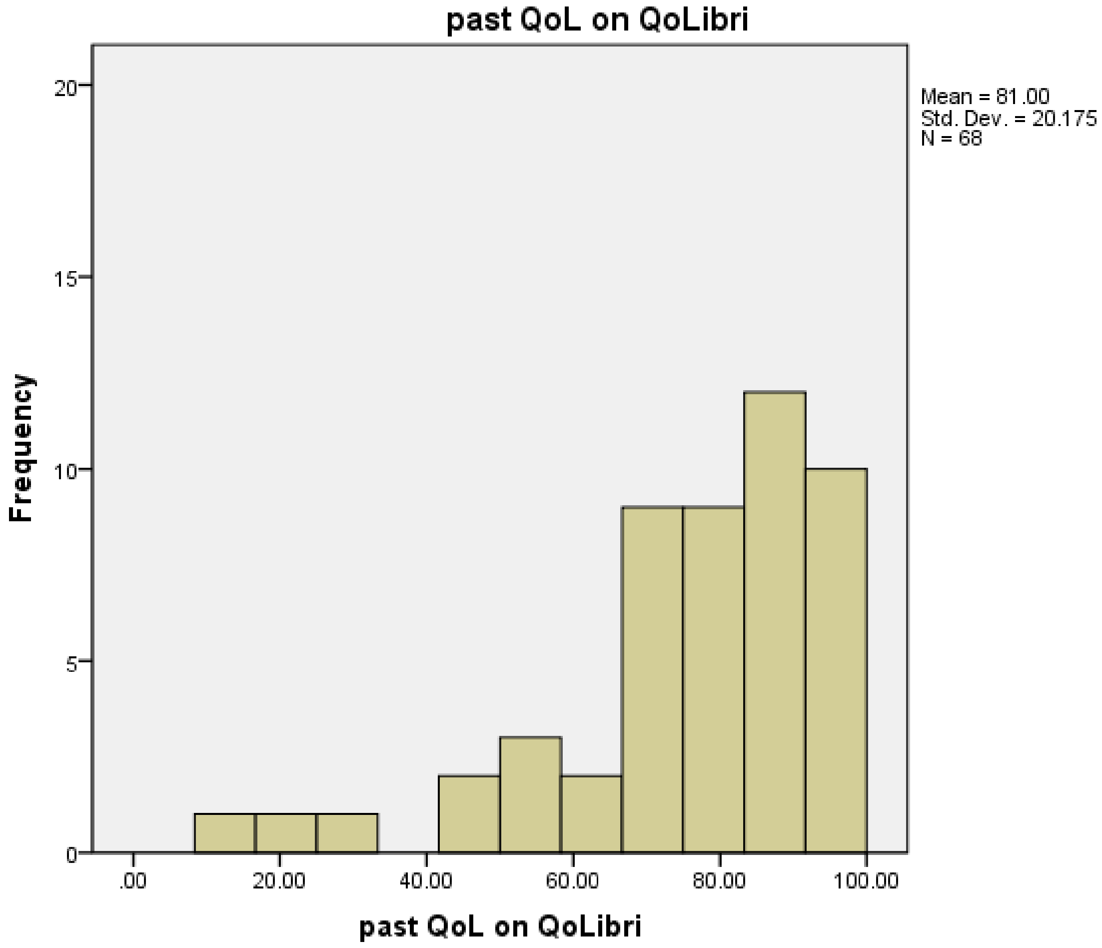
Appendix 5.3: Distribution Data

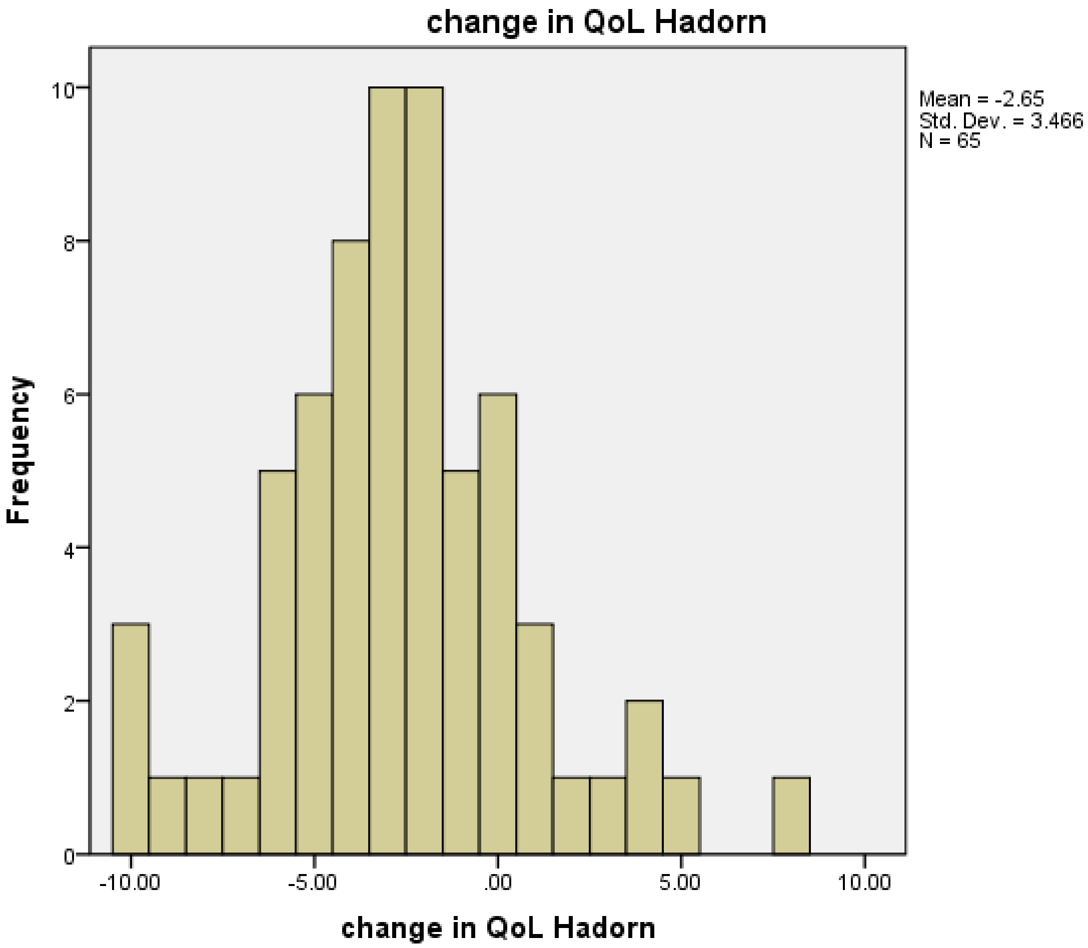
	N	Minimum	Maximum	Mean	Std. Deviation	Skewness	Kurtosis
GOSE	68	3.00	7.00	4.3529	1.06175	.861	.147
Hadorn current	66	.00	10.00	5.2955	2.54041	-.371	-.176
Hadorn pre-injury	65	1.00	10.00	7.9615	2.03160	-.978	.756
QoLibri pre-injury	68	12.50	100.00	81.0049	20.17469	-1.444	2.180
QoLibri current	68	.00	91.67	36.4583	25.03496	.508	-.397
QoLibri change	68	-100.00	29.17	-44.5466	33.03863	.347	-.585
Hadorn change	66	-10.00	8.00	-2.5455	3.53524	.315	.798
INCOM - general	64	41.00	94.00	72.4531	11.33604	-.581	.423
MOS-SS mean	65	1.00	5.00	3.7283	1.11741	-.611	-.750
LOT-R	64	6.00	28.00	17.2656	5.49817	-.236	-.750
Brief COPE component 1: positive	66	11.31	35.79	24.4853	6.44499	-.060	-.845
Brief COPE component 2: avoidant	66	7.82	25.31	17.0282	4.81907	.059	-.977
Brief COPE component 3: emotional	66	7.47	22.41	14.3086	3.57343	.368	-.494
Brief COPE component 4: religion	66	15.48	109.41	53.7736	25.37788	.600	-.299

