

**Quality of Life and Psychosocial Development in Adolescents with
Epilepsy: A Qualitative Investigation using Focus Group Methods**

And Research Portfolio

PART ONE

(Part Two bound separately)

M Janie McEwan

July 2002

**Submitted in partial fulfilment of the requirements for the degree of Doctor of
Clinical Psychology**

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For mum and dad

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Chapter 1: Small Scale Service Related Project

Evaluation of Assessment Triage as a Waiting List Initiative in a West of Scotland, Direct Access, Adult Psychology Service

Small Scale Service Related Project submitted in partial fulfilment of the requirements
for the degree of Doctor of Clinical Psychology

Prepared in accordance with guidelines for contributors to *Clinical Psychology Forum*
(see Appendix 1.1)

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INTRODUCTION

The development of efficient waiting list initiatives is important to direct access clinical psychology departments (Cawley & Read 1999). The Psychology Professional Practice Guidelines (1995) state services must be “accessible to our clients and dictate that “where a long waiting list develops for a service, psychologists should ... make every effort to improve response times”. “Waiting for a first appointment” was described as the main factor depicting poor service by service users and the second largest factor by GPs (McAuliffe & MacLachlan 1992). Furthermore, it has been suggested that as well as delaying treatment, waiting lists may significantly impact on the effectiveness of treatment once provided due to failure to attend and escalation of problems over time (Herlihy *et al.* 1998). Hicks and Hickman (1994) proposed that if treatment is delayed individuals resort to maladaptive coping strategies, thus increasing the severity of their original problem. Long waiting lists have also been shown to reduce both client confidence and morale amongst clinical psychologists (Brown *et al.* 1999; Corrie 1999).

In response, various waiting list initiatives have been created in attempts to reduce waiting lists within psychology services (e.g. Dawson 1997). Shawe-Taylor *et al.* (1994) evaluated the use of initial assessment appointments. Benefits included a reduction in perceived severity of the problem by the client, an increase in the perception of their ability to cope and less interference with daily life. In addition, an increase in the belief that clinical psychology could help with their problems has also been reported (Shawe-Taylor *et al.* 1994). Geekie (1995) in assessing a similar initiative demonstrated reductions in the number of treatment sessions required. Other advantages of such a system are the opportunity to screen and filter referrals. Initial formulations can be made

which allow referrals to be assessed for urgency. Those deemed in urgent need of treatment can be offered sessions immediately and those deemed less severe can be provided with advice and information enabling them to use waiting time more productively. Stevenson *et al.* (1997) also purported the benefits of interim measures such as self-help literature and anxiety management groups run by assistant psychologists as an interim to commencing treatment. Importantly, McAuliffe and MacLachlan (1992) and Geekie (1995) demonstrated that both clients and GPs were in favour of initial assessment appointments.

A triage assessment system was introduced to a psychology department in the West of Scotland in February 1999. It was intended that the use of a triage system would benefit the service on several levels:

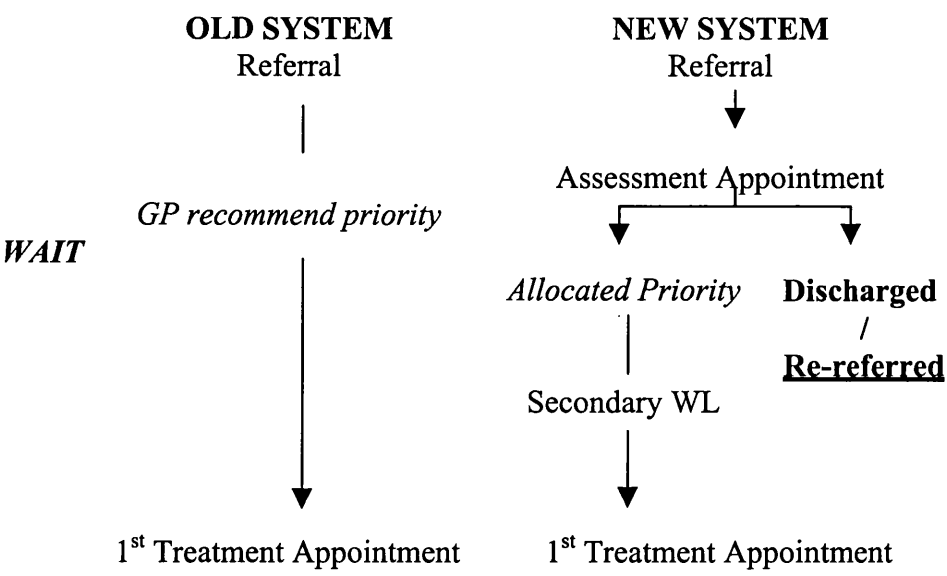
- Reduce length of wait for access to psychology services
- Reduce overall waiting times to treatment
- Enable appropriate filtering of referrals
- Enable appropriate prioritisation of referrals

The department possessed a skill mix of clinical psychologists, counselling psychologists, CBT specialists and counsellors. The Management Advisory Service to the NHS (MAS, 1995) described 3 levels of psychological skills with Level 3 being the most complex and multi-theoretical. The MAS stated that psychologists are distinguished from other disciplines by their ability to operate at level 3. Given the skill mix available in the department these skills could be maximised by referring clients requiring Level 1 and Level 2 skills to the other specialities available within the

department, thereby freeing psychology resources to focus at Level 3. Assessment appointments enabled referrals to be allocated to the most appropriate speciality and provided a means of filtering inappropriate referrals.

The department aimed to have all clients seen for initial assessment within 9 weeks of referral. Clinical psychologists carried out the majority of the assessment interviews. Clients were informed that if appropriate they would be placed on a secondary waiting list following assessment. An initial formulation of their problem was made allowing allocation of priority and referral to the most appropriate service for treatment. The client was told which service they would be seen by, the estimated length of time they would have to wait for an appointment and, if appropriate, advice and/or self help was provided in the interim. The clinical psychology department aimed to see every high priority referral within 8 weeks of assessment, with those assigned medium priority automatically reassigned to high once 8 weeks had passed. Inappropriate referrals were re-referred and patients who no longer required the assistance of the department or who only required one session were discharged. Previous to the introduction of the assessment triage system, the process was for clients to be placed on the clinical psychology waiting list to await an appointment at which point they would be taken on for treatment or discharged (see Figure 1). Priority status of each referral was based solely on the recommendation by the GP at the referral stage.

Figure 1: Diagrammatic Representation of Referral System Pre and Post Assessment Triage



This study aimed to assess the effectiveness of the triage system in meeting its original aims. Particular emphasis was placed on its aim as a waiting list initiative.

METHOD

Data was gathered for 1998 and 1999 for referrals to the South of the Healthboard. Referrals from the North of the Health Board were excluded as the waiting lists are held separately. Data was confined to the months June-December (inclusive). This provided an accurate summary of referrals both before and after the introduction of the assessment triage system, in February 1999, whilst allowing for adjustment to the new system. All referrals had been allocated appointments.

Data from June-December 1998

Data from 1998 (n=171) was obtained from paper records held within the department and entered onto computer spreadsheet using SPSS Version 9.0. The data contained

information on all referrals to the department within this time period and the first appointment offered to them. No information was provided on whether the appointment was attended.

Data from June-December 1999

Data from 1999 (n=121) was obtained from two separate existing databases on Access and SPSS Version 6.0. The database contained information from the assessment appointment. It is important to note that only those who attended their assessment appointments were held on the database. This prevents a definite estimate of referral rate being made, however assuming an average DNA rate of 20-30% (Hicks & Hickman 1994) one can assume 1998 and 1999 referral rates were roughly equal. Appointment dates following assessment were obtained from paper records of the psychology secondary waiting list and these were cross-matched with the existing database. Data was combined onto one database on SPSS Version 9.0.

Attempts were made to complete any missing data by locating case notes.

All analysis of data was completed using SPSS.

RESULTS

Waiting Times

Mean waiting time from referral to appointment for 1998 was 13.63 weeks (SD of 7.82, range 0.86 to 33.14 weeks). Comparison of waiting time by priority assigned by GP at referral revealed a mean wait time for high priority patients of 5.51 weeks (SD = 5.08); mean wait time for soon priority patients as 12.20 weeks (SD = 9.14) and a mean wait

time for those without any indication of priority as 14.47 (SD = 7.52) weeks (see Table 1).

Table 1: Mean Wait Time by Priority Assigned by GP at referral (June-December 1998)

GP Priority Assigned	N	Mean	Median	SD
<i>High</i>	13	5.51	4.14	5.08
<i>Soon</i>	12	12.20	7.36	9.14
<i>Unassigned</i>	146	14.47	14.57	7.52
<i>TOTAL</i>	171	13.63	13.14	7.82

Analysis of waiting times for 1999 data focused on three periods (see Table 2):

- **Wait Total:** Referral date to first treatment appointment
- **Wait a:** Referral date to assessment appointment
- **Wait b:** Assessment appointment to first treatment appointment

Mean wait total was 23.56 weeks (SD = 12.04; range 4.14 to 50.57 weeks) for 1999.

Mean wait a was 9.04 (SD = 4.01; range = 1.00 to 24.43) and mean wait b was 14.91 weeks (SD = 10.15; range = 0.71 to 36.14 weeks).

Table 2: Mean Waiting Times for June-December 1999

	N	Mean	SD	Min	Max
Wait (total)	60	23.56	12.04	4.14	50.57
Wait (a)	121	9.04	4.01	1.00	24.43
Wait (b)	60	14.91	10.15	0.71	36.14

Following assessment 48.8% of patients (n=62) were seen by clinical psychology. Patients were allocated as high or medium priority (see Table 3). Mean wait time (total) for high priority =17.08 weeks (SD = 8.20; n=17); mean wait time (total) for medium priority = 25.99 weeks (SD =12.55; n=42). Mean wait time (b) for high priority patients = 9.77 weeks (SD = 7.50) and mean wait time (b) for medium priority =16.81 weeks (SD = 10.5)

Table 3: Mean Wait Time (Total and b) by priority allocated following assessment (June-December 1999)

PRIORITY		WAIT (B)	WAIT (TOTAL)
HIGH	Mean	9.77	17.08
	N	17	17
	Std	7.50	8.20
	Deviation		
	Minimum	0.71	6.86
	Maximum	29.14	33.71
MEDIUM	Mean	16.81	25.99
	N	42	42
	Std	10.50	12.55
	Deviation		
	Minimum	1.14	4.14
	Maximum	36.14	50.57

Closer investigation of waiting times revealed 53% of those seen by clinical psychology commenced treatment within 12 weeks of referral, with 75% within 24 weeks (see table 4 for summary).

Table 4: Frequency of Wait Time (Total) June-December 1999

Wait Time (Total)	N	%
0-3 wks	7	11.7
4-6 wks	7	11.7
7-9 wks	12	20.0
10-12 wks	6	10.0
13-15 wks	3	5.0
16-18 wks	3	5.0
19-21 wks	2	3.3
22-24 wks	5	8.3
25-27 wks	7	11.7
28-30 wks	4	6.7
31-33 wks	2	3.3
34-36 wks	2	3.3
TOTAL	60	

Three clinics are used in the South of the area. Investigation revealed the longest waiting times to be at Clinic A, with Clinic B slightly lower. Clinic C waiting times were markedly lower, however this also reflected fewer referrals (see Table 5 for summary)

Table 5: Mean Wait Times (a, b and total) by clinic (June-December 1999)

		WAIT (A)	WAIT (B)	WAIT (TOTAL)
CLINIC A	<i>Mean</i>	9.72	17.43	27.13
	<i>N</i>	53	30	30
	<i>SD</i>	4.12	10.39	12.61
	<i>Min</i>	1.29	1.29	4.71
	<i>Max</i>	24.43	36.14	50.57
CLINIC B	<i>Mean</i>	8.80	13.93	21.78
	<i>N</i>	56	25	25
	<i>SD</i>	3.90	9.48	10.45
	<i>Min</i>	1.00	1.71	6.86
	<i>Max</i>	18.57	33.14	38.86
CLINIC C	<i>Mean</i>	7.17	4.69	11.09
	<i>N</i>	12	5	5
	<i>SD</i>	3.53	3.44	4.65
	<i>Min</i>	2.43	0.71	4.14
	<i>Max</i>	13.71	7.57	15.14

Referral Agent

As the service is a direct access service it was not surprising that the majority of referrals were from GPs with 72.5% of referrals coming from GPs for the 1998 period and 73.6% of referrals for the 1999 period (see Table 6).

Table 6: Frequency of Referral Agents June-December 1998

Referrer	1998		1999	
	N	%	N	%
GP	124	72.5	89	73.6
Psychiatrist	21	12.3	19	15.7
CMHT	19	11.1	8	6.6
Other	7	4.1	5	4.1
<i>TOTAL</i>	171		121	

Outcome of Assessment Appointment

Following assessment appointments 16 patients (13.2%) were discharged. Of those discharged, 5 (4.1%) were deemed to have the problem resolved prior to assessment and 6 (5%) only needed a single session. Another 3 referrals (2.2%) were referred on to another service and the rest were allocated to the treatment approach deemed most appropriate for their problem. Of these 13 patients (10.7%) were allocated to counselling; 41 (33.9%) were allocated to CBT specialists; 9 (7.4%) were allocated to counselling psychology and the rest were allocated to either clinical psychology or deemed suitable for clinical psychology or one of the other services (see Table 7). It is important to note however that investigation of data revealed 29 of the 41 allocated for CBT Specialists alone were actually taken on by clinical psychologists.

Table 7: Outcome of assessment appointment

Outcome of Assessment	N	%
Discharged	16	13.2
Referred to other service	3	2.2
Counselling	13	10.7
CBT Specialist	41	33.9
Counselling Psychologist	9	7.4
Clinical Psychologist	31	25.6
Clinical Psychologist or CBT	7	5.8
Clinical or Counselling Psychologist	1	0.8
<i>TOTAL</i>	121	

DISCUSSION

Examination of data revealed that referral rates for the 2 periods pre and post introduction of the assessment triage system reflected similar referral rates (estimating DNA rates for 1999 to be around 20-30%). The type of referral agents for both time periods were also similar, with the majority of referrals coming from GPs.

Reducing Length of Wait for Access to Psychology Services

The introduction of the assessment triage system was successful in meeting the target of reducing overall wait for access to the service. All patients referred to the department in June-December 1999 were seen for initial assessment within 9 weeks of referral, which compared with a mean wait of 13.63 weeks in 1998.

Reducing Waiting Times

Comparison of means for overall waiting times demonstrated that clients were actually waiting longer to commence treatment in 1999 compared to 1998 data (23.56 weeks to 13.63 weeks respectively). Although, out of these, 53.4% of clients were taken on for

treatment within 12 weeks of referral, with the other 75% having commenced treatment within 24 weeks of referral. Examination of mean wait times for 1999 data also revealed longer waiting times at Clinics A and B compared to Clinic C (although as noted earlier Clinic C reflected fewer referrals). The increase in overall waiting times in comparison to 1998 data could be a result in part of adjustment to a new system and it may be that the waiting times may begin to improve, with more clients commencing treatment within 12 weeks or fewer. Waiting times at individual clinics may suggest the need for an increase in resources at those clinics that hold the longest waiting times (namely Clinics A and B) or an increase in the sharing of resources between sites.

