

A COMPARISON OF THE QUALITY OF LIFE OF VULNERABLE YOUNG MALES WITH SEVERE EMOTIONAL AND BEHAVIOUR DIFFICULTIES IN A RESIDENTIAL SETTING AND YOUNG MALES IN MAINSTREAM SCHOOLING

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Accessible summary

- The findings from this study reveal that the notion of anticipated and deleterious differences in quality of life (QoL) between children with severe emotional and behavioural problems and those without such difficulties is not supported. Indeed, results reveal counter-intuitive findings with children with emotional and behavioural problems reporting better QoL than those without such presenting problems on a number of QoL sub-scales.
- The type of QoL measure and related sub-scales appears to be sensitive to differing aspects of self-report QoL, with in some instances, some QoL sub-scales being more discriminatory between groups compared to other QoL sub-scales. Consequently, the choice of QoL measure is critically important in accurately and reliably determining QoL in children with significant emotional and behavioural problems.

Abstract

One hundred and seventy four males completed a quality of life assessment utilising: PedsQL (Varni et al., 2001), and SF36 (Ware and Sherbourne, 1992). The adolescents aged 13-16 years old were in a Scottish Centre for young males with social, emotional, behavioural and educational problems. To identify similarities and differences, a control group (n= 110) of males in 3rd and 4th year in a mainstream secondary school were also administered the PedsQL and the SF36 self rating scales. The effectiveness of the PedsQL and the SF36 for assessing quality of life for adolescent males was investigated. There were significant differences between the groups in the Centre and between the Centre groups and the control group in terms of their quality of life. The results between the groups were found in the PedsQL subscales 'physical functioning' where secure > control (p=0.04); secure > residential (p= 0.008); and PedsQL subscale 'social functioning' day > control (p=0.026); secure > control (p=0.037). SF36 subscales 'role physical functioning' secure > residential (p<0.001); day > residential (p<0.001). SF36 'role mental functioning' day > residential (p=0.001). This study provides a unique insight to the complex dimensions influencing the QoL of this specific group of young people.

Introduction

The majority of Looked After and Accommodated children and young people (LAAC) are in care as a result of their parents being unable to care for them. They frequently come from backgrounds with high incidences of substance misuse and mental health problems (Bundle, 2002; Wade et al., 2010) and typically have experienced abuse or neglect (Cocker and Scott, 2006). There is little doubt that children who have been maltreated are at high risk of poor mental health (Ashton-Key and Jorge, 2003; Brodie et al., 1997; Caroline Walker Trust, 2001; House of Commons Select Committee, 1998; Meltzer et al., 2004; Residential Care Project, 2004; Rivron, 2001; Smith, 2000). The young people in care are recognised as a socially excluded group in society (Gilman, 1998). Looked after young people are 4 times more likely to be unemployed, have poor health outcomes and are 60 times more likely to be sent to prison (Cocker and Scott, 2006). These young people are marginalised by both society and their own antisocial behaviours (Gilman, 1998).

It is accepted that the experience of being in care will have an impact on a child's physical and mental wellbeing. Quality of life assessments can be a measure of their perception of how life is for them. Quality of life is the persons "perceptions of their positioning in life in the context of the culture and value system in which they live and in relation to their goals, expectations, standards and concerns" (WHO QoL Group, 1994). QoL of a young person is holistic and includes for example physical and mental health, social functioning, education and relationships. However, it is more how they perceive themselves and if they perceive their needs are being met that is important. It could be considered that it is the way in which the young person views their surroundings with their coping styles that influences how they perceive within particular contexts (Edwards et al., 2002).

There should be a minimum quality of life for young people in the care system (Bullock et

al., 1994). However, there may be differences in people's views of an adolescent's quality of life. This could mean that the young person, parents (Apajasalo et al., 1996), carers (Davidson-Arad et al., 2004) social workers, researchers and health professionals may all have a diverse view of what good health is (Bailey et al., 2002). It is important to try and establish a quality of life benchmark for young people in care.