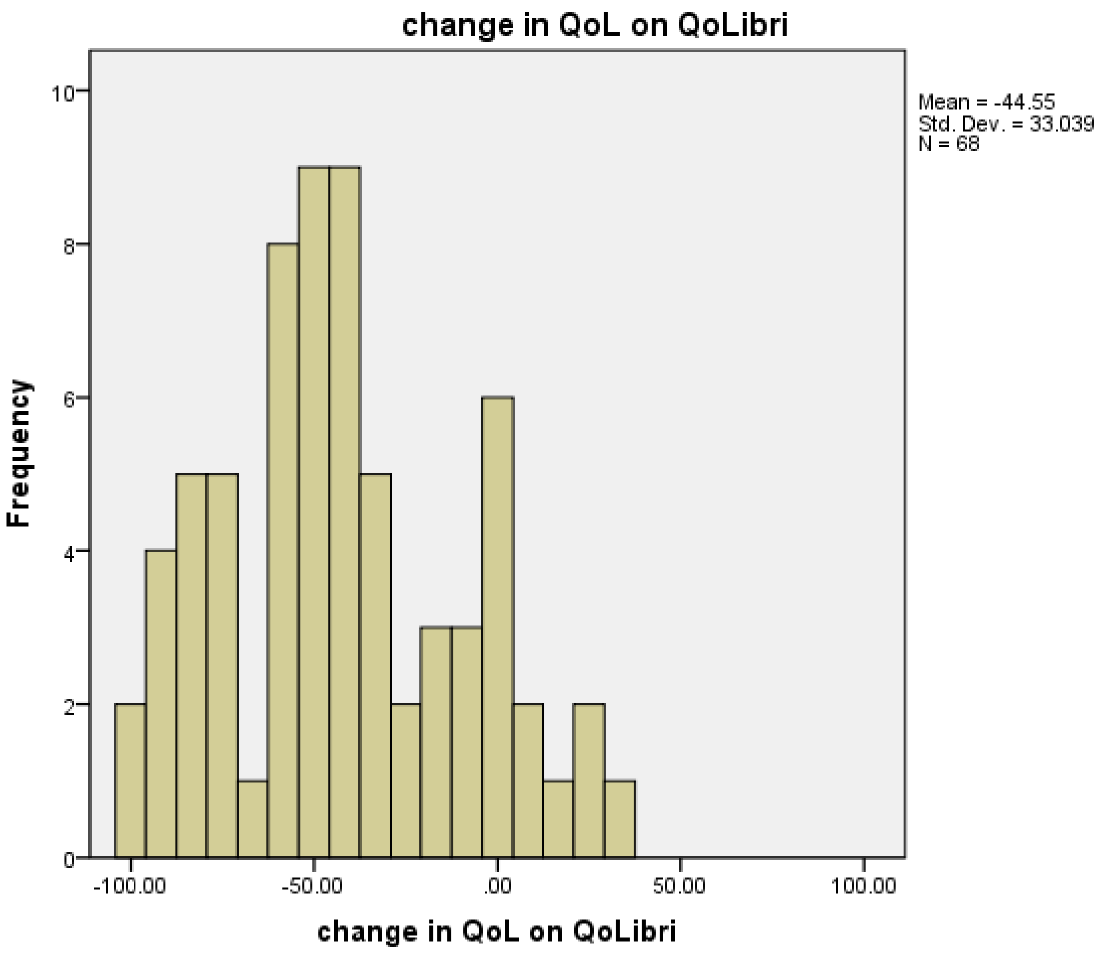

Hadorn current
Mean = 5.30
Std. Dev. = 2.54
N = 66
Frequency
20
15
10
5
0
.00
2.00
4.00
6.00
8.00
10.00
Hadorn current

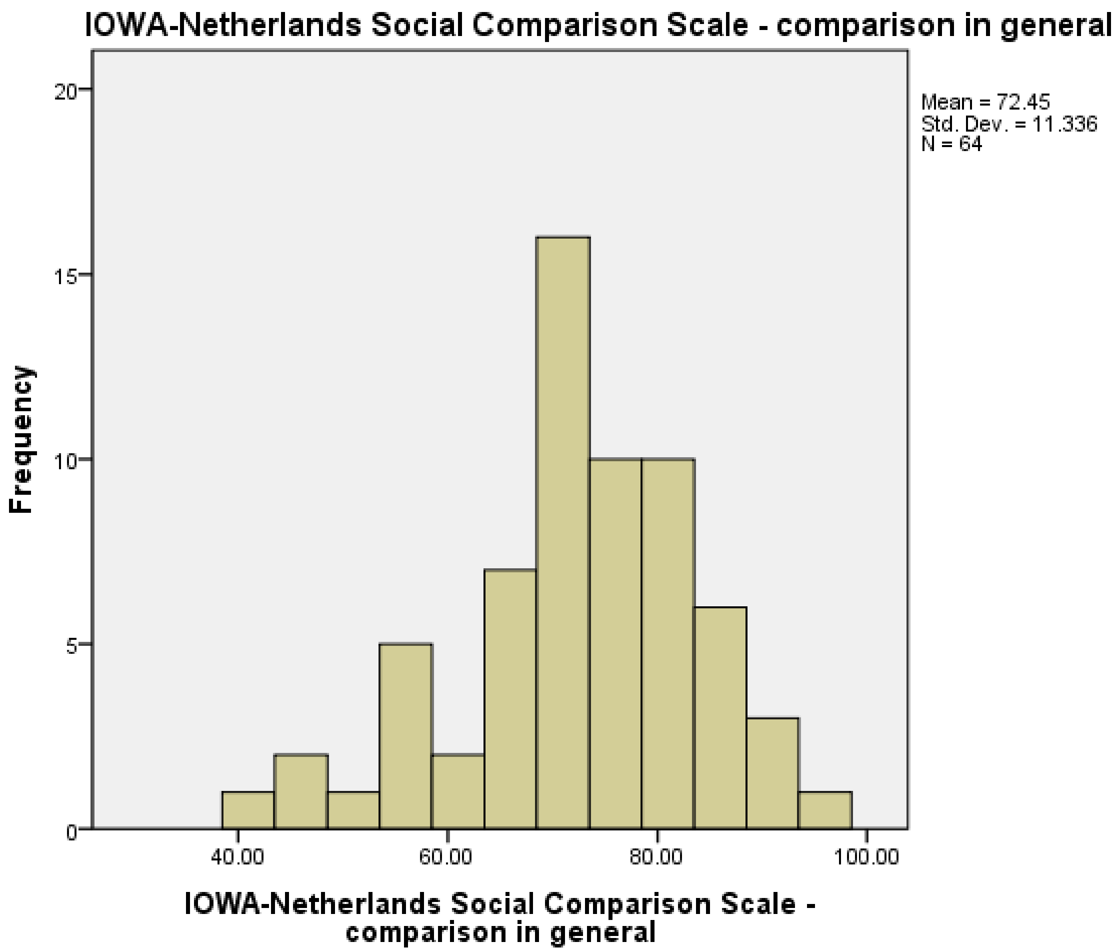

Hadorn pre-injury
Mean = 7.96
Std. Dev. = 2.032
N = 65
Frequency
20
15
10
5
0
.00
2.00
4.00
6.00
8.00
10.00
Hadorn pre-injury