Filtering of Referrals

The triage system appeared to be partially successful at filtering referrals. Following assessment, 14.4% of referrals were discharged and a further 52% of referrals were recommended for one of the other services within the department, leaving only 32.2% allocated to clinical psychology. However, although 33.9% of referrals were allocated to CBT specialists, 29 of these 41 referrals (71%) were actually taken on by clinical psychology. Although it was appropriate clinically for a clinical psychologist to treat these patients, the aim of maximising the Level 3 skills of the psychologist was not being met. It can be assumed that this was increasing overall waiting times for those patients placed on the clinical psychology waiting list and thereby reduced the efficiency of the assessment triage system as a waiting list initiative. This would perhaps suggest the need for an increase in resources to work at Level 2. This could be in the form of an increase in clinical psychologists or CBT specialists.

Prioritisation of Referrals

The use of the assessment clinic enabled referrals to be prioritised. However, although those deemed high priority were seen more quickly they were still waiting an average of 17.1 weeks after assessment, with medium priority patients waiting 26.0 weeks. At the time of this study, allocation of priority was based on clinical judgement and no specific guidelines existed within the department to guide this. It may be useful to operationalise the terms for allocation to specific priority categories. In addition, only 2 priority categories were used (high and routine). It may be beneficial to allocate referrals by high, medium and routine, retaining the allocation of high priority only for those needing to be seen urgently.

CONCLUSIONS AND RECOMMENDATIONS FOR FUTURE RESEARCH

It would seem that the triage system was successful in meeting the majority of its original aims, particularly in meeting the Professional Practice Guidelines in providing quicker access to psychology services. However, improvements could be made to increase its efficiency. In particular, results would suggest the need for an increase in targeted resources, specifically with regards to CBT Specialists, and re-operationalisation of priority categories.

Further research could examine client and referrers' perception of the system, particularly with regards to satisfaction (McAuliffe & MacLachlan 1992; Geekie 1995), prevention of escalation of problems (Herlihy *et al.* 1998) and impact of advice and self-help literature provided at assessment (Stevenson *et al.* 1997). In addition, future analysis of the impact of the assessment triage system on DNA rates would be useful.

Current records did not provide the data to conduct this investigation and so future records of DNA rates should be routinely recorded.

RECOMMENDATIONS FOR SERVICE

- Increase in resources to operate at Level 2 skills (CBT Specialists or Clinical Psychologists) to maximise appropriate use of skill mix of department
- Increase in resources for Clinical Psychology at Clinic A and Clinic B
- Operationalise decision criteria for priority categories and introduce high, medium and routine categories
- Record DNA information

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Chapter 2: Major Research Project Literature Review

A Systematic Review of Quality of Life in Children and Adolescents with Epilepsy

How well are we defining the components?

Major Research Project Literature Review submitted in partial fulfilment of the
requirements for the degree of Doctor of Clinical Psychology

Prepared in accordance with guidelines for contributors to *Seizure* (see Appendix 2.1)

Keywords: Systematic Review, Quality of Life, Adolescent, Child, Epilepsy

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ABSTRACT

A sizeable literature focusing on QOL in children and adolescents with epilepsy has been produced over the last few years. However, relatively little emphasis has been placed on defining these issues from direct exploration of children's and adolescents' views. Qualitative methodologies are proposed in this review as an appropriate means of eliciting such information.

This review systematically investigated the extent to which studies of QOL in children and adolescents with epilepsy have used recognised qualitative methodology. Articles for inclusion were identified by searching the term "epilepsy", combined with "adolescent(s) and/or child(ren)" and "psychosocial and/or quality of life". Selected articles were reviewed and rated using CASP guidelines for qualitative research by 2 independent raters.

Seventeen studies were retrieved through literature search. Of these 6 used some form of qualitative methodology either individually or combined with quantitative methods. However, only 1 study met quality criteria for selection in this systematic review.

A summary of both selected and excluded studies is presented and methodological limitations discussed. Recommendations for appropriate methodology for investigation of QOL issues in children and adolescents are given.

INTRODUCTION

Quality of Life (QOL) has been defined as the “individual’s evaluation of the quality of their lives as it relates to their own personal expectations”¹. When an individual has a chronic condition, for which a total cure is not expected, QOL is considered an important outcome measure for healthcare.

Epilepsy can have a profound impact on psychosocial function and QOL. Studies have shown that epilepsy impedes the development of independence and impairs social function, peer relationships, self esteem, mood and cognition²⁻⁸. For children and adolescents, these issues can be particularly challenging, as the development of a healthy self-identity is recognised as a core developmental task and is directly influenced by the development of successful peer relationships and appropriate levels of autonomy⁹⁻¹¹. Problems with this development have been found to result in depersonalisation and can subsequently lead to low self-esteem, depression, loneliness, anxiety and behavioural problems^{2-8,12}. As a result, service providers have become increasingly aware that traditional measures of outcome focusing solely on medical aspects, such as seizure frequency, are not adequate. Subsequently, they have begun to acknowledge that the inclusion of psychosocial factors is vital in providing a holistic approach to care and management^{13,14}.

A sizeable literature focusing on QOL in children and adolescents with epilepsy has been produced over the last few years^{5,15-28}. However, relatively little emphasis has been placed on defining these issues from direct exploration of children’s and adolescents’ views. As stated above QOL is the “individual’s evaluation” of the quality of their lives

in relation to “personal” expectations. It is therefore essential that research studies investigating QOL in children and adolescents focus on direct descriptions and definitions.

Several scales have been developed to investigate QOL and associated risk factors in children and adolescents with epilepsy^{3,29-33}. A recent editorial emphasised that the content of a measurement scale is only likely to be valid if QOL components were derived from a sample of the population in which the tool is to be used³⁴. Whilst some of these scales have attempted to involve adolescents and children in the development of items, several methodological issues can be identified which question the validity of the content of all of the above scales.

Firstly, many of these scales have been adapted from those previously designed for use with adults. It can be argued that adaptation of adult scales is inappropriate as this fails to acknowledge important aspects of child and adolescent development and functioning. Secondly, some of these studies have investigated QOL in epilepsy by using generic child based scales. This is likely to undermine the impact of specific epilepsy-related variables, such as seizures and medication, on QOL. Thirdly, none of these scales has content based solely on the personal views of affected individuals. The majority has either combined personal views of QOL with proxy views or used proxy perspectives of QOL alone. Finally, several of these scales are completed by a proxy informant (parent or clinician) rather than the individual themselves.

Indeed, the majority of the above studies have relied on proxy informants to define QOL in children and adolescents. Proxy reports have been demonstrated to lack validity and it

has been noted that the assessment of QOL varies depending on the perspective of the observer³⁵⁻³⁷. Whilst parent and clinician viewpoints are valid in themselves, they are not valid substitutes for the personal perspective and should not be considered as such. Therefore, in proxy rated scales, not only may the content of the scale be questionable, but also the QOL ratings are invalid as representations of the personal perspective.

Qualitative research provides a solution to the difficulties described above, by supplying a methodology that was explicitly developed to investigate experiences from the perspective of affected individuals^{38,39}. Indeed, it has been stated that qualitative research is in fact the most suitable methodology for exploratory research in QOL, where the aim is identification and description of components⁴⁰.

The application of qualitative methodology is becoming more common in health related research. Data collection techniques are flexible enough to be adapted to meet the needs of different target groups and therefore negate the need for proxy informants.. A recent review of the use of qualitative methodologies to investigate QOL in children and adolescents, in issues such as asthma, smoking, teenage pregnancy and AIDS, concluded that these approaches are valid and reliable for eliciting information from these age groups⁴¹. Furthermore, the approach is “bottom-up” and enables definition of QOL as described directly from individuals, rather than from adaptations of QOL models devised for other groups. Therefore, the validity of identified QOL components is increased, firstly by defining issues from direct exploration and secondly, through the use of a “bottom-up” approach. In addition, qualitative methodologies facilitate in-depth exploration of issues that would not be possible through quantitative methods alone.

Whilst it is important to explore QOL in children and adolescents with epilepsy, we must be able to conclude that research findings are valid and reliable. Questions can be raised regarding the validity of the findings of any study investigating QOL in children or adolescents which does not elicit views directly from affected individuals or use measures derived directly from their views. As argued, qualitative methodologies are particularly suitable for this type of exploration.

Therefore, this review aimed to systematically investigate the extent to which studies of QOL in children and adolescents with epilepsy have used recognised qualitative methodology. Studies were assessed using quality criteria rating sheets defined by CASP (Critical Appraisal Skills Programme) Guidelines for qualitative research⁴² (see Appendix 2.2). Emphasis was also given to the composition of the study sample, with reference to the use of proxy informants and the appropriateness of the age range employed. Studies investigating QOL in children and adolescents that did not utilise qualitative techniques were discussed with reference to their limitations.

METHODS

Search Strategy

Articles for inclusion in this review were identified by searching the term “epilepsy”, combined with “adolescent(s) and/or child(ren)” and “psychosocial and/or quality of life” on the electronic databases PsychINFO (from 1984 to present); MEDLINE (from 1990 to present); EMBASE (from 1988 to present); Cochrane Library; and CINAHL (from 1982 to present). Further articles were identified through visual search of the

bibliographies of retrieved studies and hand searches of key specialist journals: *Epilepsia*, *Seizure* and *Developmental Medicine and Child Neurology*.

Article Inclusion and Exclusion Criteria

Articles were included in the review if they demonstrated the use of sound qualitative methodology (as defined by CASP Guidelines), focused on children or adolescents (5-18 years) with epilepsy, and addressed issues pertaining to QOL or psychosocial function.

Data Abstraction

The data abstracted from each article included the methodology used (qualitative, quantitative or combined); the type of informant (self-rated, proxy-rated or mixed); sample size, sample age range, exclusion criteria, measurements used and the issues identified relating to the impact of epilepsy on QOL / psychosocial function. These details are summarised in Tables 1-3.

Study Quality Criteria

Articles were assessed by 2 independent raters using rating scales based on CASP Guidelines for quality of qualitative research (see Appendix 2.2). These require the demonstration of:

1. an appropriate sampling strategy (e.g. details regarding how and where participants were selected; details provided on non-participants; and consideration of saturation of data in relation to sampling size i.e. ensuring theoretical saturation is obtained, where no additional data is gained by further collection, to increase reliability of findings).

2. rigorous data analysis (e.g. explanation of how analysis was carried out; attempts to ensure the reliability of data by methods such as feeding back results to participants, repetition of analysis by more than one researcher and use of triangulation methods i.e. the combination of methods to take into account as many aspects of a problem as possible)
3. accurate interpretation of data (provision of adequate quotes to support findings)
4. a clear statement of the aims of the research with consideration of qualitative methodology as the most appropriate approach
5. transferability of results (i.e. relevance of study to the wider population beyond the study sample, which is increased by use of methods to increase validity and reliability of results and provision of details of participants and non-participants)

As criteria 1 – 3 related to issues of reliability and validity of findings, it was determined that studies must meet a minimum of these 3 criteria to be selected for inclusion in this review.

RESULTS

Seventeen studies focusing on the investigation of QOL in children or adolescents with epilepsy were retrieved through literature search. Out of these 6 used some form of qualitative methodology either individually or combined with quantitative methods. However, only 1 of these met quality criteria for inclusion in this systematic review.

Summaries and discussion of retrieved studies will be presented under 3 headings: Excluded Studies A (studies in which qualitative methodology was not used), Excluded

Studies B (studies which used qualitative methodology but did not meet criteria for inclusion in the review) and Included Studies (studies which met criteria for inclusion). A brief discussion of the limitations of the excluded studies will be presented first, followed by discussion of selected studies. The reader is referred to Tables 1-3 for more detailed description of individual studies.

Insert Table 1 here

EXCLUDED STUDIES A

Eleven studies were identified through the literature search that focused on children or adolescents with epilepsy, and addressed QOL or psychosocial function but did not use qualitative methodology, and therefore could not be included in the review.

All of these 11 studies used questionnaire designs. Of these, 2 administered questionnaires to young people only^{17,24}; 3 combined the results of questionnaires completed by both young people and proxies^{15,21,22}; and 6 used questionnaires administered to proxies only^{5,20,23,27,29,32}. The majority of these studies investigated correlates of QOL, such as seizure type and frequency. Readers are referred to Table 1 for details of studies.

As discussed previously, proxy reports of QOL are not valid reports of personal representations. However, even in the studies which used self-rated questionnaires^{17,24} criticisms can be made regarding the use of a very small sample size (n=31), 18 of whom

were seizure free²⁴ and the use of a scale which was developed using proxy views of QOL¹⁷.

Further criticisms of the above studies relate to the use of generic scales^{15,20,22}, inadequate exclusion criteria, which did not consider the impact of co-morbid learning disabilities^{5,22} and use of a wide age range³².

Insert Table 2 here

EXCLUDED STUDIES B

Five studies were identified through the literature search which used qualitative techniques either alone or combined with quantitative methods but did not demonstrate sufficient quality criteria, or provide sufficient information for assessment of qualitative techniques, to be included in this review. A brief summary of these studies will be presented under the following 2 headings. More details of these studies can be found in Table 2.

Combined Qualitative and Quantitative Methodology studies

Four studies used a combination of qualitative and quantitative methods to explore QOL^{3,16,30,33}. One to these studies¹⁶ described the results of a free text section incorporated into a 30-item questionnaire, containing items on seizure variables; medication; attitudes towards seizures; medication and communication with doctors; and

the perceived effect of epilepsy on activities, relationships, school life and personal self-esteem. However, although the study implied the use of qualitative methodology, there was no evidence that the data gathered were analysed using recognised qualitative techniques and therefore the study did not meet any of the criteria for inclusion. Given the large number of participants (896 children, 400 of whom completed the free text section), appropriate analysis of qualitative aspects of the study could have led to rich and descriptive information to complement the data obtained from the overall questionnaire study.

The remaining 3 studies used qualitative methodology using focus groups^{30,33} or one-to-one interviews³ to develop specific measures of QOL for children and adolescents with epilepsy. However, insufficient details of the qualitative aspects of these studies were provided to assess quality using the above criteria. Furthermore, no examples of quotes generated from focus groups were presented. In addition, whilst it is commendable that these studies used qualitative methods to elicit information about QOL directly from children and adolescents, criticisms can be made regarding the application of these methods in 2 of the studies^{30,33}. In one study³³ focus groups were composed of both children and parents. This is likely to have biased results, as children may not have felt they could be open. Furthermore, it is possible that a greater percentage of parent views may simply have been expressed because children felt intimidated by the process. In addition, it is not clear whether the groups combined children across all ages or whether any attempts were made to combine particular age groups. Unfortunately, the authors do not provide any information regarding these issues. Similar criticisms can be made with regards to the other study³³. Whilst focus groups were composed of just adolescents in this study, topics for discussion were selected from the viewpoint of clinicians and

previous literature, rather than items generated spontaneously by the adolescents. Again, this is likely to have reduced the validity of the content of the scale, as it may not be a valid representation of the most significant issues related to QOL for young people with epilepsy.