There are very few studies which have specifically investigated the quality of life of LAAC. Gilman and Handwerk (2001) stated that quality of life and the young person's perception should be assessed appropriately as they enter residential care and not assumed to be less than their peers. It is important therefore that reliable and valid QoL instruments are identified to consistently assess QoL of LAAC. (Eiser and Lawford, 2009; Hong et al., 2007; Laaksonen et al., 2007). Within this study the two QoL instruments were administered. These were the PedsQL which is frequently used with children and young people and the gold standard SF36.

Background

Adolescents are able to articulate positive and negative aspects relating to their quality of life (Ramjil et al., 2006). Concerns about self reporting have been the subject of investigation yet there has been consistent evidence found that children and young people can provide reliable and valid responses across the age categories (Coghill et al., 2009; Hong et al., 2007; Varni et al., 2007).

The reliability and validity of the PedsQL has been confirmed in more than 75 studies reported in peer-reviewed journals. Such studies have included over 25,000 children and their parents. For example Varni et al. (2007) report internal consistency Cronbach's alpha coefficient of >0.7 and Limbers et al. (2007) identified excellent Factorial Invariance. In

addition Scarpelli et al. (2008) and Connelly and Rapoff (2006) observed a test-retest Cronbach $\alpha = 0.89$.

The PedsQL consists of 23 items which are designed to measure aspects of QoL in healthy and ill children and adolescents. These items provide a total scale and four sub-scales which include the following: physical functioning (8 items); emotional functioning (5 items); social functioning (5 items) and school functioning (5 items). According to Varni et al., 2008 this can be completed within five minutes. A five point Likert format is utilised from 0 (never) to 4 (almost always), with no weighting for the items. The PedsQL requires the participant to recall the past month.

The SF36 is one of the most widely used and evaluated QoL questionnaires (Garrat et al., 2002). It is often referred to as the gold standard and has led to the development and analysis of other QoL instruments which use the SF36 as their basis (Asher et al., 2003; Ware, 2008; Ware and Sherburne, 1992). It has excellent test-retest reliability (Asher et al., 2003; Ware, 2008; Ware and Sherburne, 1992) and discriminate validity (Creed et al., 2002; Jorngarden et al., 2006). The internal consistency of the SF36 for use with adolescents is consistent with Cronbach alpha greater than 0.7 (Ware, 2008).

Since its publication in 1992 it has been cited in over 4,000 publications and used in more than 600 randomised clinical trials. The SF36 has been supported by the US Food and Drug Administration. Ware (2008) argues that the SF36 offers the opportunity for longitudinal studies from adolescent to adulthood which facilitates comparisons to be made across the lifespan of the individual. Using the SF36 with adolescents adds credence to this study due to the body of knowledge associated with this measure.

The SF36 is a 36 multi-purpose, short-form health survey. For these 36 questions, the response categories vary depending on the question. These range from 2 (yes, no) to 6 (all of the time, most of the time, a good bit of the time, some of the time, a little of the time, none of the time). Young people are invited to recall the past 4 weeks. There are 8 domains, building a profile of functional health and well-being scores including: limitations in physical activities because of health problems (10); limitations in social activities because of physical or emotional problems (2); limitations in usual role activities because of physical health problems (4); bodily pain (2); general mental health: psychological distress and wellbeing (5); limitations in usual role activities because of emotional problems (3); vitality (energy and fatigue) (4) and general health perceptions (6) (Ware and Sherbourne, 1992).

Method

Setting

This residential Centre is the largest multi-service centre in Scotland and provides a specialist resource for young people who have a complex and acute mix of social, emotional, educational and behavioural problems, bringing much-needed safety, structure and stability to their lives. Placements at this Centre are sought by local authorities usually after other care providers encompassing child welfare, youth justice and mental health have not been successful in meeting the complex needs of these young people.

Participants

One hundred and seventy four males aged 13-16 years old were recruited from a Scottish residential establishment. In addition a control group (n= 110) of males in 3rd and 4th year aged between 13 years to 15 years 11 months were also recruited from a mainstream secondary school of mixed social economic background. Most participants completed all items within the instruments while a few omitted a small number of responses.