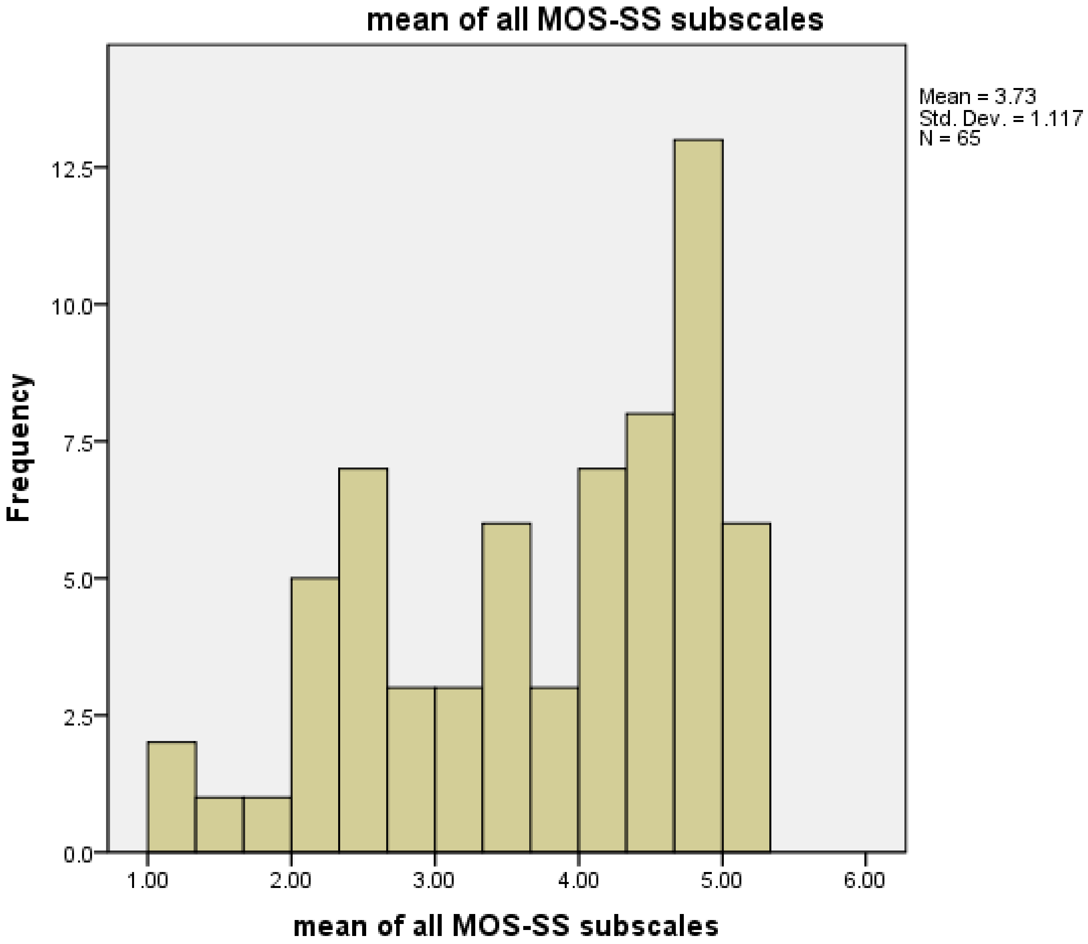

current QoL on QoLibri
Mean = 36.46
Std. Dev. = 25.035
N = 68
Frequency
0
2
4
6
8
10
.00
20.00
40.00
60.00
80.00
100.00
current QoL on QoLibri