Furthermore, in all 3 studies, data from these methods were combined with expert knowledge, literature review and adaptation of existing QOL scales^{30,33}. As argued above, this combination of data is likely to have reduced the validity of QOL as it would have been described by the individuals only. In addition, 2 of the 3 scales are completed by a mixture of both self-ratings and proxy-ratings^{3,30} and the other is completed by proxy alone³³. Again, this raises questions about the validity of the QOL measurements made by these scales.

As all 3 of these studies investigated QOL in epilepsy from the perspective of both adolescents and their carers, it would have been of benefit for both perspectives to be presented separately. As discussed previously, proxy perspectives are valid provided they are described in this way and not used as substitutes for the personal perspective. An analysis of the inter-relationship between the responses of young people and their parents could have contributed to our understanding of QOL for this group of people. However, none of the studies conducted such an analysis.

Qualitative Methodology Only studies

One study was identified which used one-to-one interviews to investigate the QOL of young people with epilepsy but did not meet criteria for inclusion²⁸. The study met

criterion 4 but did not provide sufficient information to meet criterion 1 and did not demonstrate sufficient rigor or data to meet criteria 2, 3 or 5. In particular, results were not fed back to participants and no attempt was made to validate themes by independent analysis. In addition, a wide age range was used, with subjects aged between 13 and 25 years of age.

Nevertheless, results from interviews with 24 young people attending outpatient units demonstrated that the majority of the sample reported having been the victims of prejudice, especially bullying and teasing whilst at secondary school. Most reported feelings of apprehension about telling others about their epilepsy, especially members of the opposite sex and potential employers. Most participants described supportive, positive relationships with families and close friends and parental overprotection was rarely reported as a significant problem. The study concluded, on the basis of a measure of coping which unfortunately was not described, that the majority of the sample was coping well with their condition.

Insert Table 3 here

INCLUDED STUDIES

Only 1 study met criteria for inclusion in this systematic review. The study was presented in 2 separate papers, the first presenting the results of the study²⁶ and the other describing the research process²⁵. For the purposes of clarity the following discussion considers the papers jointly. Details of the study are summarised in Table 3.

The study met all the criteria 1-5. A qualitative focus group methodology was used to explore the health-related quality of life (HRQOL) in pre-adolescent children aged between 6 years and 10 years 4 months. Children and their parents were involved in identifying QOL components, however parent and child groups were conducted separately. A clear and justifiable sampling strategy was demonstrated as well as clearly described data collection and rigorous data analysis, using techniques of feeding back to participants, triangulation and analysis by more than one researcher. Data were well presented and it was clear which selected quotes had come from children and which had come from adults. Furthermore, appropriate and explicit inclusion and exclusion criteria were applied, with children who had major co-morbid conditions, such as learning disabilities or who were unable to function in mainstream schools, being excluded.

A further strength of the study was the adaptation of techniques to the target population. “Child life specialists” were employed as co-planners, moderators and co-designers of the study. Several techniques were used to promote engagement and encourage elicitation of discussion from the children. Examples of techniques were drawing environmental maps (i.e. a drawing of the most important places in the child’s life, which the child then used to describe experiences they had had in each place) and using playdough to express emotions about life with epilepsy.

Separate focus groups were conducted for children and parents. In total 9 focus groups, comprising a total of 29 children, and 17 parent groups, totalling 42 parents, were run. Results of data analysis identified 5 dimensions of QOL, which were described by the authors as follows:

1. the experience of epilepsy (which represented the entire context, setting and situation of coming to terms with and understanding epilepsy);
2. life fulfilment and time use (which concerned practical issues in day-to-day activities affected by epilepsy);
3. social issues (which included internal and external social consequences of epilepsy);
4. impact of epilepsy (which related to personal and psychological impacts); and
5. attribution (which included explanatory issues, how much and what burdens and concerns were truly related to epilepsy).

The authors noted that the theme of “attribution” was only identified by parents. The main distresses experienced by children were described as relating to daily life restrictions, loss of independence, perception and treatment by peers, unease about how seizures would be handled by outsiders and concern about the adverse effects of medication. Results from both parent and child groups were combined in the analysis. However, as mentioned earlier, quotes were identified separately.

The above study provides an example of the appropriate application of qualitative methodologies for investigating QOL in children. However, a few criticisms can be made about the study. One is the failure to consider developmental factors in relation to QOL. Children had been stratified into focus groups by age (6-9 year olds and 10-12 year olds) and in terms of duration of epilepsy (under and over 12 months). However, data from these groups were not analysed to report the impact of these variables on content of themes. A secondary analysis comparing these data may have provided useful information on the association between both age and duration of illness on QOL.

SUMMARY OF RESULTS

Seventeen studies were identified through literature search that focused on the investigation of QOL in children or adolescents with epilepsy. However, only 6 studies investigated QOL using some form of qualitative methodology that focused on the direct views of adolescents, either individually or combined with quantitative methods. Out of these, only 1 study met quality criteria for inclusion in this systematic review.

DISCUSSION

This review has demonstrated that in spite of the sizeable literature on QOL in children and adolescents with epilepsy relatively few studies have investigated QOL through direct exploration of children' and adolescents' views. Out of the 17 studies mentioned in this review, only 5 considered the views of the affected child or adolescent directly and independently from proxies^{16,17,24-26,28}. Furthermore, methodological limitations have been highlighted in 4 of these, related to sample size²⁴; appropriateness of QOL measurement¹⁷, inadequate presentation of data to support findings¹⁶ and inadequate methods to increase validity of results²⁸. The remaining 13 studies used proxy informants or combined self-reports with proxy-reports (see Tables 1 and 2).

QOL is the "individual's evaluation" of the quality of their lives in relation to "personal" expectations. It is therefore essential that research studies investigating QOL in children and adolescents focus on the direct descriptions and definitions of the individuals themselves. It can not be reliably concluded that research that does not use direct

approaches, or which implements scales developed from proxy investigation of QOL issues, is presenting reliable and valid representations of QOL.

Studies using qualitative approaches to directly investigate QOL in children and adolescents with epilepsy have described restrictions of activities^{25,26}, loss of independence^{25,26}, difficulties with peer relationships, particularly unease about telling others^{25,26,28} and experiences of bullying and prejudice²⁸, although, in general, positive relationships with families were reported²⁸. Further concerns were the adverse effects of medication^{16,25,26} and fear of seizures^{16,28}. It is interesting to note that studies using proxy informants highlighted issues such as educational attainment and cognitive difficulties^{3,21,30,32,33}. However, as can be seen, these were not identified as significant factors in studies that focused solely on the views of the young person^{25,26,28}. This perhaps reflects the different perspectives held by proxy informants. Furthermore, limitations have been highlighted with regards to the development of current QOL measurements for children and adolescents with epilepsy^{3,30,33}. As argued previously, studies using scales developed from the QOL definitions of proxies are not necessarily measuring the most important aspects for young people with epilepsy.

In relation to this point, the majority of the studies that used quantitative methodology, administered questionnaires to examine the correlates of QOL in children and adolescents with epilepsy. Results of these studies can be found in Table 1. Although a quantitative methodology is appropriate for such investigation, studies must ensure that the original content of these questionnaires is valid and that items reliably measure QOL as defined by individuals themselves. A useful approach may be to use a combination of qualitative and quantitative methodology in the investigation of QOL in children and

adolescents, as has been used with other client groups⁴³. Qualitative approaches can be used to generate meaningful and valid data that can be used to develop QOL measures. This has the added advantage of being able to use language used by the target group for items in the scale. Once developed, quantitative studies can be conducted using these scales to investigate correlates of QOL in epilepsy, such as seizure frequency and timing of diagnosis.

A final point is that, despite childhood and adolescence incorporating periods of great change, none of the 17 studies explicitly considered the impact of developmental aspects of function in relation to QOL in epilepsy. Analysis of such factors in relation to QOL could contribute greatly to our understanding of QOL in children and adolescents with epilepsy.

CONCLUSIONS

As stated previously Quality of Life (QOL) has been defined as “the individual’s evaluation of the quality of their lives as it relates to their own personal expectations”¹. Proxy reports are not valid substitutes for personal perceptions of QOL³⁵⁻³⁷. However, this study has demonstrated that the majority of studies that have investigated QOL in children and adolescents have used proxy reports, either in the definition of QOL or in the development of scales to measure QOL in young people with epilepsy. Inevitably, this raises questions regarding the validity of the findings of these studies. There is a need for studies that focus directly on the views of children and adolescents with epilepsy. Well designed qualitative studies, such as that conducted by Ronen et al^{25,26}, provide an appropriate and valid methodology for such exploration.

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TABLE 1: Excluded Studies A (studies in which qualitative methodology was not used)

Author(s)	Year	Methodology	Measures Used	Sample Informant	Sample Size	Sample Age Range	Exclusion Criteria	Results
Devinsky et al	1999	Quantitative	QOLIE-AD-48 ³⁰	Self	197	11-17 years	Co-morbidity NOT co-morbid LD	Older adolescents (aged between 14 and 17 years); those with more severe epilepsy; more symptoms of neurotoxicity; and lower socioeconomic status were more likely to report poor overall HRQOL. Older adolescents more likely to perceive a greater negative impact on life and general health, and had more negative attitudes toward epilepsy than younger.
Norby et al	1999	Quantitative	39 bipolar Visual Analogue Scale Questionnaire	Self	31 with epilepsy 342 controls	9-13 years	Co-morbidity	No significant difference between children with epilepsy and controls. No significant difference between gender, with the exception of vitality, where boys scored higher than girls. Boys also presented with higher self-esteem, although girls had higher scores for elation.
Austin et al	1996	Quantitative (longitudinal)	CSCS ⁴⁴ CBCL ⁴⁵⁻⁴⁷ CATIS ⁴⁸ APGAR ⁴⁹	Mixed	117 with epilepsy 111 with asthma	12-16 years (8-12 years at recruit)	Co-morbidity (but not clear if same at follow up)	Adolescents with active epilepsy had lowest levels of QOL in comparison with adolescents with asthma or inactive epilepsy. Even those with inactive epilepsy demonstrated lower levels of QOL compared with adolescents with inactive asthma in relation to several domains of QOL. Severe seizures and female sex were also found to be associated with more problems.
Hoare & Mann	1994	Quantitative	SPPC ³⁰ CBCL ⁴⁵⁻⁴⁷	Mixed	62 with epilepsy 91 with diabetes	8-15 years	None reported	Children with epilepsy found to be consistently more behaviourally disturbed and demonstrated lower self-esteem than children with diabetes. Long duration of illness was found to be most consistently associated with poor behavioural adjustment in both groups.

TABLE 1: Excluded Studies A (continued 2 of 4)

Author(s)	Year	Methodology	Measures Used	Sample Informant	Sample Size	Sample Age Range	Exclusion Criteria	Results
Hanai	1996	Quantitative	Survey	Mixed	334 families and teachers	School age (not specified)	None	<p>Major family concerns were “the future” and “seizures”. More concern for “forget to take medicine” and “school records” for those in mainstream education.</p> <p>More concern for “health conditions other than seizures” and “relationships with siblings” in those not in mainstream education. Main concerns of children were “seizures” and “medication”. Over 50% of parents of both groups felt “no special” concerns regarding epilepsy but 29% rated “taking medicine every day” and 29% recorded “onset of seizures” as particular concerns. At school 67% of families felt “no special” concerns but 21% felt was difficulty “keeping up with learning”. Some concern “prejudices and discrimination may occur” at school, by both families and teachers, “affecting the child’s future”; “physical education and participation in school event”; “privacy” and “confidentiality is insufficient”. 55% of teachers and 60% of families felt “if the seizures can be controlled, children should participate in all activities under individual considerations”. However, a large number of teachers felt the “even if seizures can be controlled, prohibition is necessary for some sports such as swimming”.</p>

TABLE 1: Excluded Studies A (continued 3 of 4)

Author(s)	Year	Methodology	Measures Used	Sample Informant	Sample Size	Sample Age Range	Exclusion Criteria	Results
Sabaz et al	2001	Quantitative	QOLCE ³³ CBCL ⁴⁵⁻⁴⁷ CHQ-parent version ⁵¹	Proxy	102 families	4-18 years	Severe- Profound LD	Children with refractory epilepsy without learning disabilities were more likely to have emotional, behavioural and cognitive problems and be less competent in socialising and school performance. Overall lower level of QOL in children with learning disabilities and epilepsy than in those without co-morbid learning disabilities, independent of seizure frequency or number of medications. Children with learning disabilities had reduced levels of physical function, cognition, emotional well-being, social function and behaviour.
Camfield et al	2001	Quantitative	IPES ²⁹	Proxy	97 mothers	12-16 years	Co-morbidity	Children with IPES scores above the median had parents who were more stressed; more respectful siblings; lower self-esteem; and experienced more emotional problems. The total impact on child and family life was associated with seizure frequency, total number of medications, number of visits to a physician in the previous year and number of nights spent in hospital for neurological reasons.
Hoare	1993	Quantitative	Modified IES ⁵² Resources & Stress ^{53,54}	Proxy	108 mothers	5-15 years	None	Epilepsy has the greatest impact on children with additional disabilities impacting on the managements of epilepsy, including side effects from medications; the child's adjustment and development; and restrictions on the family. Early onset intractable epilepsy accompanied by additional disabilities was shown to have a widespread adverse effect on the child and family's quality of life and overall adjustment.

TABLE 1: Excluded Studies A (continued 4 of 4)

Author(s)	Year	Methodology	Measures Used	Sample Informant	Sample Size	Sample Age Range	Exclusion Criteria	Results
Hoare & Russell	1995	Quantitative	Impact of Childhood Illness Scale ³²	Proxy	21 parents	6-17 years	None reported	The most common concerns reported by parents were injury (n=7); alertness (n=5); moodiness (n=5); teasing (n=5); friendships (n=5); maths or reading (n=12); intelligence (n=8); medication (n=14); independence (n=5); care skills (n=6); problems explaining the illness to the child (n=9); and problems with discipline (n=6). The parents of children with poorly controlled epilepsy had more concerns.
Hoare et al	2000	Quantitative	Impact of Childhood Illness Scale ³²	Proxy	102 parents of children with epilepsy 148 with diabetes	9.66 years (mean epilepsy) 12 years (mean diabetes)	None reported	Children with epilepsy had poorer QOL than those with diabetes with the main effect being the impact on the parents and the family. Impact on development and impact on health were also found in the epilepsy group but not in the diabetes group.
Dorenbaum et al	1985	Quantitative	CBCL ⁴³⁻⁴⁷	Proxy	38 mothers	6-16 years	None	Highest risk for maladjustment for children with epilepsy was in social functioning with scores for overall social functioning and social competence falling well below cut-off in comparison to norms. With younger children no particular area of social maladjustment was represented, however with adolescents these difficulties were particularly apparent in terms of school competence.

