Adolescents represent 19.5% of the total Jamaican population([2](#_ENREF_2)) and although most adolescents seem to successfully transition to adulthood there are factors that may negatively impact this progression. Factors unique to each adolescent, such as self-esteem, cognitive ability or state of health may impact their development; while extrinsic factors such as their family, school and community environment also influence their developmental trajectory. Chronic illness shares a bidirectional relationship with adolescent development – physical, cognitive and socio-emotional.

This may result in development of negative emotions, involvement in risky behaviours and worsened disease outcomes for the adolescent. Previous studies on chronically ill adolescents have suggested that psychosocial factors may have greater impact on adjustment to the chronic illness than do biomedical factors, including even disease severity ([55-57](#_ENREF_55)). Previous research in Jamaica has identified the presence of caring relationships, having someone they trust and someone to hold them to high expectations as the most significant protective factors among 15 to 19 year olds, with less involvement in high-risk activities ([6](#_ENREF_6)). A core characteristic such as resiliency may serve to mitigate against these potential negative consequences and further positively influence quality of life, disease severity and adolescents’ sense of hope.

Resilience is that interaction between an individual and their environment that determines how they bounce back from adversity or change. Resilience is no longer considered purely inherent or static, but in fact something that can be learned and built upon - developing key personal characteristics as one experiences different events in life. Resilient adolescents have been shown to have better self-esteem and be less likely to engage in risky behaviour as compared to their non-resilient counterparts ([21](#_ENREF_21)). Resilience has also been associated with improved quality of life in adolescents with chronic illness and improved medical outcome([20](#_ENREF_20)). Promotive or protective factors are terms coined to refer to those factors within the individual, family, peer group, school and wider community that contribute to resilience([22-24](#_ENREF_22)). Previous research in Jamaica has identified the presence of caring relationships, having someone they trust and someone to hold them to high expectations as the most significant protective factors among 15 to 19 year olds, with less involvement in high-risk activities ([6](#_ENREF_6)).

Previous studies on chronically ill adolescents have suggested that psychosocial factors have greater impact on adjustment to the chronic illness than do biomedical factors, including even disease severity ([55-57](#_ENREF_55)). One proposed method of mitigating the morbidity and mortality associated with chronic illness later in life is to optimize treatment during adolescence and inculcate good health-seeking and self-management behaviour. There is limited data available on the impact resiliency has on disease outcome in adolescents. In this study we aim to explore the risk and protective factors that influence disease outcome and quality of life in Jamaican adolescents with chronic illness and compare these with healthy adolescent controls.

Primary objective

1. Examine the relationship between resiliency and health outcomes in adolescents
   1. quality of life

b. self-management – medication adherence, clinic attendance

c. psychological outcomes – anxiety, depression and self-esteem, high risk behaviours , body satisfaction

1. ~~to explore sexual decision making in adolescents with chronic disease, with a particular focus on sickle cell disease and HIV where the disease may be sexually or vertically transmitted and~~

We hypothesize that 1) Jamaican adolescents with chronic illness experience increased psychological co-morbidity compared to healthy peers; 2) there is a positive relationship between resiliency and clinical and psychosocial outcomes in adolescents with chronic illness 3) that adolescents with chronic illness experience a worse quality of life, 4)that adolescents with chronic illness engage in more risky behaviours than their healthy peers

Methodology

A case-control study design was adopted and was conducted during 2015-2016. Data was collected utilising paper -based self-administered interviewer-assisted surveys . Participants living with chronic illness were recruited from the specialty clinics (endocrine clinics -diabetes mellitus, pulmonology clinics - asthma, Sickle cell Unit - sickle cell disease and paediatric infectious diseases clinics in the Kingston Metropolitan region in specialty clinics. While healthy adolescents (controls) will be recruited from the schools of the chronically ill adolescents and from their neighbourhoods for those not enrolled in school.

**Participants**

Adolescents age 10 to 19 years old will be recruited into 4 groups

1) Adolescents with sickle cell anaemia (HbSS as confirmed by haemoglobin electrophoresis)

2) Adolescents with insulin-dependent diabetes mellitus

3) Adolescents with physician diagnosed asthma

4) Adolescents known to be HIV positive (perinatal and behavioural infected adolescents)

5) Healthy adolescents with no known chronic illness (as determined by self-report)

Adolescents with chronic illness will be recruited in the Kingston metropolitan region from:

Out - patient specialty clinics at

* + UHWI (paediatric and adult endocrinology clinics, paediatric and adult pulmonology clinics, paediatric infectious disease clinic)
  + Bustamante Hospital for Children (pulmonology clinic)
  + KPH (medical out-patient clinic)
  + Chest hospital (pulmonology clinic)
  + Spanish Town hospital (medical out-patient clinic, HIV clinic)
  + The Sickle Cell Unit, UWI
  + Comprehensive health centre (HIV clinic)

Each adolescent recruited with a chronic illness will be matched (by gender and age within 3-6 months of the case) with 2 class mates (for those attending school) or 2 matched neighbourhood controls within their community (for out-of-school participants) for comparison. Each control participant will be asked to complete a screening questionnaire (Appendix 12) to rule out any diagnosed chronic illness to ensure their eligibility as a control participant.