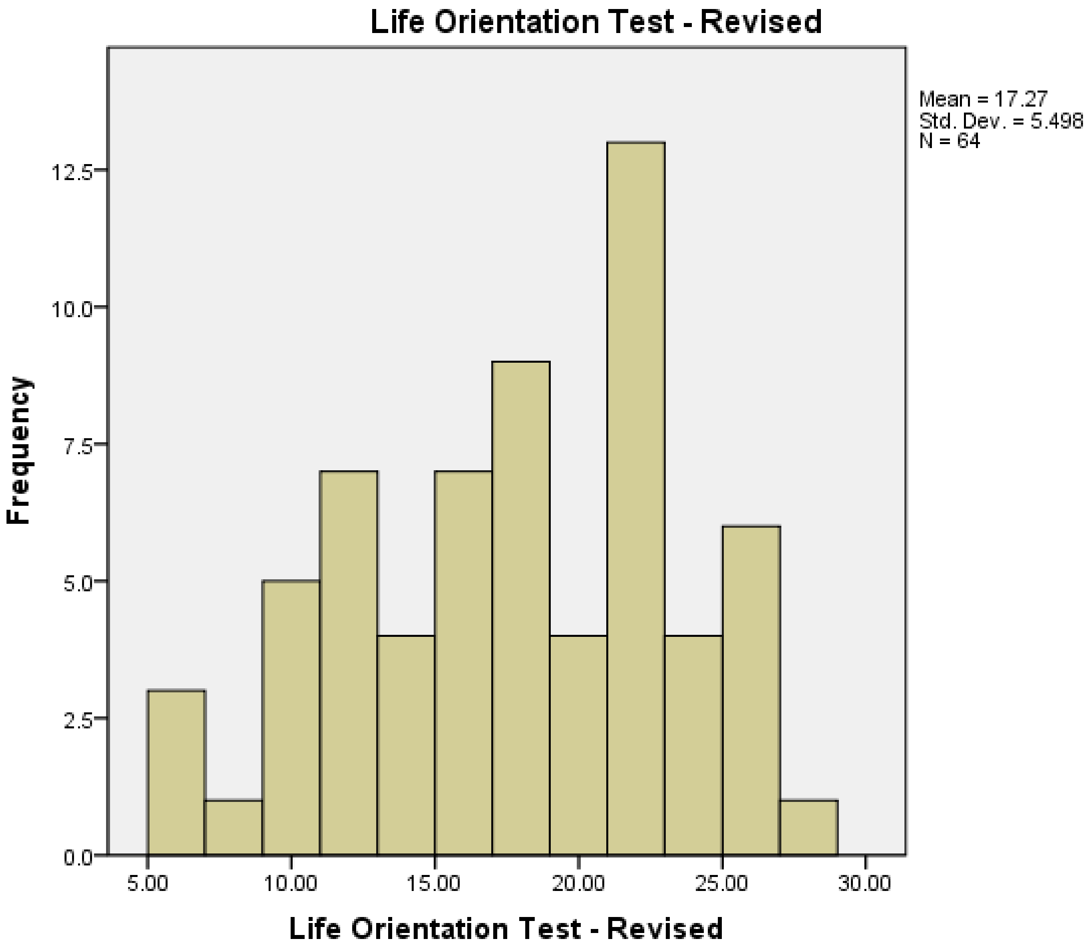

past QoL on QoLibri
Mean = 81.00
Std. Dev. = 20.175
N = 68
Frequency
20
15
10
5
0
.00
20.00
40.00
60.00
80.00
100.00
past QoL on QoLibri

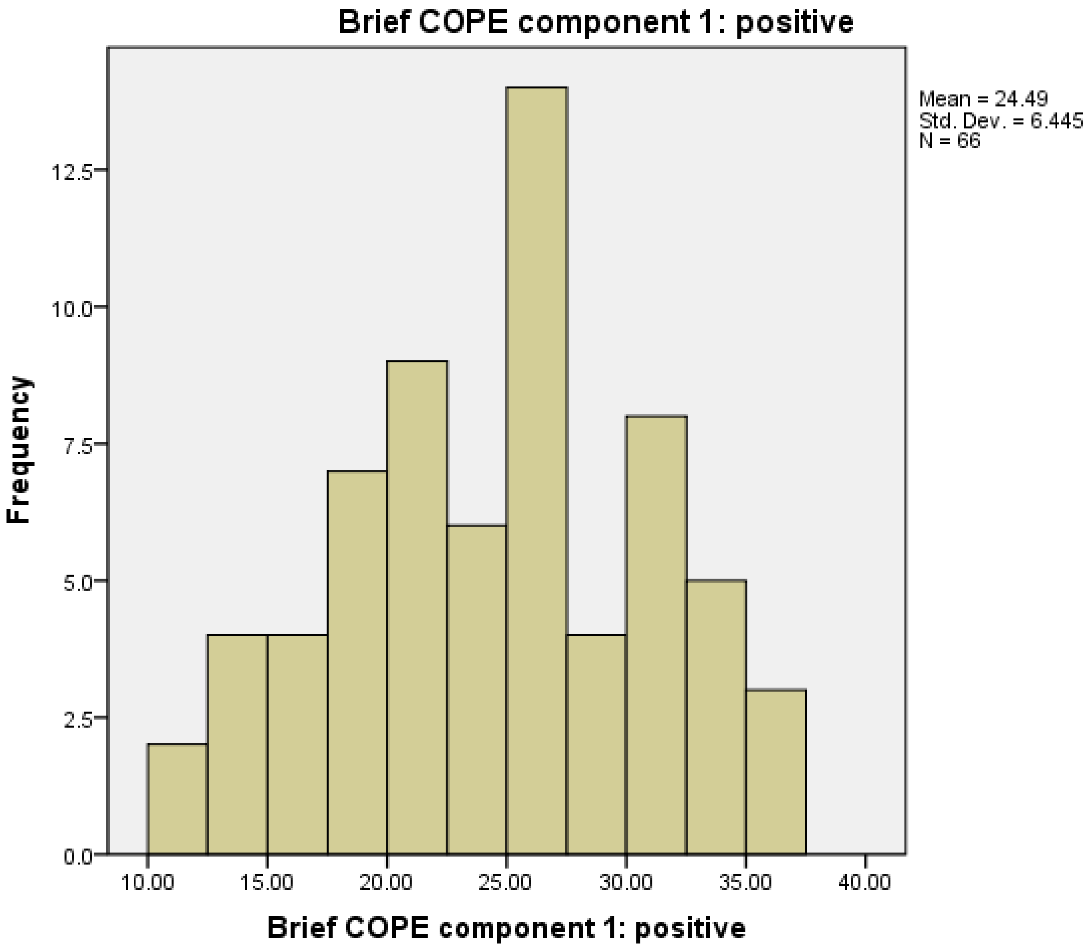

change in QoL Hadorn
Mean = -2.65
Std. Dev. = 3.466
N = 65
Frequency
0
2
4
6
8
10
-10.00
-5.00
.00
5.00
10.00
change in QoL Hadorn