TABLE 2: Excluded Studies B (Studies which used qualitative methodology but did not meet criteria for inclusion in the review)

Author(s)	Year	Methodology	Measures Used	Sample Informant	Sample Size	Sample Age Range	Exclusion Criteria	Summary of Results
Wilde & Haslam	1996	Qualitative	Interviews	Self	24	13-25 years	Co-morbidity	Majority of sample reported prejudice, especially bullying and teasing whilst at secondary school. Many participants were critical of the medical profession and support services. Most reported feelings of apprehension about telling others about their epilepsy, especially members of the opposite sex and potential employers. Most described supportive, positive relationships with families and close friends. Parental overprotection was rarely reported as a significant problem.
Brown	1994	Qualitative / Quantitative combined	Blanket Survey Analysis of free text	Self	896 400 completed free text	6-18 years	None reported	Results from questionnaire: 50% reported seizures made them feel helpless, scared, frustrated or different from others; 41% described feeling panicky about seizures; 33% felt embarrassed and 33% felt angry about seizures; 42% didn't mind seizures; 42% felt medication didn't work but 82% reported taking medication regularly; 60% felt medication caused tiredness; over 50% believed medication led to poor concentration; 36% said doctors had never explained epilepsy to them and of those who had received information, 51% reported they did not understand what they had been told. Comments in the free text section were described as having focused on the same issues described above.

TABLE 2: Excluded Studies B (continued 2 of 2)

Author(s)	Year	Methodology	Measures Used	Sample Informant	Sample Size	Sample Age Range	Exclusion Criteria	Summary of Results
Sabaz et al	2000	Qualitative / Quantitative combined (design stage)	Focus Groups	Mixed	24 children + parents (8 groups) (<i>pilot study</i>)	4-18 years	Progressive Neurological Disorder	Scale was found to be a reliable and valid measure, sensitive to differences in epilepsy.
		Quantitative (validation stage)	QOLCE	Proxy	63 parents	4-18 years	Visual/Hearing Impairment Epilepsy Surgery NOT co-morbid LD	HRQOL was shown to reduce with increase in seizure severity, independent of age, gender, age at onset or IQ.
Cramer et al	1999	Qualitative / Quantitative combined (design stage)	Focus Groups	Mixed	5-10 adolescents (<i>pilot study</i>)	11-17 years	Co-morbid NOT co-morbid LD	Identified 8 sub-scales relating to quality of life: epilepsy impact; memory/concentration; attitudes towards epilepsy; physical functioning; stigma; social support; school behaviour and health perceptions.
		Quantitative (validation stage)	QOLIE-AD-48	Mixed	197 adolescents + parents	11-17 years	Co-morbid NOT co-morbid LD	
Batzel et al	1999	Qualitative / Quantitative combined	One-to-one Interviews	Mixed	n=not specified (<i>pilot study</i>) 120 adolescents + parents	12-19 years	None reported	139 items were identified with respect to adjustment in 8 psychosocial areas: 1. family background 2. emotional adjustment 3. interpersonal adjustment 4. school adjustment 5. vocational outlook 6. adjustment to seizures 7. medical management 8. antisocial activities.

TABLE 3: Included Studies

Author(s)	Year	Methodology	Measures Used	Sample Informant	Sample Size	Sample Age Range	Exclusion Criteria	Summary of Results
Ronen et al	1999 2001	Qualitative	Focus Groups	Self Proxy (results not combined)	29 children (9 groups) 42 parents (17 groups)	6-12 years	Co-morbidity	Identified five dimensions of quality of life: 1. the experience of epilepsy 2. life fulfilment and time use 3. social issues 4. impact of epilepsy 5. attribution (parents only) Main distresses experienced by children were described as relating to daily life restrictions, loss of independence, perception and treatment by peers, unease about how seizures would be handled by outsiders and concern about the adverse effects of medication.

Chapter 3: Proposal for Major Research Paper

**Quality of Life in Adolescents with Epilepsy: A Qualitative
Investigation using Focus Group Methods**

Major Research Proposal submitted in partial fulfilment of the requirements for the
degree of Doctor of Clinical Psychology

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Prepared in accordance with guidelines (see Appendix 3.1)

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SUMMARY

Having a chronic medical disorder such as epilepsy can have a profound impact on quality of life (QOL) and psychosocial development, impeding the development of independence and impairing social function, peer relationships, self esteem, mood and cognition (Batzel *et al.* 1991; Westbrook *et al.* 1992; Hoare 1993; Hoare & Kerley 1991). An exploration of QOL in adolescents with epilepsy will be carried out using recognised qualitative approaches. Focus groups will be conducted to explore themes. This approach will enrich the information gathered from previous research, which has tended to focus on proxy reports of QOL or merged the issues relevant to clients, carers and clinicians. The study will provide a framework for understanding the impact of epilepsy on psychosocial function throughout adolescence.

INTRODUCTION

One of the core developmental tasks of adolescence is the development of a sense of identity (Carr 1999). Having a chronic medical disorder such as epilepsy can have a profound impact on such development resulting in stigmatisation, impeding the development of independence and impairing social function, peer relationships, self esteem, mood and cognition (Batzel *et al.* 1991; Westbrook *et al.* 1992; Hoare 1993; Hoare & Kerley 1991).

Effective management of epilepsy in adolescents requires an understanding of the social world and inner experiences of the adolescent and the impact of epilepsy upon these. Clinicians have become increasingly aware that traditional measures of outcome

focusing solely on medical aspects, such as seizure frequency, are not adequate and inclusion of psychosocial factors is vital in providing a holistic approach to care and management (Spieth & Harris 1996). However, investigation of such issues is complicated by the wide range of development across the 12 to 17 year old age group, the changes associated with developmental progress and the use of proxy informants in the exploration of issues.

Several scales have been developed to measure psychosocial difficulties for adolescents with epilepsy. The Quality of Life in Epilepsy Inventory for Adolescents (QOLIE-AD-48) (Cramer *et al.* 1999) and the Adolescent Psychosocial Seizure Inventory (APSI) (Batzel *et al.* 1991) are two examples of these. These instruments contribute to the awareness of and communication about the impact of epilepsy on the life of the adolescent. However there are some limitations in the construction of these scales.

Whilst focus groups were conducted with adolescents in the construction of the QOLIE-AD-48, these were structured by domains selected from the viewpoint of clinicians and previous literature, rather than items generated spontaneously by the adolescents themselves. As a result, it could be argued that the issues raised may not have been those foremost in the adolescents' experiences or concerns. Furthermore, data analysis of items for the final inventory combined the concerns of adolescents, their carers, their clinicians and topics from previous literature and existing scales. It is possible that this could have resulted in the most pertinent views of adolescents being overshadowed by more consistent and congruent concerns raised by others involved in their care. Similarly, items for the APSI were derived from previous literature and both adolescents and parents were asked to rate the presence or absence of factors from this pre-generated list. Items for the final scale were selected from a combined summary on the basis of

both adolescent and parent ratings. In addition, neither scale made an attempt to consider the issues relevant at different developmental stages across this age range, merging the views of 11-17 year olds in the QOLIE-AD-48 and up to 19 years of age in the APSI. It can be hypothesised that focus and content of concerns are likely to change during adolescence, as the young person approaches adulthood.

Whilst these scales have gone some way to enhancing the acknowledgement and understanding of issues, other than medical factors, important in the experience of an adolescent with epilepsy, a purely adolescent focused exploration of the issues pertinent to them would enrich this further. In addition, exploration of issues at different stages within adolescence would provide an understanding of any developmental difference in issues and the impact of epilepsy during adolescence.

Qualitative approaches are ideal for this type of exploration and would be valuable in enabling a more in-depth exploration of the impact of epilepsy on the lives, social world and inner experiences as described by adolescents themselves. This would help to generate a framework of the difficulties and concerns arising at different stages during adolescence for those with epilepsy and facilitate a more holistic approach to their clinical management.

AIMS AND HYPOTHESIS

Aims

This study aims to explore and describe the QOL of adolescents with epilepsy. This will provide a more in-depth and representative description of the experience of having epilepsy in adolescence than previous research. The study will also aim to present a framework for understanding and guiding assessment and intervention.

Objectives

- To describe QOL in adolescent with epilepsy
- To describe the relevant issues at different stages during adolescence, related to the experience of having epilepsy
- To present a framework for understanding the impact of epilepsy throughout adolescence

PLAN OF INVESTIGATION

Participants

Participants will be selected from tertiary epilepsy centres in Scotland: The Fraser of Allander Neurosciences Unit at the Royal Hospital for Sick Children, Glasgow and the Epilepsy Unit at the Western Infirmary, Glasgow. Additional participants may be recruited through Epilepsy Action Scotland.

Participants will be a) aged between 12 and 17 years old with b) a diagnosis of epilepsy. Participants with a) deteriorating neurological health and/or b) established non-epileptic seizure disorder as the primary clinical problem will be excluded from the study.

To enable a description of participants, information will be gathered on name, date of birth, gender, postcode, seizure type, seizure frequency, medication and date of diagnosis. All data will be entered onto a computerised database and anonymised to protect confidentiality and meet data protection requirements.

Measures

The primary method for obtaining data will be the focus group. Focus groups are composed of individuals who are unfamiliar to each other but who share characteristics relevant to the study. Groups are typically conducted several times with different individuals in order to identify trends in the perceptions and opinions expressed, which can later be revealed through systematic analysis. The focus group method assumes that an individual's attitudes and beliefs do not form in a vacuum and that people often need to listen to other's viewpoints in order to form their own. The method, therefore, provides a natural environment for an individual to reflect on and form their own opinions on topics that they may not have thought about in great detail beforehand (Marshall & Rossman 1995). Focused questions will be asked to encourage discussion of the topics the study aims to explore. Initially questions will remain open, encouraging participants to generate the items of most relevance to them. Later, if the issues identified in previous literature have not been discussed (e.g. Batzel *et al.* 1991; Westbrook *et al.* 1992; Hoare 1993; Hoare & Kerley 1991), these will be introduced to

facilitate discussion as to the relevance of these items to the group. All participants will be encouraged to contribute to the group.

Design and Procedure

Identified potential participants will be approached by post or by an Epilepsy Specialist Nurse, in person, at clinics for teenagers with epilepsy. Those interested in participating will be given written information (see Appendix 3.2) and invited to complete and return a consent form (see Appendix 3.3). Consent will be requested from one parent or guardian for participants under 16 years old and a separate information sheet (see Appendix 3.2) and consent form (see Appendix 3.3) will be provided to parents in this instance.

Focus groups will be run to gather data (Krueger 1994). Participants will be allocated to groups on the basis of age. Groups will be split into two main groups representing 12-14 year olds and 15-17 year olds. Groups will aim to have around 6 individuals in each and a minimum of 2 groups per age group will be run with further groups organised as necessary. Groups will last around 2 hours with breaks. Groups will be audio-taped and flip charts used to record and summarise data. The information gathered during groups will be supplemented at the end of the group by providing an opportunity for participants to write down any additional issues that they may have felt uncomfortable sharing within the group (see Appendix 3.4).

Data will be coded and categorised using transcription and thematic coding to identify central themes from focus groups and compare similarities and differences between groups (Flick 1998; Flick 1995a; Mayring 1983). QSR NUD*IST 4.0 for Microsoft

Windows, a computer package designed specifically for the analysis of qualitative data, will be used to facilitate this process (Microsoft 1997).

Once analysed results will be fed back to participants by post with the opportunity for comment on their relevance and any issues of importance the participants feel may have been missed.

Settings and Equipment

Focus groups will be held at sites in Glasgow, with travel expenses and refreshments provided for participants. Tape recorders and microphones will be used to audio-tape groups and flip charts will be used to provide a written summary of themes generated within groups.

Data Analysis

Data generated from focus groups will be transcribed using a word processing package. Data will be coded and categorised using thematic coding (Flick 1995; Mayring 1983). In this way, central themes from focus groups will be identified and similarities and differences between groups can be explored. QSR NUD*IST 4.0 for Microsoft Windows, a computer package designed specifically for the analysis of qualitative data, will be used to facilitate this process (Microsoft 1997). Information from each group will be coded to enable identification of source of each piece of data. In addition, data generated before and after introduction of themes from previous literature will be coded so as to be identifiable.

PRACTICAL APPLICATIONS

The study is intended to accurately describe the QOL of adolescents with epilepsy. This will fill an existing gap in the current research which has often attempted to define these issues using proxies or potentially confounding the validity of data gathered by merging concerns of clinicians/carers and adolescents. It is hoped this information can be used to provide a framework to enable a better understanding of QOL in this population. This will in turn promote a more holistic approach to the management of epilepsy in adolescents within a developmental perspective and will help to guide assessment and intervention.

TIMESCALES

Ethical approval, review of case notes, recruitment of subjects, development of protocol for focus groups and preparation of materials will be completed during July to October 2001. It is hoped that data collection will commence in November 2001 and continue for a period of 6 months. Data analysis will be conducted on an ongoing basis and write up is planned to commence in May 2002.

ETHICAL APPROVAL

Ethical approval will be sought from West Ethics Committee, North Glasgow University Hospital NHS Trust and the Yorkhill Research Ethics Committee, Yorkhill NHS Trust (see Appendix 3.5).

ADDENDUM

Prior to submission to ethics, amendments were made to the inclusion and exclusion criteria for participants (see below). Amendments were also made to the age range of the focus groups from 12-14 years old and 15-17 years old, respectively, to 12-13 years old, 14-15 years old and 16-18 years old. This was to enable better exploration of age related differences.

Amended Inclusion and Exclusion Criteria

Participants will be included if they are a) aged between 12 years 0 months and 18 years 0 months with b) a diagnosis of epilepsy of c) at least 6 months duration, d) had experienced at least one seizure in the past year and e) were able to participate verbally in a group. Participants with a) deteriorating neurological health, b) established non-epileptic seizure disorder as the primary clinical problem and/or c) significant learning difficulties will be excluded from the study.

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Chapter 4: Major Research Project Paper

Quality of Life and Psychosocial Development in Adolescents with Epilepsy: A Qualitative Investigation using Focus Group Methods

Major Research Project Paper submitted in partial fulfilment of the requirements for the
degree of Doctor of Clinical Psychology

Prepared in accordance with guidelines for contributors to *Seizure* (see Appendix 4.1)

Keywords: Adolescence, Epilepsy, Quality of Life, Focus Groups

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ABSTRACT

A focus group technique was used to describe the quality of life in adolescents with epilepsy. Twenty-two adolescents aged between 12 years 4 months and 18 years 0 months (6 males and 16 females) were stratified by age (12-13 years; 14-15 years and 16+ years) into 6 focus groups.