Design

This study is a between groups design consisting of three groups within the Centre (day, residential and secure) and a control group consisting of young people at a nearby secondary school. The study was approved by the ethics committee of the University of [REDACTED]

Procedure

Young people in the Centre were issued the two instruments (PedsQL and SF36) during the first week of their admission to the Centre. Within the control group participants the mainstream school were invited to complete the same assessment instruments in their personal and social education class.

Analysis

Both the SF36 and the PedsQL were calibrated from 0-100 with 0 being the worst health related quality of life.

To establish if there were any differences between the groups, an analysis of variance was used. Due to confidentiality restrictions the researcher did not have access to the date of birth of the young people in the control group, however the groups are likely to be broadly equivalent in terms of educational year groupings between centres.

Where there was a statistically significant finding a post hoc Bonferroni test was conducted to explore the findings of the analysis of variance between the groups

Results

To allow for comparison between the four groups (day, residential, secure and control) the mean scores and standard deviations of the PedsQL and SF36 subscales as a function of group type are shown in Table 1.

TABLE 1. ABOUT HERE

The higher the score in the QoL instrument indicates the greater the self perception of respondents health related quality of life. Although it might be reasonable to expect that compared to the control group young people in the Centre would have lower scores in their quality of life, this was not evident in the data in Table 1.

TABLE 1. ABOUT HERE

Further analysis was undertaken to find if there was any significant differences in the QoL between the groups of young people. A one-way between-groups ANOVA was undertaken with the data from the PedsQL and the SF36. The results demonstrated firstly for the PedsQL that there was no significant differences between the groups in the overall total scores ($F_{(3,279)}=1.41, p=0.24$). The results of the one-way between-groups ANOVA of PedsQL and PedsQL subscales are now shown in Table 2.

TABLE 2. ABOUT HERE

Comparison of the groups on the subscales of the PedsQL with ANOVA ,the main effect of the group revealed two significant differences in the PedsQL subscale scores ‘physical functioning’ ($F_{(3,281)}=3.83, p=0.01$) and ‘social functioning’ ($F_{(3,279)}=4.5, p<0.01$).

A post hoc Bonferroni test confirmed a significant difference between the young people in secure and residential groups and between the secure and control groups in the PedsQL subscale 'physical functioning'. That is to say, the boys in secure group scored their 'physical functioning' higher than the boys in the control group ($p=0.043$) and the secure group also scored higher than boys in the residential group ($p=0.008$).

A significant difference was also observed between the control group and the day group ($p=0.026$) and the control and the secure group ($p=0.037$) in the 'social function' subscale of the PedsQL. That is to say the boys in both the day and secure groups rated their quality of life in 'social functioning' to be greater than the control group.

The same process was applied to the data obtained from the SF36. The results from the ANOVA found the main effect of group revealed significant differences in four of the SF36 subscales. The results follow in Table 3.

TABLE 3. ABOUT HERE

Firstly in 'role physical functioning' ($F_{(3,227)} = 8.15, p < 0.01$). The post hoc Bonferroni test confirmed difference between the residential and secure groups ($p < 0.001$) and residential and day groups ($p < 0.001$). This demonstrates that the young people in secure and day groups reported higher quality of life on the subscale of 'role physical functioning' than the young people in the residential group. Interestingly there was no significant difference between the Centre as a whole and the control group.

Data from the ANOVA to investigate the main effect of group revealed significant

differences in the SF36 subscale score in 'role mental functioning' ($F_{(3,276)}=5.57, p<0.01$). A post hoc Bonferroni test confirmed the difference between the young people in day and residential groups ($p=0.001$). The young people in the day group scored highest in the 'role mental functioning' subscale and significantly higher than the residential group.

Examination across the subscales of the SF36 with ANOVA revealed significant differences in the SF36 subscale scores in the 'social functioning' ($F_{(3,270)} =2.80, p= 0.04$) and 'mental health' ($F_{(3,271)} =2.96, p=0.03$) subscales. A post hoc Bonferroni test did not confirm a significant difference between the groups on either of these subscales.