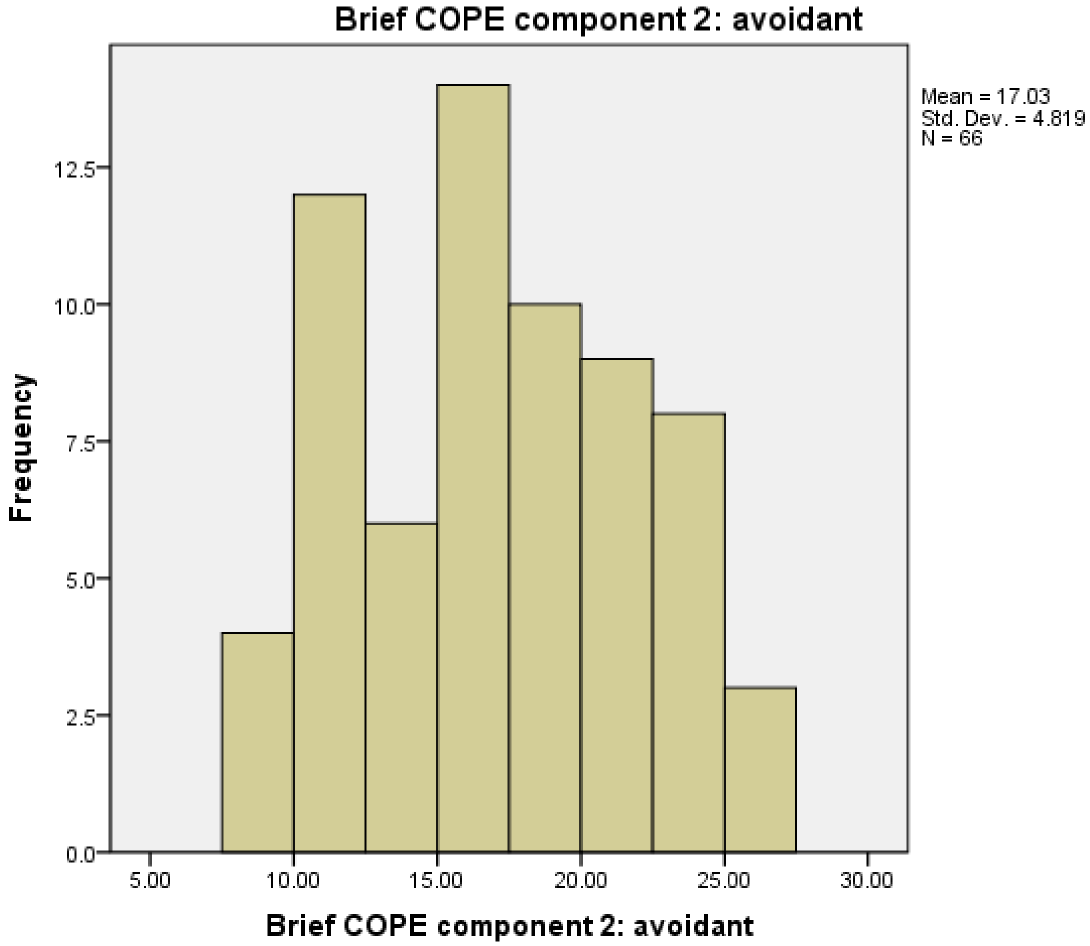

change in QoL on QoLibri
Frequency
10
8
6
4
2
0
-100.00
-50.00
.00
50.00
100.00
change in QoL on QoLibri
Mean = -44.55
Std. Dev. = 33.039
N = 68