Data from focus groups were transcribed and QSR NUD*IST 4.0 for Microsoft Windows was used during analysis to generate central themes. Several procedures were undertaken to increase validity and reliability of findings. Analysis identified 2 main themes comprising a) issues related to adolescent development (identity formation) and b) epilepsy related variables, with 5 and 4 main sub-themes, respectively ('peer acceptance', 'development of autonomy', 'school related issues', 'epilepsy as part of me' and 'future; and 'medication issues', 'seizures', 'knowledge of epilepsy' and 'sense of uncertainty'). Main issues related to peer acceptance and development of autonomy. In contrast to previous studies, academic difficulties were not highlighted as an issue. No significant age-related differences in issues were identified.

A conceptual model representing the impact of epilepsy on QOL and psychosocial development in adolescence is presented. Clinical implications and suggestions for future research are reported. The study highlights the need for research to investigate QOL directly from adolescents and consider issues in the context of a developmental perspective. Qualitative methodologies are shown to be appropriate for using with adolescents and negate the need for the use proxy informants which previous studies have often used.

INTRODUCTION

The formation of a coherent sense of identity, separate from parents, is recognised as one of the core developmental tasks of adolescence^{1,2,3}. Adolescence is a time of significant transition in terms of biological changes, alteration in one's role and development of appropriate and healthy peer relationships. Successful completion of these tasks is vital for healthy identity formation (i.e. the process by which an individual develops a comfortable and coherent idea of who they are, which relies heavily on positive evaluation by both themselves and other people). Difficulties with identity formation directly impact on the adolescent's quality of life (QOL), i.e. "the individual's evaluation of the quality of their lives as it relates to their own personal expectations"⁴. Problems can result in depersonalisation and subsequently lead to low self-esteem, depression, loneliness, anxiety and behavioural problems⁵.

Studies have consistently shown that epilepsy impacts on both peer relationships and the development of independence and autonomy in children and adolescents⁶⁻²⁰. Risk factors for poor QOL in teenagers have been identified as aged between 14 and 17 years²¹; "active" epilepsy and greater seizure severity^{14,21,22,23}; higher numbers of medications^{21,24}; longer duration of illness²⁵ and co-morbid learning difficulties^{12,26}. Some studies have suggested that young people who are seizure free do not demonstrate poorer QOL than age matched controls²⁷. However, comparison of QOL in adolescents with epilepsy, diabetes and asthma, have found poorer QOL in those with epilepsy, irrespective of whether epilepsy was "active"^{22,28}.

Whilst providing useful information on the impact of epilepsy in adolescence, many of these studies can be criticised for the methodologies employed. As stated above QOL can be defined as “the individual’s evaluation of the quality of their lives as it relates to their own personal expectations”⁴. Therefore, research using methodology that focuses on adolescents’ descriptions and definitions is essential. However, most studies have relied on proxy informants or adapted pre-existing adult scales for use with young people¹⁵. Adaptation of adult scales is inappropriate because they fail to acknowledge important aspects of adolescent development and functioning. Similarly, proxy reports lack validity, because the assessment of QOL has been shown to vary depending on the perspective of the observer²⁹⁻³¹. Useful reviews of the methodological difficulties associated with assessment of QOL in children and adolescents with epilepsy have been published³²⁻³³. Furthermore, none of the studies has explicitly considered developmental issues, despite the significant transitions made as the adolescent progresses towards adulthood. In light of these shortcomings, there is a need for studies investigating QOL issues elicited directly from adolescents. Furthermore, there is a need to consider these issues within a developmental perspective.

Qualitative research provides an effective methodology for investigating experiences from the perspective of the individuals³⁴⁻³⁶. Techniques can be adapted to meet the needs of the target client group, thereby overcoming many of the methodological issues mentioned above. Furthermore, the data generated are rich and meaningful and provide a more in-depth exploration of issues than can be provided using quantitative methods. The “bottom-up” perspective of the qualitative approach enables definition of the issues as described from a personal perspective, rather than using predetermined topics based on QOL models derived from other groups. Consequently, the data generated can be

used effectively to provide new information, develop and/or revise existing frameworks and generate hypotheses for future exploration. A recent review of the use of qualitative methodologies to investigate QOL in children and adolescents, in issues such as asthma, smoking, teenage pregnancy and AIDS, concluded that these approaches are valid and reliable means of eliciting such information³⁷. Focus groups are particularly suited to adolescent-focused exploration because they reflect the way adolescents discuss issues, both within peer groups and the school setting³⁸⁻³⁹. The group format also provides validation of the views expressed by members of the group and reveals which views are generally held and which are more unique to an individual's circumstances. This type of information would be less accessible without the interaction found in a group. However, in spite of the advantages, few studies have used qualitative techniques to explore QOL in adolescents with epilepsy.

AIMS and DESIGN

This study aimed to use recognised qualitative methods to describe QOL in adolescents with epilepsy. The study was designed to meet quality criteria for qualitative research as defined by CASP (Critical Appraisal Skills Programme) guidelines⁴⁰. Focus groups were used to gather data, which were then transcribed and analysed by thematic coding. Participants were stratified by age to explore any changes in developmental tasks and related QOL at different stages during adolescence.

The number of groups required was determined during the research process. Power calculations are not appropriate in qualitative analysis as sample size is not defined in advance but is deemed sufficient when theoretical saturation is reached. This is when no

new data is being gathered by running further focus groups and thereby the research questions have been answered fully⁴¹.

AIMS

- 1. To describe the experience of having epilepsy in adolescence
- 2. To contribute to our understanding of the perceived impact of epilepsy on QOL in adolescence
- 3. To explore any changes in QOL issues as the adolescent progresses towards adulthood.
- 4. To present a conceptual framework for understanding the impact of epilepsy in adolescence

Insert Table 1 here

METHOD

Participants

Twenty-two adolescents aged between 12 years 4 months and 18 years 0 months (6 males and 16 females) participated. Participant characteristics are presented in Table 1. As can be seen several participants had more than one seizure type and the majority had seizures at least monthly. Seven participants were on anti-epileptic medication

polypharmacy and one was not on any medication. Six focus groups were held with between 2 and 5 participants in each (see Table 2).

Insert Table 2 here

Participants were selected from the databases of two tertiary epilepsy centres in Scotland: the Epilepsy Unit at the Western Infirmary, Glasgow and the Fraser of Allander Neurosciences Unit at the Royal Hospital for Sick Children, Glasgow. Participants were included if they were a) aged between 12 years 0 months and 18 years 0 months with b) a diagnosis of epilepsy of c) at least 6 months duration, d) had experienced at least one seizure in the past year and e) were able to participate verbally in a group. Participants with a) deteriorating neurological health, b) established non-epileptic seizure disorder as the primary clinical problem and/or c) significant learning difficulties were excluded from the study. Case notes were reviewed for all patients aged between 12 and 18 years to establish suitability. Information was recorded on name, address, date of birth, gender, postcode, seizure type, seizure frequency, medication and date of diagnosis. All data were entered onto a computerised database and anonymised to protect confidentiality and meet data protection requirements.

Potential participants were approached by post or by an Epilepsy Specialist Nurse, in person, at clinics for teenagers with epilepsy. Those interested in participating were given written information and asked to complete a consent form. For participants under 16 years old, consent was also required from a parent or guardian and a separate

information sheet was provided to parents in this instance. Participants aged 16 years or over provided independent consent.

In total, 64 teenagers were invited to participate in the study. Of these 28 agreed to participate, however 6 were unable to attend due to reasons such as family illness or transport difficulties. A further 19 did not respond and 17 declined to participate. Reasons given for non-participation were, “shyness about talking in groups”, exam, school and work commitments. However, many of those who responded to say they were unable to participate expressed regret and requested details about the outcome of the study.

Procedure

Data were gathered using standard focus group procedures³⁸⁻³⁹. Six focus groups were conducted with between 2 and 5 participants in each. Participants were stratified into focus groups by age (12-13 years; 14-15 years and 16+ years) to enable exploration of any changes in factors related to QOL at different points in adolescence. All focus groups were held on evenings or at weekends at the Fraser of Allander Neurosciences Unit in Glasgow. Travel expenses were offered to participants. Ethical approval was gained from both sites.

Groups lasted 2 hours with a ½ hour break in which participants were given refreshments. Groups were audio-taped to enable verbatim transcription. Confidentiality and housekeeping issues were addressed at the beginning of the group and participants were informed that they would be given the opportunity to write down

any issues they felt were too personal at the end. Each focus group comprised 3 main sections. The first section incorporated an icebreaker, in which everybody introduced themselves and described their hobbies and interests. Following this, participants were asked to identify the places and people important in their daily lives, as this led naturally into discussion about the impact of epilepsy upon these. Identified items were recorded on a flipchart for continued reference during the group. The remainder of the section involved unstructured discussion about these topics, in which adolescents were encouraged to generate issues of most relevance to them. The moderator's role was to encourage flow and elaboration of discussion using reflective statements and questions and to check the relevance of items for the whole group. During the second section of the group, 2 picture sheets, reflecting some of the issues identified in previous literature, were distributed (see Appendix 4.2). This was a secondary strategy designed to promote discussion, should participants have had difficulty generating spontaneous conversation. This also provided an opportunity for testing out the relevance of some previously determined items to the group. Finally, towards the end of the group participants were given the opportunity to write down more sensitive issues. At this point, participants were also asked to record the 3 main ways in which epilepsy affected their daily lives.

Data Analysis

Audio-taped data from each of the 6 focus groups were transcribed onto a word processing package (see Appendix 4.3). Thematic coding was used to code data from groups and written sheets⁴². Data collection continued until theoretical saturation⁴¹ was obtained. Saturation was reached in the fourth group, however, given that one of the study's aims was to investigate age-related differences, it was felt necessary to conduct

at least 2 groups per age band. Following initial analysis, the relationships between codes were studied and used to generate central themes. Later analysis investigated the similarities and differences between groups. QSR NUD*IST 4.0 for Microsoft Windows, a computer package designed specifically for the analysis of qualitative data, was used to facilitate analysis⁴³.

Several procedures were undertaken to increase validity and reliability of findings. An independent researcher analysed one third of the data in order to reduce researcher bias on the identification of themes. Data from transcription of focus groups were triangulated with written information provided by participants and identified themes and representative quotes were fed back to participants by post for comment on their relevance. All feedback expressed agreement with the content of themes. Themes were also discussed with 2 senior experienced colleagues to check appropriateness and content.

Insert Figures 1 and 2 here

RESULTS

Analysis identified 2 main themes comprising a) issues related to adolescent development (identity formation) and b) epilepsy related variables, with 5 and 4 sub-themes in each, respectively. These sub-themes were made up of further sub-elements (see Figures 1 and 2).

The following text provides a summary of the content of themes with illustrative quotes. Further selected quotes are presented in Tables 3 and 4. Numbers of participants generating quotes related to particular themes have been provided, however as this is qualitative data, these should be interpreted with caution and not used to quantify the data in terms of generalising to a larger population⁴⁴. Developmental and age-related differences are incorporated into the discussion of themes and supporting quotes to represent the homogeneity of themes across age groups are provided in Tables 5 and 6.

Insert Tables 3 and 4 here

Theme One: Adolescent Development Issues (Identity Formation)

This theme describes issues related to one of the core developmental tasks of adolescence i.e. the development of self-identity (See Figure 1). Sub-themes were identified as ‘Peer Acceptance’, ‘Development of Autonomy’; ‘School Related Issues’, ‘Epilepsy as Part of Me’ and ‘Future’.

Peer Acceptance

Nineteen of the participants reported experiences of bullying and social isolation: "I feel left out because I can't go sometimes with my friends and things like that"; "at school, the boys in my year and other boys in other years pick on me, they call me names and things just because I've got epilepsy, I've had that since I started school". Eight told of experiences of actual rejection by friends because of epilepsy and 11 expressed fears about rejection from peers, particularly boyfriends or girlfriends, if they found out: "if they didn't take it that well, leave you or something, because you see all these hospital

programmes and the boyfriend goes away and leaves them". The decision to disclose their epilepsy was a significant factor for all participants. This decision was complex and based on many factors including frequency of seizures, time spent with friends and safety reasons, such as "I had to tell mine because I go out with my friends a lot and if I'm going ice skating or something like that or swimming, my mum will always say be careful and tell my friends to watch out for me". One teenager verbalised part of her concern as "if you think about it, the reason you've got it is because there's like, there's this sort of block in your brain, so people are going to think you're stupid".

However, in spite of this, 7 of the teenagers, particularly those in the older age group, described friends knowing as a supportive factor. They reported that friends had been interested in finding out more information about the condition and how they could help if a seizure occurred: "most people when they've seen attacks that I have ... they might be frightened and that because it's not a pleasant thing to see but because of that they like to make sure that they know what to do if it happens". Nevertheless, 2 of the younger participants had as yet not revealed their epilepsy to any friends and one engaged in specific behaviours to keep their epilepsy secret, such as making an excuse to go to the toilet to take medication. Two participants had auxiliary teachers to support them at school, which was perceived as a significant barrier to making friends: "it feels as if I'm apart from my friends because I'm with (my auxiliary), so my friends don't come with me because she's there, so if I didn't have her I'd feel more involved in things". Seven teenagers expressed how they felt that other people were scared of epilepsy because of a general lack of knowledge in society, which led to prejudice.

Development of Autonomy

This theme incorporated elements relating to ‘restrictions in activities’, ‘experimentation’, ‘overprotective adults’ and ‘lack of privacy’. Seventeen participants described restrictions imposed by others. However, interestingly, 8 of these also placed restrictions on themselves in order to keep safe or avoid possible embarrassment if they had a seizure: “if I was swimming or horse riding I would always make sure I’ve got people round me, if I went swimming I would always make sure that my mum or my dad or some friends are with me, I always make sure there’s people round me to make sure I don’t hurt myself”. However, 6 teenagers stated that they did not feel they avoided trying new activities because of their epilepsy expressing “I don’t really worry about it, I only really worry about going to the dancing because of all the lights”. These themes were reflected across age groups (see Tables 5 and 6). Parents were seen as over-protective by 12 participants, although this was not reported as a significant problem and instead it was generally felt that they would “rather be overprotected than not at all, you know that you’re not alone”. Furthermore, 6 teenagers reported that their parents had become less over-protective as they had gained more knowledge about epilepsy and its associated risks: “at the beginning my mum didn’t want me staying in the house by myself, but now I haven’t had a fit in 6 months so she’s alright with me”.

School Related Issues

Only one of the adolescents, who was in the oldest age group, reported issues related to academic performance, whereby she’d missed exams because of seizures. By far the biggest issue relating to school was the reaction of teachers, reported by 13 of the participants (see Tables 3 and 5). Nine felt that teachers did not know enough about the condition and tended to “over-react” to seizures with comments made such as “once

when I had one (seizure) at school, I had 6 teachers all around me and that and they were all over-reacting and that" and "teachers would never let me go anywhere on my own, when I went to the toilet, I had to have people with me". Two participants reported having been restricted to school grounds during breaks because of safety concerns, thereby segregating them from their peer group.

Five teenagers described positive and appropriate reactions from teachers reporting "everybody knows I have epilepsy and they're really good about it, and teachers as well". However, 4 of these also reported negative experiences, suggesting that appropriate management may often be down to the individual teacher, rather than school policy.