**Inclusion criteria**

* Adolescents age 10 to 19 years
* Chronically ill adolescents with one of four chronic illnesses
  + (asthma, insulin-dependent diabetes mellitus, HIV or sickle cell disease)
* Chronically ill participants must have been diagnosed at least 1 year prior to the start of the study.
* School or community control of a case with no known chronic illness
* Consent and/or assent forms received as appropriate to age of adolescent

**Exclusion criteria**

Participants will be excluded if they

* + are acutely ill on presentation to clinic
  + have more than 1 chronic illness (confirmed by interview with patient/parent and review of medical notes where available)
  + have a neurological disorder (eg. stroke) or intellectual impairment that precludes ability to respond to questions
  + have not had their diagnosis disclosed to them (in particular HIV) and this will be clarified with clinic personnel and caregiver
  + attend boarding school
  + fail to return a signed consent and/or assent form

**Sample size**

The paucity of studies investigating resilience in chronic illnesses influenced the ability to determine the sample size based on this variable. A sample size of 57 participants per group is adequate to detect at 80% power a difference between self-esteem score means when two groups are compared using a two-sided hypothesis test. This was calculated using mean (sd) for group 1 as 2.27 (1.16) and mean (sd) for group 2 as 2.82 (0.92), values obtained from comparison of self-esteem in adolescents with leukemia and diabetes mellitus([58](#_ENREF_58)). In the absence of available data on measuring resilience on a comparative basis, a sample size of 60 per group will be used in this study.

**Ethical considerations**

Ethical approval will be sought from the UHWI/UWI/FMS Ethics Committee, Ethics committee for Ministries of Health and Education. There are minimal foreseeable risks to the participants and all efforts will be directed to maintain strict confidentiality. No participant will be chosen because of easy availability, diminished autonomy or social bias. Any participant who becomes distressed during the study will be referred to the Adolescent Medicine (Teen) Clinic at the UHWI for further care.

**Data collection**

*Procedure*

After receiving ethical approval, the South Eastern Regional Health Authority (SERHA) and the administration of the relevant hospitals and health centres will be approached for approval to conduct the study in the relevant outpatient clinics. Health care providers in the clinics will be informed of the study and asked to allow recruitment of patients. Fliers highlighting the study will be posted in the clinics in highly visible spaces to increase general awareness of the study. Information on the fliers will be generic to avoid any public knowledge of the specific illnesses being reviewed and therefore assuage adolescents’ possible concerns with regard to stigma, especially those ALHIV. The physician in charge or their designate will also be asked to ask patients and parents if they are willing for research assistants to approach them to hear more about the study. Researchers/ research assistants who are not involved directly with the clinical care of persons being recruited, will approach adolescents and their parent/caregiver at the relevant clinics while they are waiting to be seen. Alternate adolescent patients (aged 10 – 19y) who present to clinic and have one of the four specified chronic illnesses will be approached as a potential participant. The purpose and procedures for the study will be thoroughly explained to the adolescent and their parent(s) and all queries will be addressed as best as possible.

Healthy controls, age and gender matched will be chosen randomly from the same school and class as the participant with a chronic illness (case). Teachers will be asked to identify all students of similar gender with dates of birth within 3 months before and after the date of birth of the case. Two of those identified will be randomly selected and invited to be control participants. Teachers will not be informed which student in the class is the case. For participants with a chronic illness (cases) that are not currently attending school, age and gender matched controls will be chosen from within cases’ neighbourhoods.

Written informed consent will be obtained before enrolment into the study from parents of those participants under 18 years, along with an assent form from the minor (17 years or younger). A consent form will be obtained from adolescent participants 18 years or older.

*Instruments*

All instruments being used are either open source or permission for use has been granted by the authors (Appendix 15). Those instruments that have not been previously used in the Jamaican adolescent population will be piloted for content and cultural relevance. Data collection will be performed in a private space by trained research assistants in the clinic for those adolescents with chronic illness, and at school or home for the healthy adolescent controls.

A medical data extraction sheet will be used to record biomedical information from medical charts including disease specific outcomes (Appendix 1). This information will be used to better determine the physical impact of the illness including growth, development and any organic pathology resulting, as well as other factors that may impact quality of life and resilience such as hospital admissions. All participants will have their weight, height and blood pressure measured. Weight will be measured to the nearest 0.1kg using a digital scale and height will be measured to the nearest 0.1cm using a stadiometer. Blood pressure will be measured to the nearest 1mmHg using an appropriately sized cuff on the right arm supported at chest level with the participant in a seated position. Participants will be asked to self-assess their sexual maturity by matching with standard Tanner stage drawings (stage 1 through 5) ([59](#_ENREF_59)), this with an aim to decrease potential recruitment refusal if a physical examination of genitalia by a researcher is required.