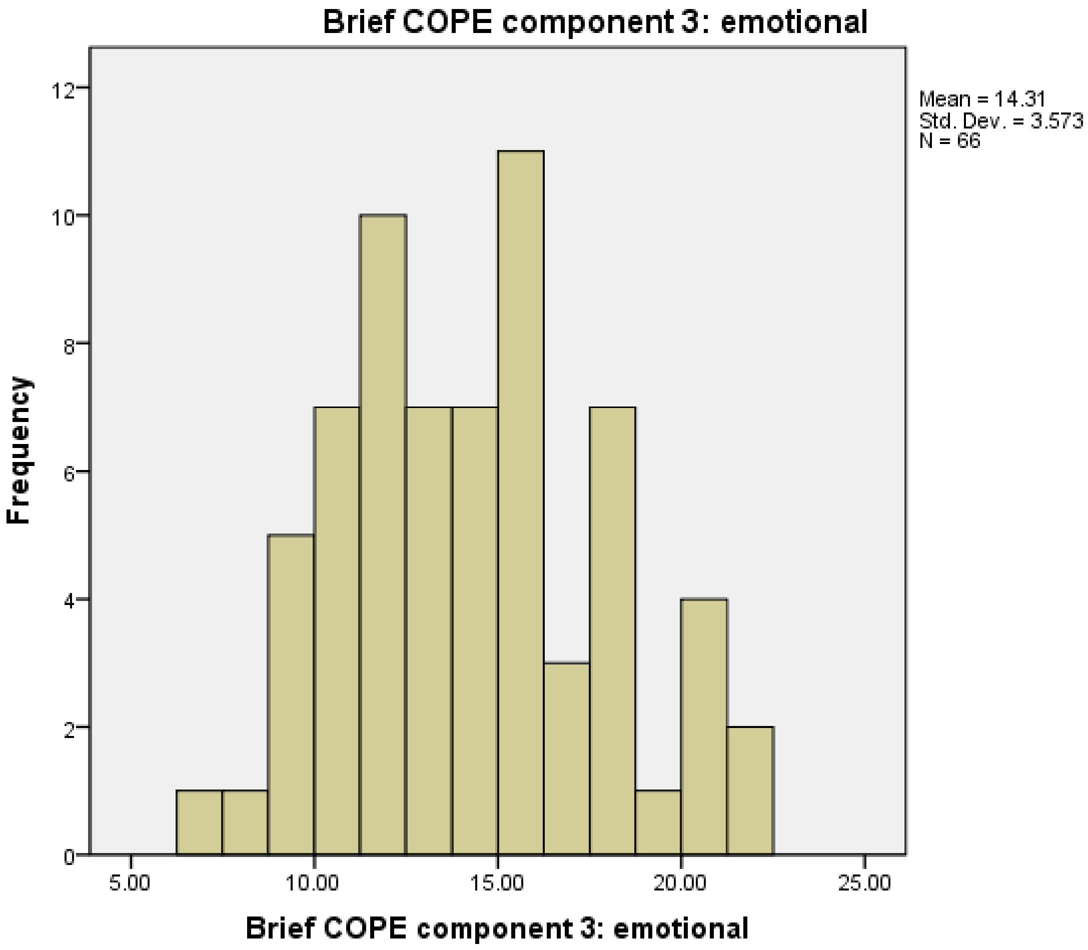

IOWA-Netherlands Social Comparison Scale - comparison in general
Mean = 72.45
Std. Dev. = 11.336
N = 64
Frequency
20
15
10
5
0
40.00
60.00
80.00
100.00
IOWA-Netherlands Social Comparison Scale - comparison in general