Epilepsy as Part of Me

This theme related to the extent to which each adolescent had come to terms with having epilepsy. Thirteen participants described how they generally felt they had got used to having epilepsy and just accepted it. Four of these expressed this in a particularly positive way: "there's added extra to me, I'm unique, I'm special". Another 4 were less positive: "(at first) I just felt different from everybody else because I had epilepsy and none of them did and I felt like they could do more stuff than me". Such comments were reflected across age groups (see Table 5). One particularly mature and poignant comment was made by one of the older adolescents: "if you think about it everybody's got their own personality and appearance and being epileptic is just part of me, a lot of my friends have asthma, that's part of them". None of the teenagers denied having the condition although, as mentioned earlier, one kept their epilepsy a secret. Furthermore, it is unlikely that those in denial would have attended the groups.

Future

This theme related to leaving home, choosing careers and having children. Thirteen teenagers from all age groups expressed awareness that epilepsy may impede the opportunity to follow certain careers and worried "about discrimination and stuff". Moving away from home was raised as an issue by 5 participants, both younger and older, with concerns voiced about safety and the risks of having a seizure if alone: "if you don't have a boyfriend or a husband, what would happen if you had a fit in the bath, if you had drowned or that"; "if you're wanting to leave home what would you do, would you go and have a friend to live with so you're not on your own if something happens? I would rather have someone with me just in case something happens". From older and younger adolescents alike, concern was expressed regarding having children and 8 reported specific worries about offspring having epilepsy, such as "there's like a chance, a percentage of it having epilepsy and that" (see Tables 3 and 5).

Insert Tables 5 and 6 here

Theme Two: Epilepsy Related Issues

It would be expected that anyone with epilepsy, irrespective of age, would have difficulties directly related to the condition itself. Adolescents are no different and sub-themes of "Medication Issues"; " Seizures"; "Knowledge of Epilepsy" and "Sense of Uncertainty" were identified (see Figure 2). However, descriptions of their difficulties revealed how having to face these issues in adolescence posed particular challenges.

Medication Issues

The most important factors with respect to medication surrounded issues of compliance and others checking on whether they had taken their medication. Remembering to take medication was a particular issue for 9 participants, across all age groups: “it’s like trying to remember all the time because my dad will ask if I’ve taken my pills and I’m like “no” and he says you have to take it”. However, comments seemed to reflect that these difficulties were due to lifestyle and not a cognitive deficit: “they’re up in my room and I’m downstairs watching TV and I just can’t be bothered going up to get them”. Frequent changes in medication and resultant side effects were mentioned as additional problems by 2 participants (see Table 4). Three teenagers also commented that medication acted as a physical reminder of their condition, made them feel different and increased the risk of disclosure which, in turn, increased the risk of peer rejection and bullying: “loads of times I go back to my mates house and I make an excuse to go to the bathroom and take my medicine”. Seven mentioned that they felt medication placed restrictions on activities, particularly experimenting with alcohol. Across the age groups, 5 participants felt that parents were over-vigilant about checking whether they had taken their medication (see Table 6). However, in spite of these expressed difficulties, none felt that their medication was unnecessary.

Seizures

Two teenagers reported having been vulnerable to crime because of seizures: “once I had a fit ... done the usual, fell back and this time I was out cold, everyone was putting me in the recovery position and all that, you’d think it was alright but then somebody actually went into my bag and stole my mobile phone”. Twelve expressed a fear of seizures, particularly in relation to drowning, injury or embarrassing themselves such as “I’m kind

of scared about the bath. I told her (mum) that I was really afraid to go to the bath, she stayed with me just in case a couple of times, but I didn't get used to it".

Knowledge of Epilepsy

This theme encapsulated 3 main issues: 'own knowledge'; 'other people's awareness of epilepsy' and 'knowledge of legislation'. There were mixed views as to whether enough information had been provided about their epilepsy, although perhaps not surprisingly it was the younger adolescents who felt they needed to know more. Older adolescents appeared to have been given more information.

Four teenagers expressed apprehension about speaking to doctors about issues such as alcohol consumption and pregnancy, in case it implied they were drinking alcohol or having sex under-age. However, in spite of this, they felt the opportunity to talk to doctors and nurses was helpful. Furthermore, leaflets about epilepsy were reported to be particularly useful by 4 teenagers. One participant described how "when I first found out they gave us a lot of leaflets and my mum gave them to my 2 best friends rather than me telling them because that was quite difficult, trying to explain stuff that I didn't even understand". Of interest, is that during one of the groups, one of the participants had a complex partial seizure. It was clear from this that the majority of the group had never seen a seizure, in spite of having epilepsy. One participant expressed that she "didn't realise there was actually so many forms, I've had the eyes rolling and the shaking and the foam from the mouth but that's mine, I didn't know about the staring and he's conscious through it as well".

All participants were aware of legislation relating to driving and career limitations, however their knowledge was not always accurate. In one example of this, 4 of the younger participants expressed different views on how long someone had to remain seizure free before they could drive: "I think it's you can only drive if you've not had a seizure for ... 5 years". "5 is it, I thought it was 2?". "Mm, no 5", "Yeah 5".

There was a general sense amongst the groups that there was a lack of knowledge about epilepsy in society and that more accurate information should be provided to reduce the fear of epilepsy and promote accurate and realistic management of seizures. Three of the teenagers commented on the fact that media portrayals tended to be negative: "when you watch stuff like Casualty and Holby City they make it out that it's bigger than it is".

Sense of Uncertainty

This theme encapsulated the overall sense from the teenagers about the likely outcome of their epilepsy. Five stated that they felt remaining seizure free was greatly down to luck and that they had to take each day as it came: "I've almost been seizure free for a year, I was the same last year, I'd almost been seizure free for a year and then I took a seizure. The seizure was because I'd grown, the amount of medicine I was taking wasn't enough to control it anymore, but that could happen if I get older again". Two knew family members who still had epilepsy into adulthood. However, none demonstrated feelings of hopelessness. On the contrary, 9 expressed a general hope that they would eventually grow out of epilepsy or would be able to continue to tolerate the condition stating "I think mine might just get milder but I don't think it will go away completely".

Insert Figure 3 here

DISCUSSION

In spite of the sizeable literature on QOL in adolescents with epilepsy, relatively little emphasis has been placed on defining QOL by direct exploration of adolescents' views. The qualitative methodology employed in this study was designed explicitly to report these.

Focus groups were found to be a valid method for gaining adolescents' views. An open focus group approach was supplemented by the use of pictorial images to prompt discussion and by the opportunity to record more sensitive issues in written format. However, it emerged that all the issues identified were in fact covered in the unstructured focus group discussion. Furthermore, participants expressed that they found the group format supportive and enjoyable. These factors suggest that they felt comfortable discussing issues and demonstrate the reliability and validity of this approach for exploring QOL with adolescents.

Analysis identified and validated several themes and sub-themes that encapsulated the experience of having epilepsy in adolescence. By far the greatest impact on QOL involved the negative impact on peer relationships and on the development of autonomy and independence. This is consistent with some previous studies^{7-10,16-17,20}. Disclosure of epilepsy to one's peer group was perceived to be a particularly difficult and complex

issue. These themes demonstrate that the primary impact on QOL perceived by adolescents related to aspects of their psychosocial development. First and foremost, teenagers were negotiating the developmental tasks of adolescence, such as the formation of peer relationships, autonomy and ultimately, self-identity. Having epilepsy was not removed from these factors. Rather, it was seen as embroiled within normal development as a factor presenting additional challenges to the successful completion of these developmental tasks. Figure 3 represents a conceptual model of these findings. In this model, good QOL is presented as a function of successful adjustment to having epilepsy, both in terms of illness-related factors and in the promotion of successful identity formation. It is proposed that these elements are inter-related and that both must be addressed for successful adjustment to epilepsy and subsequent achievement of acceptable QOL. Figure 3 therefore provides a means of conceptualising factors related to epilepsy, and a means of assessing QOL on an individual basis. The model helps to identify which elements may need to be addressed to promote good QOL in each adolescent.

A further finding of the study was that participants did not identify academic difficulties as a significant issue, in spite of these having been identified in some previous studies^{6,8,10,14,26}. In contrast, school-related difficulties largely related to problems with teachers, rather than academic performance. However, it should be noted that those studies which had identified academic performance as a significant factor in QOL used proxy informants, either alone or combined with self-ratings. This discrepancy may highlight the methodological difficulties with using proxies to define QOL.

Another aim of the study had been to explore age-related issues in the perception of QOL. Focus groups were explicitly stratified by age to enable this comparison. It was expected that choice of career, driving, moving away from home, pregnancy and alcohol consumption would be more prominent topics for older adolescents. However, with the exception of perceptions of knowledge about epilepsy and legislation related to careers and driving, the issues raised remained fairly stable across adolescence.

The proposed model may provide some explanation for both the non-reporting of academic concerns and the absence of age-related differences demonstrated in this study. It may be that the majority of participants were focusing on gaining peer acceptance and developing autonomy. These goals were perhaps overshadowing issues like careers and moving away from home. We may therefore find that once adolescents have developed a more stable sense of identity, they are more able to move on to consider other issues, such as career choice. Other explanations for the lack of age-related variation include the general cultural change in the “time period” for adolescence. It has been suggested that adolescence is lengthening both at its’ onset, with earlier puberty, and at its’ end, due to the increasing number of people going on to further education and remaining financially dependent on parents for longer⁴⁴.

Implications for Future Research

Studies are needed to test out the applicability of the conceptual framework proposed and to investigate further age-related issues. In particular, it may be worthwhile for future studies to include a wider age range (for example 10-20 years).

Furthermore, although data were gathered on timing of diagnosis and seizure variables, the design of this study does not enable reliable comparisons to be made about QOL in relation to these. Future studies might consider adjustment to epilepsy in relation to such factors. For example, in relation to developmental tasks, studies may find that timing of diagnosis has a significant bearing on the process of identity formation. Similarly, with seizure variables, greater severity and frequency of seizures have been identified as risk factors for poorer QOL²¹⁻²³. Research investigating these specific variables within a developmental perspective may contribute to our understanding of which particular aspects of epilepsy pose the greatest difficulties for adolescents.

It is hoped that data generated from this study might be used to develop an outcome measure of QOL for use in clinical practice with adolescents with epilepsy. This approach of combined qualitative and psychometric methodologies was recently implemented in the development of an outcome scale for adults with learning disabilities and epilepsy⁴⁵⁻⁴⁶. One benefit of this approach is the feasibility of using language originating from direct experience and from direct quotes to develop items appropriate for the scale. This increases both the content and face validity of the scale and also its' applicability because of the use of everyday language.

Finally, a wider implication of the findings of this study is that any condition that compromises psychosocial developmental, particularly identity formation, in adolescence may have a negative impact on QOL. Future research could test out the applicability of the proposed model in relation to other health difficulties in adolescence.

Implications for Practice

This research study has identified that the impact of epilepsy on QOL in adolescence directly relates to core developmental tasks and in particular, identity formation. Service providers and clinicians should work with adolescents, their families and their teachers to promote successful development, in particular to reduce restrictions on autonomy and difficulties in peer relationships.

The study has also demonstrated that valid and reliable reports can be obtained from adolescents directly. Proxy reports are not valid as personal reports and should not be used as substitutes for direct communication. Time needs to be spent with adolescents in clinics and care settings to evaluate the impact of their condition on QOL from their perspective.

Furthermore, some of the issues raised by adolescents suggest that changes could be made to the delivery of care. Consideration is needed as to the best person and format for discussing more sensitive issues such as alcohol consumption and pregnancy. Some participants expressed that they would feel embarrassed discussing such issues with doctors, however were able to discuss these in the focus groups. Perhaps such an approach would be usefully incorporated into clinical practice. Furthermore, there was a feeling from younger participants that they had not received enough information, which should be addressed. Participants found leaflets particularly useful, so written adolescent-focused information may be a good way of supplementing the information provided at appointments. Finally the model proposed could be used to guide assessment and identify issues which need to be addressed for each individual. The

model could be presented to patients and their families as well as to doctors in training to highlight the importance of addressing such issues in the care of adolescents with epilepsy.

Limitations of the study

The methodology employed in this study was designed to meet quality criteria as rated by CASP Guidelines for qualitative research⁴⁰ and several techniques were implemented to increase the reliability and validity of findings. However, it should be noted that the themes identified reflect the views of a relatively small number of participants. Further research is needed to reliably apply these to a larger cohort of adolescents with epilepsy.

Conclusions

This study has demonstrated that focus groups are a valid and reliable means of eliciting views on QOL from adolescents with epilepsy. Findings demonstrated that the primary impact on QOL perceived by adolescents related to aspects of psychosocial development, in particular developmental tasks leading to successful identity formation. A conceptual framework encapsulating the themes generated in this study has been proposed, in order to assess and understand QOL in adolescents with epilepsy (see Figure 3). Within this model, good QOL is proposed to rely on successful adjustment to having epilepsy, both in terms of illness-related factors and in identity formation. Future studies of QOL should continue to elicit views directly from affected individuals and to consider QOL within a developmental framework, such as that proposed in this study.