Table 4 provides a summary of the results obtained in this study. Table 4 illustrates the domains where there were significant findings then details of which groups this is pertaining to. No other domains and subscales in the PedsQL and SF36 provided significant results.

TABLE 4. ABOUT HERE

Discussion

It would be reasonable to expect that the young people in mainstream school would have the highest quality of life between the groups, followed by the young people in day care who live with their families, then LAAC in residential care and finally the young people in secure care having the worst experiences. This was not the case. The day group had the highest rating for their quality of life followed by secure, control and finally the young people in the residential group. However, the PedsQL total score found the differences between the groups to be not significant.

Cocker and Scott (2006) observed that LAAC had poorer health outcomes compared to a

non-LAAC population. Within this current study the PedsQL subscales revealed significant differences in the 'physical functioning' subscale with the secure group having scored highest followed by day, control and finally residential group. This result was similar to that demonstrated by the SF36 subscale 'role physical functioning'. These results would suggest that young people's perceptions of their health and physical functioning may differ from previous research evidence.

It would be expected that the control group would provide the norm in relation to completion of QoL instruments. However, there were further unexpected findings in the PedsQL subscale 'social functioning' in which the day and secure groups scored significantly higher than the control group. In addition, while not significant, the residential group within the Centre also scored higher than the control (Table 4). These results are surprising as it would have been expected that the participants in the control group would have scored higher than each of the three groups within the Centre. A plausible explanation for this phenomenon is that these perceptions may be due to the limited reference groups available to young people at the Centre. This may have given young people in the Centre a skewed perception of what is "normal". In this sense the findings of this research are informative.

The analysis of the data obtained from the SF36 also brought about some surprising results. No significant results between any of the groups within the Centre and the control group were observed. In comparison of groups within the Centre statistically significant results were demonstrated in relation to only two subscales. The day and secure group fair better than the residential group on the SF36 subscales 'role physical functioning'; in addition the day group fair better than the residential group on SF36 subscale 'role mental functioning'.

These results appear counter-intuitive and do not appear to validate the allocation of

resources in supporting vulnerable young people. It may be valuable to conduct further research to explore for example why groups within the Centre rate aspects of their QoL higher than the control group and also why the residential group typically rate themselves lower than both the day and secure group participants in relation to their QoL.

This study was also interested in whether the two quality of life instruments (PedsQL and the SF36) would provide similar profiles and results for the groups of young people. Only one such finding was observed: both instruments noted the secure group scoring highest in physical functioning. This was a significant finding in the PedsQL but non significant in the SF36. Otherwise it transpired that the profiles of the young people in the secure and day groups had inconsistent features when comparing the results from the two QoL instruments.

In conclusion it is a rather remarkable profile where the young people in secure care rate their quality of life in physical functioning as greater than all the other groups, including the control group. In addition the young people in the day and secure groups rated their social functioning higher than the both the young people in residential care but also most unexpectedly higher than the young people in main stream school.

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	GROUPS			
	Day	Residential	Secure	Control
Number	39	74	61	111
	mean (SD)	mean (SD)	mean (SD)	mean (SD)
PedsQL				
Total	83.70 (10.86)	79.02 (12.70)	82.29 (10.10)	81.17 (14.01)
physical	89.58 (13.82)	86.91 (15.17)	94.36 (8.55)	88.63 (13.84)
emotional	75.77(13.89)	71.01 (18.84)	70.33 (22.83)	75.81 (20.30)
social	90.38 (17.34)	81.76 (18.79)	88.61 (15.25)	75.81 920.30)
school	75.51 (15.81)	72.60 (20.50)	68.61 (51.16)	75.32 (16.50)
SF36				
physical	93.42 (11.86)	86.08 (23.56)	95.41 (18.33)	88.76 (24.11)
social	84.21 (20.69)	77.78 (23.48)	74.39 (26.36)	84.10 (22.29)
role physical functioning	93.59 (17.41)	74.16 (32.52)	91.19 (19.38)	81.89 (21.65)
role mental functioning	93.86 (15.94)	73.87 (32.39)	85.38 (28.04)	83.88 (21.07)
vitality	69.90 (14.45)	68.58 (17.04)	66.60 (24.39)	68.61 (19.31)
pain	83.40 (20.82)	80.39 (22.35)	85.69 (21.89)	82.63 (18.02)
general health	72.63 (19.21)	69.61 (19.95)	72.77 (21.26)	73.81 (19.06)
change in health	56.58 (23.02)	64.86 (24.80)	61.48 (24.82)	68.12 (23.04)
mental health	77.63 (16.51)	67.92 (19.80)	69.10 (25.96)	74.62 (17.75)