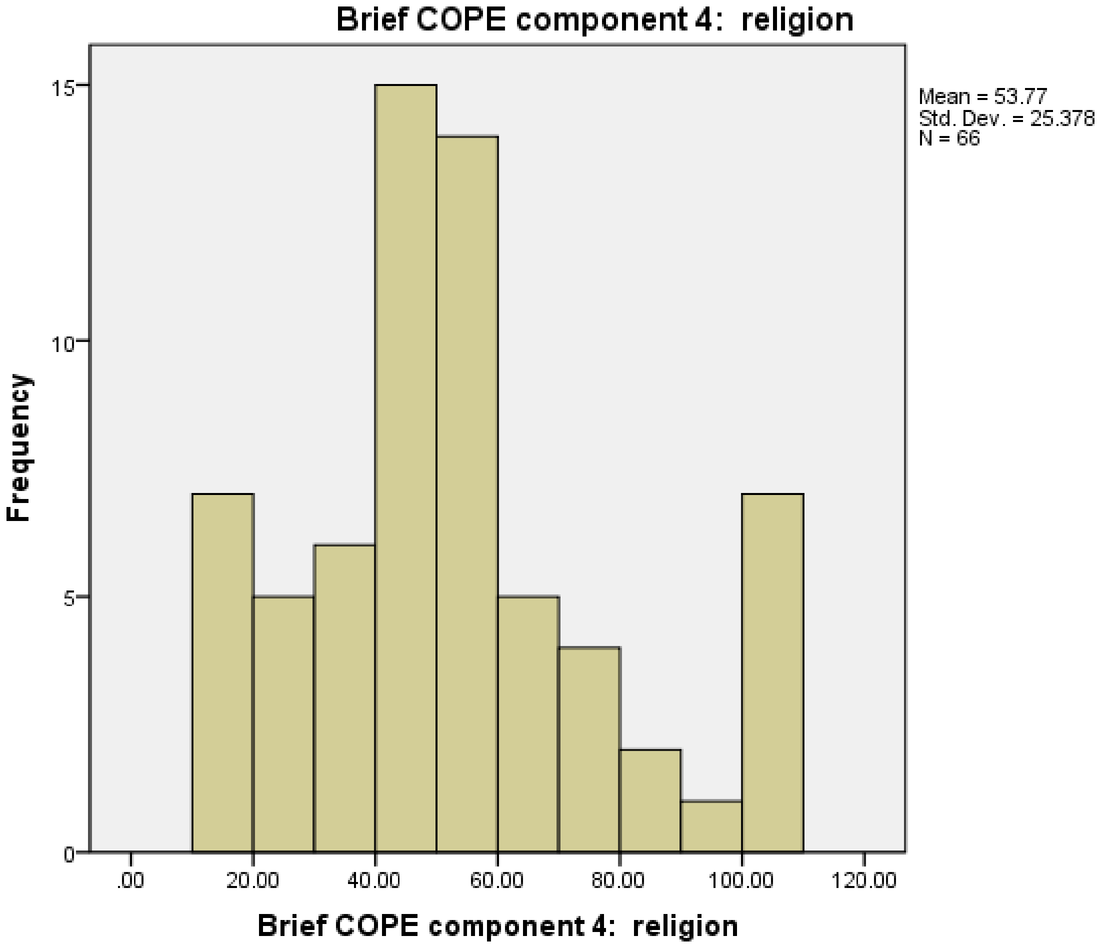

mean of all MOS-SS subscales
Mean = 3.73
Std. Dev. = 1.117
N = 65
Frequency
12.5
10.0
7.5
5.0
2.5
0.0
1.00
2.00
3.00
4.00
5.00
6.00
mean of all MOS-SS subscales


Life Orientation Test - Revised
Mean = 17.27
Std. Dev. = 5.498
N = 64
Frequency
12.5
10.0
7.5
5.0
2.5
0.0
5.00
10.00
15.00
20.00
25.00
30.00
Life Orientation Test - Revised


Brief COPE component 1: positive
Mean = 24.49
Std. Dev. = 6.445
N = 66
Frequency
12.5
10.0
7.5
5.0
2.5
0.0
10.00
15.00
20.00
25.00
30.00
35.00
40.00
Brief COPE component 1: positive


Brief COPE component 2: avoidant
Mean = 17.03
Std. Dev. = 4.819
N = 66
Frequency
0.0
2.5
5.0
7.5
10.0
12.5
5.00
10.00
15.00
20.00
25.00
30.00
Brief COPE component 2: avoidant


Brief COPE component 3: emotional
Mean = 14.31
Std. Dev. = 3.573
N = 66
Frequency
0
2
4
6
8
10
12
5.00
10.00
15.00
20.00
25.00
Brief COPE component 3: emotional


Brief COPE component 4: religion
Mean = 53.77
Std. Dev. = 25.378
N = 66
Frequency
15
10
5
0
.00
20.00
40.00
60.00
80.00
100.00
120.00
Brief COPE component 4: religion

Appendix 5.4: Descriptive statistics for the measures used in the study, including Cronbach’s alpha statistic for reliability.

Appendix 5.4: Descriptive statistics for the measures used in the study, including Cronbach's alpha statistic for reliability.

	N	Mean	SD	No of items	Cronbach's alpha
IOWA-Netherlands Social Comparison Scale - comparison in general	64	72.45	11.34	23	.86
IOWA-Netherlands Social Comparison Scale - upwards comparison	64	17.97	5.27	6	.91
IOWA-Netherlands Social Comparison Scale - downwards comparison	64	17.09	4.52	6	.86
Brief COPE - Self-distraction (possible scores 1-8)	66	4.65	1.89	2	.57
Brief COPE - Active Coping (possible scores 1-8)	66	5.41	2.05	2	.84
Brief COPE – Denial (possible scores 1-8)	66	3.83	1.88	2	.79
Brief COPE – Substance Use (possible scores 1-8)	65	3.06	1.67	2	.97
Brief COPE - Use of emotional support (possible scores 1-8)	66	4.92	1.74	2	.74
Brief COPE - Use of instrumental support (possible scores 1-8)	66	5.02	1.71	2	.78
Brief COPE - Behavioural Disengagement (possible scores 1-8)	66	3.88	2.13	2	.70
Brief COPE – Venting (possible scores 1-8)	66	4.21	1.91	2	.63
Brief COPE - Positive Re-framing (possible scores 1-8)	65	4.15	1.86	2	.66

Brief COPE – Planning (possible scores 1-8)	66	4.92	1.99	2	.77
Brief COPE – Humour (possible scores 1-8)	66	3.30	2.23	2	.90
Brief COPE – Acceptance (possible scores 1-8)	66	2.27	1.05	2	.79
Brief COPE – Religion (possible scores 1-8)	66	3.33	1.91	2	.95
Brief COPE - Self-blame (possible scores 1-8)	66	3.79	2.06	2	.68
MOS-SS Emotional /informational Support	65	3.39	1.19	8	.95
MOS-SS Tangible support	65	3.88	1.31	4	.96
MOS-SS Affectionate support	65	3.91	1.34	3	.97
MOS-SS Positive Social Interaction	65	3.74	1.29	3	.97
MOS-SS Additional item	65	3.72	1.34	1	N/A
mean of all MOS-SS subscales	65	3.73	1.12	19	.96
Life Orientation Test – Revised	64	17.27	5.50	6	.99