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Table 1: Participant Characteristics

Gender Male Female	6 16
Age Mean Range	14 years 1 month 12 years 4 months – 18 years 0 months
Age at Diagnosis Mean Range	7 years 0 months 1 month – 13 years 6 months
Seizure Type Simple Partial Complex Partial Generalised Myoclonic	9 5 16 1
Seizure Frequency Daily Weekly Monthly Every 2-6 months Every 6-12 months Less than once per year	6 2 6 4 3 1
Medication Carbamazepine Sodium Valproate Lamotrigine Levetiracetam Topirimate Clobazam Bromide None Polypharmacy	11 3 7 2 3 3 1 1 7
Educational Status Mainstream School Special Education School leaver	 19 2 1

Table 2: Composition of Focus Groups

Focus Group	Number of Participants
A	3 (all female)
B	5 (3=female; 2=male)
C	2 (1=female; 1=male)
D	5 (4=female; 1=male)
E	4 (3=female; 1=male)
F	3 (2=female; 1=male)

Table 3: Selected Illustrative Quotes from Theme 1
(M / F = gender; number = age)

Theme 1: IDENTITY FORMATION ISSUES
Sub-Theme: Peer Acceptance
<p><i>Boyfriends / Girlfriends</i></p> <p>“Just like, for example, if they didn’t take it that well, if they leave you or something. Because you see all these hospital programmes and the boyfriend goes away and leaves them” (F,12)</p> <p>“just incase they do see me taking a seizure and they think, I don’t want to be with her because I don’t want to see them” (F,15)</p>
<p><i>Social Isolation</i></p> <p>“well, I feel left out because I can’t go sometimes with my friends and things like that” (M,12)</p> <p>“you know what I said earlier about camps? Well if I could go without having a leader with me all the time. Then I’d have more friends, sometimes I just get stuck with the leader. Epilepsy, it’s like a barrier” (F, 17)</p>
<p><i>Teasing</i></p> <p>“I was just sitting at school one day ... and at primary school my mum had just made me tell a couple of people, and the boy that had been sitting beside me at primary school had told another boy about it and he just started making fun of me and pretending he was going into a fit” (F,12)</p> <p>“at school, the boys in my year and other boys in other years pick on me. They call me names and things just because I’ve got epilepsy. I’ve had that since I started school” (F,17)</p>
<p><i>Disclosure</i></p> <p>“I had to tell mine because I go out with my friends a lot as well and if I’m going ice skating or something like that or swimming, my mum will always say be careful and tell my friends to watch out for me” (F,12)</p> <p>“I’ve only told one person. I just think I want a couple to know but I don’t want everyone to know in case they run around the street telling everyone I’ve got epilepsy. I wouldn’t want thousands of people to know” (M,13)</p> <p>“If you think about it, the reason you’ve got it is because there’s like, there’s this sort of block in your brain, so people are going to think you’re stupid” (F,18)</p>

<p><i>Other's Fears of Seizures</i></p> <p>“girls, like even my friends, when they see that I’m going to take one, they’re like “get away from me” and that makes me feel really bad because my friends are saying that. But they say it in a kind of kiddy on kind of way sometimes. But other girls who are scared, really scared of it, they just keep staying there and screaming about it and that makes me feel bad” (F,17)</p> <p>“well, most people when they’ve seen attacks that I have ... they might be frightened and that because it’s not a pleasant thing to see but because of that they like to make sure that they know what to do if it happens” (M,17)</p>
<p>Sub-Theme: Development of Autonomy</p>
<p><i>Over-Protective Parents</i></p> <p>“I think my mum and dad worry more than I do” (F,12)</p> <p>“I’d rather be overprotected than not at all. You know that you’re not alone” (F,12)</p> <p>“at the beginning my mum was didn’t want me staying in the house by myself, but now I haven’t had a fit in 6 months so I just, she’s alright with me” (F,15)</p>
<p><i>Restrictions on Activities</i></p> <p>“I can’t go on trips without my mum being there. Well, I can go on trips but not trips where you have to sleep over night” (M,14)</p> <p>“If I was swimming or horse riding I would always make sure I’ve got people round me, or go karts. If I went swimming I would always make sure that my mum or my dad or some friends are with me. And horse riding, just in case I fall off. And I’m always wearing a helmet, I always make sure there’s people round me to make sure I don’t hurt myself” (F,12)</p> <p>“I don’t really worry about it. I only really worry about going to the dancing because of all the lights” (F,15)</p>
<p><i>Lack of Privacy</i></p> <p>“my granny and grandad, it’s like every time I go in the bath they don’t let me lock the door and even when I’m going to the toilet they don’t let me lock the door. My gran used to stay in the bathroom with me and I just had to put the curtain bit over and it was dead embarrassing” (F,12)</p> <p>“I’m not allowed to lock the door of the bathroom at bathtime in case I take one in the bath” (F,17)</p>

<p>Experimentation</p> <p>“my friends sometimes goes out with his best friends, has a few drinks, and he always says “do you want to go out with Saturday night and get pissed” and I just have to say “no” because if I have too much alcohol I’ll just take about 4 or 5 seizures at night. I just feel left out sometimes” (M,14)</p> <p>“I can’t have any red wine, only white wine mixed with lemonade. But once you’re 18 everyone expects you to be able to drink” (F,17)</p>
<p align="center">Sub-Theme: School Related Issues</p>
<p>Teachers Reactions</p> <p>“Once when I had one (seizure) at school, I had 6 teachers all around me and that and they were all over-reacting and that” (M,13)</p> <p>“teachers would never let me go anywhere on my own. Like when I went to the toilet, I had to have people with me” (F,16)</p> <p>“I was in the choir one night after school and so was my sister. I mean, I only take absences, where I just kind of stare and then come out of it, I don’t take fits or anything. But she (the teacher) obviously saw me kind of swaying a bit so she knew I was going to take one. So she was like “everybody out the room” and dragged everybody out the room and just panicked sort of thing. It was so embarrassing and I never knew this was happening. So she left my sister in the room with me and everyone else had to stand in the corridor along with the teacher. And I found out about this after choir that night and never went back” (F,17)</p> <p>“I got banned from leaving the school grounds in school hours. For basically, going out the school to get my lunch in case I dropped on the road again (having a seizure)” (M,16)</p> <p>“the worst reactions I’ve had have been not from friends but from teachers. There was one time ... I hadn’t done my homework the night before because I had to come here to get the results of my brain tests and that and I told her and she was like “oh right, that’s fine”. She did a vocab test on the stuff we were meant to have learned ... and we had to go up individually to get our papers back and she said “well, if in fact these brain tests say it’s all in working order, why don’t you apply your brain to this work”. My mum wanted to phone up and complain” (F,18)</p>
<p>Academic Difficulties</p> <p>“I think you could probably say mine aren’t very well controlled. In February, for example, I had 28 in one day. And, em mostly one every day from January through until the end of March and that was restrictive. There were just a few things that I really wanted to do and it didn’t spoil that, nothing got spoiled then except my schoolwork. They actually decided I wasn’t going to do any exams this year” F,18)</p>

Sub-Theme: Future
<p><i>Leaving Home</i></p> <p>“If you don’t have a boyfriend or a husband, what would happen if you had a fit in the bath, if you had drowned or that” (F,12)</p> <p>“If you’re wanting to leave home. What would you do, would you go and have a friend to live with so you’re not on your own if something happens. I would rather have someone with me just in case something happens” (F17)</p>
<p><i>Jobs</i></p> <p>“I wanted to do cameras right but I wanted to do it under the sea like film whales and all that ... I think that it’s just like in case you have a seizure and that and I don’t think it’s fair, I mean I know there’s nothing you can do about that really” (F,12)</p> <p>“I worry as well, just about discrimination and stuff” (F,15)</p>
<p><i>Having Children</i></p> <p>“there’s like a chance, a percentage of it having epilepsy and that” (F,12)</p> <p>“Well, since I’ve got epilepsy, would the baby end up having epilepsy or wouldn’t it because the girl’s not got epilepsy?” (M,13)</p> <p>“You can’t take the (contraceptive) pill if you’ve got epilepsy. There is some kind of pill because Dr X told me about it. A special one you can take” (F,17)</p>
Sub-Theme: Epilepsy as Part of Me
<p><i>Positive Acceptance</i></p> <p>“I just accept it, don’t let it worry me” (M,14)</p> <p>“There’s added extra, to me I’m unique, I’m special” (F,16)</p> <p>“If you think about it everybody’s got their own personality and appearance and being epileptic is just part of me. I mean quite a lot of my friends have asthma, that’s part of them” (F,18)</p>
<p><i>Negative Acceptance</i></p> <p>“I just felt different from everybody else because I had epilepsy and none of them did and I felt like they could do more stuff than me” (F,14)</p> <p>“Because you see when you tell someone, they just say “what’s it like” and just be nosy and ask lots of questions and I don’t like it you see, I don’t want to talk about it” (M,14)</p>

Table 4: Selected Illustrative Quotes from Theme 2
(M / F = gender; number = age)

Theme 2: EPILEPSY RELATED ISSUES
Sub-Theme: Medication Issues
<p><i>Compliance</i></p> <p>“I have to keep changing the tablets when I have fits and that and it just seems a hassle that I have to keep taking the tablets all the time (F,12)</p> <p>“It’s like trying to remember all the time because my dad will ask if I’ve taken my pills and I’m like “no” and he says you have to take it. One time I forgot and he forgot and the third night I took a fit” (F,12)</p> <p>“it just annoys me because at first I think I’ve found the right one and also the fact I have to change pills. The more times I have to change it the more tired I am, because when you start a new pill you’re tired at the start of it” (F14)</p> <p>“or like they’re up in my room and I’m downstairs watching TV and I just can’t be bothered going up to get them” (F,17)</p> <p>“loads of times I go back to my mates house and I take it ... I make an excuse “can I go to the bathroom” and take my medicine (M,14)</p> <p>“when I first found out I had it, I’d just take the tablet because my mum was being dead worried about me all the time, but then I didn’t like having it, I felt different from everybody else” (F,14)</p>
<p><i>Other’s Checking</i></p> <p>“my mum counts them to make sure I’ve remembered to take them and if not I get a big lecture about them” (F,12)</p> <p>“she (mum) says “have you taken your pill” and I say “yeah” but sometimes she’ll ask me like over 4 or 5 times a day” (F,14)</p> <p>“my parents are always asking me the question about the pills “have you taken them” (M,16)</p>
Sub-Theme: Seizures
<p><i>Experience of Seizures</i></p> <p>“sometimes I get hurt because the way it happens to me, people don’t know and they just start pushing me and that because they think I’m away in a daydream” (F,12)</p> <p>“I fell towards the door and my mum was trying to get in but she didn’t want to hurt me either. But when she opened the door she closed the door so my brother wouldn’t see and then when she put me over my face was all blue and I had marks all over my</p>

<p>face and ... she could see I wasn't breathing properly... I was almost crying because I was so scared and I couldn't talk, I couldn't talk for an hour" (F,14)</p> <p>"People didn't want to come near me at first, because the first thing that I did when I took a fit was I grabbed one of my friends and strangled her" (F,16)</p> <p>"Once I had a fit ... done the usual, fell back and this time I was out cold. Everyone was putting me in the recovery position and all that. You'd think it was alright but then somebody actually went into my bag and stole my mobile phone" (M,16)</p>
<p><i>Fear of Seizures</i></p> <p>"I'm kind of scared about the bath. I told her (mum) that I was really afraid to go to the bath, she stayed with me just in case a couple of times, but I didn't get used to it" (F,12)</p> <p>"Sometimes when I go swimming I'm really scared because we have to go in the deep end ... because once I did have an epilepsy seizure when I was in the swimming pool and I was so scared" (F,12)</p> <p>"I was really fond of cycling ... had a seizure on my bike and fell off ... I had to give up (cycling) because I was just too scared that something would happen (F, 18)</p>
<p>Sub-Theme: Knowledge of Epilepsy</p>
<p><i>Own Knowledge</i></p> <p>"when I first found out they gave us a lot of leaflets and my mum gave them to my 2 best friends ... rather than me telling them because that was quite difficult, trying to explain stuff that I didn't even understand" (F,12)</p> <p>"When I first found out I had it, I didn't realise I could do the same things as everybody else because I'd only found out I had it. I didn't really know that much about it" (F,14)</p> <p>"I didn't realise there was actually so many forms. I've had the eyes rolling and the shaking and the foam from the mouth but that's mine. I didn't know about the staring and he's conscious through it as well" (F16)</p>
<p><i>Other's Awareness</i></p> <p>"my RE teacher wasn't very good about it. Just the way he was giving the wrong information about it and saying stupid stuff. It was something to do with religion and something to do with epilepsy that meant you were something bad or something, but he was talking rubbish it" (F,14)</p> <p>"when you watch stuff like Casualty and Holby City they make it out that it's bigger than it actually is" (M,16)</p>

<p>Legislation</p> <p>“Yeah, I think it’s you can only drive if you’ve not had a seizure for (F,13) ... 5 years (Ma,13) ...5 is it, I thought it was 2 (F,13), yeah 5 (Mb,13)</p> <p>“you’ve got to be a year fit free to be able to take driving lessons” (F,15)</p> <p>“you have to work 2 years without a seizure to be a teacher in Scotland. You have to go 3 years in England” (M,16)</p> <p>“I got told, go seizure free for a year with tablets, go seizure free without tablets further than I can start driving lessons” (F,17)</p>
<p>Sub-Theme: Sense of Uncertainty</p>
<p>Keeping Seizure Free</p> <p>“with my epilepsy I have to go to bed at a certain time or it can trigger a seizure, so we don’t want to try that (staying up later) because obviously I want to keep the 3 months going without seizures” (F,14)</p> <p>“I’ve almost been seizure free for a year...I was the same last year. I’d almost been seizure free for a year and then I took a seizure. The seizure was because I’d grown, the amount of medicine I was taking wasn’t enough to control it anymore ... but that could happen if I get older again” (F,17)</p>
<p>Growing Out of Epilepsy</p> <p>“my uncle has it and he had it really really bad and he’s still got it” (F,12)</p> <p>“I think mine might just get milder but I don’t think it will go away completely” (F,13)</p>

Table 5: Theme 1: Representation of homogeneity of main sub-themes across age groups with supporting age-related quotes

THEME		12-13 year olds	14-15 year olds	16+ year olds
Peer Acceptance		"I've only told one person. I just think I want a couple to know but I don't want everyone to know in case they run around the street telling everyone I've got epilepsy. I wouldn't want thousands of people to know" (M,13)	"just incase they do see me taking a seizure and they think, I don't want to be with her because I don't want to see them" (F,15)	"at school, the boys in my year and other boys in other years pick on me. They call me names and things just because I've got epilepsy. I've had that since I started school" (F,17)
	Development of Autonomy	"my granny and grandad ... every time I go in the bath they don't let me lock the door, even when I'm going to the toilet they don't let me lock the door" (F,12)	"at the beginning my mum was didn't want me staying in the house by myself, but now I haven't had a fit in 6 months so I just, she's alright with me" (F,15)	"I'm not allowed to lock the door of the bathroom at bathtime in case I take one in the bath" (F,17)
School Related Issues		I was worried about starting highschool because I only had one teacher at primary school and she knew but if I ever went into one (a seizure) at school ... and they thought I was just daydreaming ... then I might get into trouble ... because I swap teachers a lot (F,12)	"my guidance teacher was really nice about it but some other teachers, like my RE teacher wasn't very good about it. Just the way he was giving wrong information about it and saying stupid stuff" (F,15)	"teachers would never let me go anywhere on my own. Like when I went to the toilet, I had to have people with me" (F,16) "Everybody knows I have epilepsy and they're really good about it, and teacher's aswell" (F,17)
	Future	Like if I gave it to them (children), I'd feel guilty. Cos they have it because I had it. Cos I don't know if it's a coincidence that my aunt had it" (F,12)	"Hopefully if I do get married then I'll go on to have babies, but what happens if I do have one, will he or she turn out to have epilepsy because I've passed it on?" (F,15)	"You can't take the (contraceptive) pill if you've got epilepsy. There is some kind of pill because Dr X told me about it. A special one you can take" (F,17)
Epilepsy As Part of Me		"we're kind of the same, we don't look any different from anybody else. We're just kind of different ... we're doing the same things ... we just have to be a bit careful when we're doing them" (F,12)	"I just felt different from everybody else because I had epilepsy and none of them did and I felt like they could do more stuff than me" (F,14)	"If you think about it everybody's got their own personality and appearance and being epileptic is just part of me. I mean quite a lot of my friends have asthma, that's part of them" (F,18)

Table 6: Theme 2: Representation of homogeneity of main sub-themes across age groups with supporting age-related quotes