Table 1: Mean scores and standard deviations of PedsQL and SF36 subscales

PedsQL	SS	df	ms	F	p value
<i>Total</i>					
Between groups	662.64	3	220.88	1.41	0.24
Within the groups	43603.23	279	156.28		
Total	44265.87	282			
<i>Physical functioning</i>					
Between groups	2025.07	3	675.03	3.83	0.01
Within the groups	49523.86	281	176.24		
Total	51548.93	284			
<i>Emotional functioning</i>					
Between groups	1861.17	3	620.39	1.59	0.19
Within the groups	109846.38	281	390.91		
Total	111707.54	284			
<i>Social functioning</i>					
Between groups	4651.96	3	1550.65	4.50	<0.01
Within the groups	96774.89	281	344.40		
Total	101426.84	284			
<i>School functioning</i>					
Between groups	2015.28	3	671.76	1.97	0.12
Within the groups	95115.64	279	340.92		
Total	97130.92	282			

Table 2: ANOVA results of PedsQL and PedsQL subscales

SF36	SS	df	MS	F	p value
<i>Physical functioning</i>					
Between groups	3529.33	3	1176.44	2.54	0.06
Within the groups	128641.33	278	462.74		
Total	132170.66	281			
<i>Social functioning</i>					
Between groups	4662.01	3	1554.00	2.89	0.04
Within the groups	146414.64	270	542028		
Total	151076.64	273			
<i>Role physical functioning</i>					
Between groups	14213.47	3	4737.83	8.15	<0.01
Within the groups	161103.75	277	561.60		
Total	175317.23	280			
<i>Role mental functioning</i>					
Between groups	11071.49	3	3690.50	5.57	<0.01
Within the groups	183046.57	276	663.21		
Total	194118.06	279			
<i>Mental health</i>					
Between groups	3629.81	3	1209.94	2.96	0.03
Within the groups	110784.37	271	408.80		
Total	114414.18	274			
<i>Vitality</i>					
Between groups	367.39	3	122.46	0.32	0.81
Within the groups	102440.00	271	378.01		
Total	102807.39	274			
<i>Pain</i>					
Between groups	920.40	3	306.80	0.73	0.53
Within the groups	115366.12	275	419.51		
Total	116286.52	278			
<i>General health</i>					
Between groups	770.43	3	256.81	0.65	0.59
Within the groups	106071.61	270	392.86		
Total	106842.04	273			
<i>Change in health</i>					
Between groups	4365.40	3	1455.13	2.55	0.06
Within the groups	158810.57	278	571.26		
Total	163175.98	281			

Table 3: ANOVA results of SF36 subscales

PedsQL			SF36		
Physical functioning	day- control	ns	Role physical functioning	day- control	ns
	residential- control	ns		residential- control	ns
	secure> control	s		secure- control	ns
	day-residential	ns		day>residential	s
	day-secure	ns		day-secure	ns
	secure>residential	s		secure >residential	s
social functioning	day>control	s	role mental functioning	day- control	ns
	residential- control	ns		residential- control	ns
	secure> control	s		secure- control	ns
	day-residential	ns		day> residential	ns
	day-secure	ns		day-secure	ns
	secure-residential	ns		secure -residential	ns

Table 4: Summary of significant results from ANOVA PedsQL and SF36. *non significant(ns) significant (s)