THEME		12-13 year olds	14-15 year olds	16+ year olds
Medication Issues		“It’s like trying to remember all the time because my dad will ask if I’ve taken my pills and I’m like “no” and he says you have to take it” (F, 12)	“she (mum) says “have you taken your pill” and I say “yeah” but sometimes she’ll ask me like over 4 or 5 times a day” (F, 14)	“my parents are always asking me the question about the pills “have you taken them” (M, 16)
	Seizures	“Sometimes when I go swimming I’m really scared because we have to go in the deep end ... because once I did have an epilepsy seizure when I was in the swimming pool and I was so scared” (F, 12)	“the only problem with some kinds is, see when you get a fright ... we were playing hide and seek and she (my sister) jumped out and she gave me a fright and I thought I was going to take a seizure but I didn’t” (F, 14)	“I was really fond of cycling ... had a seizure on my bike and fell off ... I had to give up (cycling) because I was just too scared that something would happen (F, 18)
Knowledge of Epilepsy		“when I first found out they gave us a lot of leaflets and my mum gave them to my 2 best friends ... rather than me telling them because that was quite difficult, trying to explain stuff that I didn’t even understand” (F, 12)	“When I first found out I had it, I didn’t realise I could do the same things as everybody else because I’d only found out I had it. I didn’t really know that much about it” (F, 14)	“I didn’t realise there was actually so many forms. I’ve had the eyes rolling and the shaking and the foam from the mouth but that’s mine. I didn’t know about the staring and he’s conscious through it as well” (F16)
	Sense of Uncertainty	“I think mine might just get milder but I don’t think it will go away completely” (F, 13)	“with my epilepsy I have to go to bed at a certain time or it can trigger a seizure, so we don’t want to try that (staying up later) because obviously I want to keep the 3 months going without seizures” (F, 14)	“I’ve almost been seizure free for a year ... I was the same last year. I’d almost been seizure free for a year and then I took a seizure. The seizure was because I’d grown, the amount of medicine I was taking wasn’t enough to control it anymore ... but that could happen if I get older again” (F, 17)

Figure 1: Adolescent Development (Identity Formation) Main Theme and Related Sub-Themes: Pathway of organisation as identified through Analysis of Transcribed Focus Groups

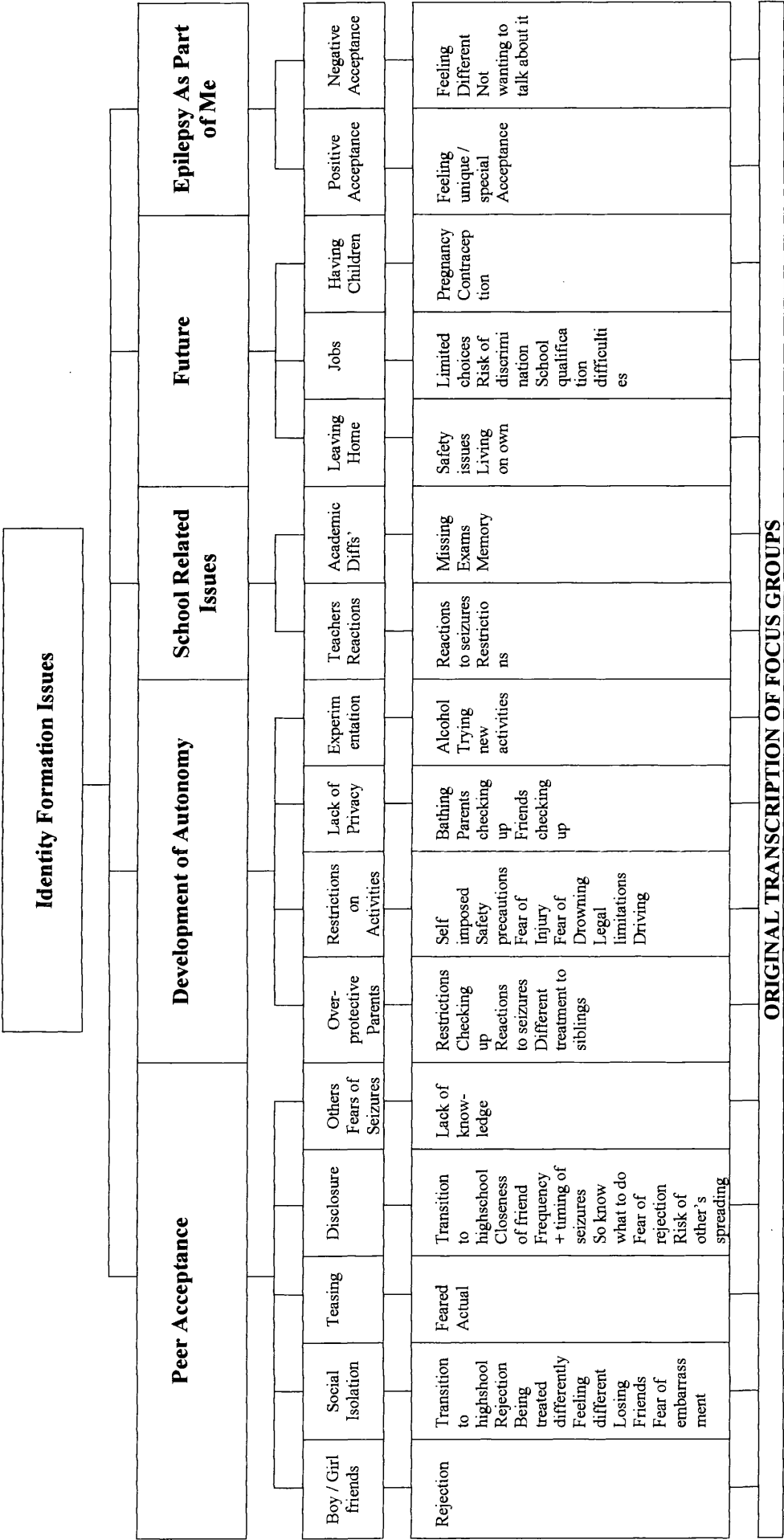


Figure 2: Epilepsy Related Issues Main Theme and Related Sub-themes: Pathway of Organisation as Identified through Analysis of Transcribed Focus Groups

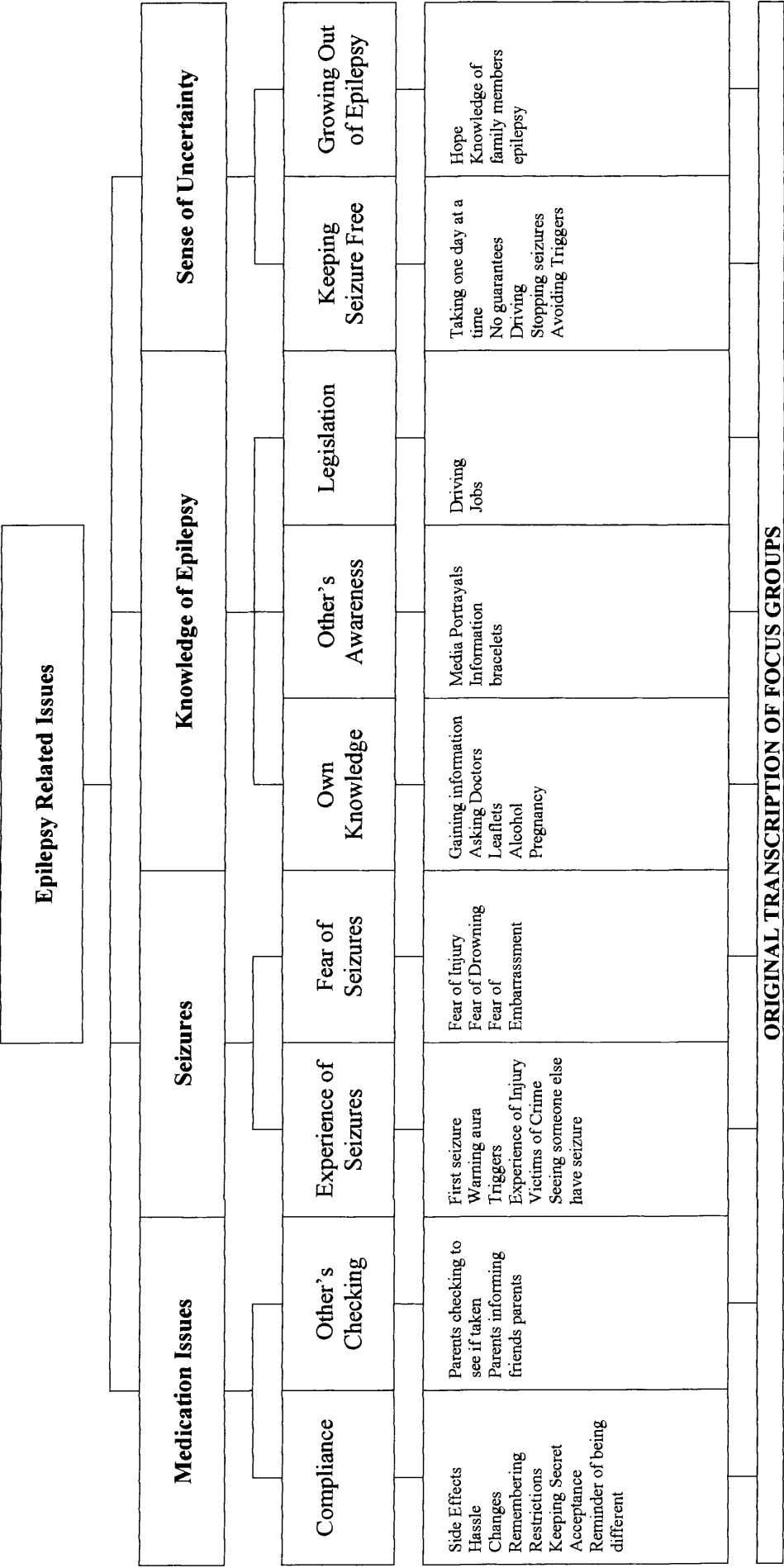
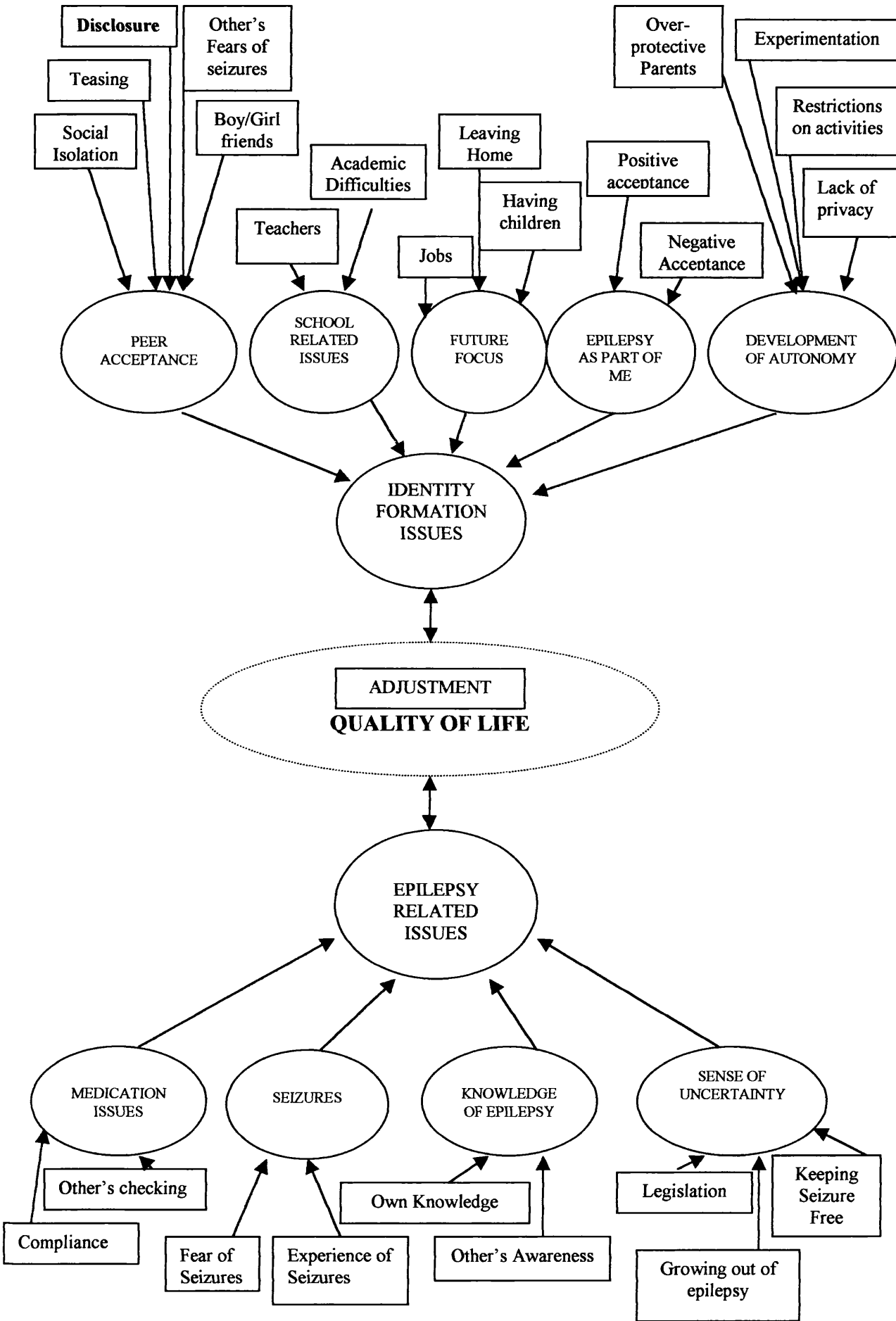


Figure 3: Model of QOL and Identity Formation in Adolescents with Epilepsy



Chapter 5: Clinical Case Research Study

The use of Self-Ratings in a Brief Multi-Component Intervention for the Treatment of Specific Dog Phobia and Panic in an Adult Male with Down's Syndrome

Clinical Case Research Study submitted in partial fulfilment of the requirements for the degree of Doctor of Clinical Psychology

Prepared in accordance with guidelines for contributors to *Journal of Applied Research in Intellectual Disabilities* (see Appendix A)

Keywords: dog phobia, panic, intellectual disability, single subject design

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STRUCTURED SUMMARY

Background

A single case study is presented investigating the effectiveness of a multi-component intervention for the treatment of a specific dog phobia in a 27-year old male with Down's Syndrome. The methodological validity of self-ratings in a client with ID is also investigated.

Method

Global ratings of anxiety and measures of within and between session change were taken. Results were examined using visual inspection and ITSACORR (Crosbie, 1993). Spearman Correlation was used to evaluate agreement between therapist and client anxiety ratings.

Results

Results demonstrated a general reduction in anxiety within and between sessions, with the exception of the third in-vivo session. A global improvement in anxiety was demonstrated and maintained at one-month follow-up. Significant correlations were demonstrated between client and therapist ratings for both anticipatory ($\rho=0.82$; $p\leq.01$) and 3 minute ($\rho=0.56$; $p\leq.01$) anxiety.

Conclusions

A multi-component intervention, comprising graded exposure and controlled breathing is effective for treating dog phobia in ID. Valid self-ratings can be obtained from people with ID, provided scales are tailored to individual abilities.