Psychosocial data will be collected using a series of questionnaires to investigate socio-demographics, resiliency, quality of life, self-esteem, body image and risky behaviours of participants.

i) General questionnaire – will enquire about socio-demographic data using the 18-item questionnaire adapted from the demographic module used in the Youth Risk and Resiliency Survey 2006([6](#_ENREF_6)) along with other questions exploring risky behaviours in adolescence. (Appendix 2)

ii) The Adolescent Resilience Questionnaire ([60](#_ENREF_60)) comprises 88 items with 12 scales measuring resilience factors in the domains of self, family, peer, school and community. This tool measures adolescents’ capacity to achieve positive outcomes despite life stressors. (Appendix 3)

iii) Adolescents’ quality of life will be investigated using the Peds QL questionnaires. All participants will be asked to complete the PedsQL core and well-being modules ([61](#_ENREF_61)). (Appendices 4 and 5).

Participants with a chronic illness will be asked to complete the relevant disease-specific version where available (PedsQL-Asthma([62](#_ENREF_62)); PedsQL – Diabetes; PedsQL -Sickle Cell disease([63](#_ENREF_63), [64](#_ENREF_64))). (Appendices 6A – 6C).

iv) Parents will also be asked to assess their child’s quality of life via proxy report using the PedsQL-Parent form. (Appendices 7A-E).

v) Disordered eating behaviours, attitudes and body image concerns will be measured using the multidimensional body-self relations questionnaire (MBSRQ) which is a 34 item questionnaire that explores the way persons relate to their body and its external appearances ([65](#_ENREF_65)). (Appendix 8).

vi) Global self-esteem will be measured using the Rosenberg self-esteem scale ([66](#_ENREF_66)) which is a 10 item self-report instrument using a four point Likert response scale. (Appendix 9).

vii) Mood disorders will be assessed using the center for epidemiological studies depression scale (short form) CEDS-10 for depressive symptoms which is a 10 item screen that has been validated in adolescents ([67](#_ENREF_67)) and the 7-item generalized anxiety disorder questionnaire (GAD 7) for symptoms of anxiety. (Appendices 10 and 11).

viii) The Adolescent decision making questionnaire (ADMQ) will be used to assess adolescents’ decision making capacity. The ADMQ is a modified version of the Flinders decision making questionnaire to create a more adolescent user-friendly questionnaire ([68](#_ENREF_68)). It has been found to have good face and construct validity, with good test-retest reliability and internal reliability with satisfactory measures of the Cronbach’s coefficient (0.7 or higher in all scales)([69](#_ENREF_69)). (Appendix 14).

ix) Raven’s Progressive matrices will be administered to participants. This is a non-verbal assessment of general intelligence which has been used on numerous occasions in the local population and has been validated. It consists of a set of increasingly complex coloured matrices that test-takers need to identify the matching symbol for. This will be used to determine whether differences in decision making-capacity are being significantly influenced by participants’ level of intelligence.

x) Healthy controls will be screened to ensure they have no known chronic illnesses using a screening questionnaire. (Appendix 12)

All questionnaires will be self-administered with no identifying data on them. Research nurses will be available to clarify any questions that are not clear to participants. Information retrieved will be kept confidential in an effort to optimize the honesty of the answers adolescents give and therefore validity of the data obtained.

Parents of participants will be given a ‘Parent Information pamphlet’ to highlight some of the potential challenges of adolescence, as well as warning signs to observe for in their adolescent(s) and where they can seek help if concerned.

It is estimated that collection of all quantitative data will take approximately 1- 1 ½ hours (60-90mins). In anticipation of possible participant fatigue due to the number of questions to be asked, participants will be given the option of a refreshment break at the halfway mark.

Variables

Biomedical - Height ; Weight; BMI; Pubertal stage – self assessed

Psychosocial data

i) Demographics – age, sex, family characteristics – birth order, parents marital status ; income

2) risky behaviours – sexual activity , substance use ,

ii) The Adolescent Resilience Questionnaire ([60](#_ENREF_60)) comprises 88 items with 12 scales

|  |  |
| --- | --- |
| **INDIVIDUAL DOMAIN** | |
| **Confidence (self and future)** | |
| **Emotional insight** | |
| **Negative cognition** | |
| **Social skills** | |
| **Empathy / Tolerance** | |
| **FAMILY** | |
| Connectedness | |
| **Availability** | |
| **PEERS** | |
| **Connectedness** | |
| **Availability** | |
| **SCHOOL DOMAIN** | |
| **Supportive Environment** | |
| **Connectedness** | |
| **COMMUNITY DOMAIN** |
| **Connectedness** |

iii) QOL ; adherence to medication as an outcome

Core and well-being – for all

Chronic illness - disease-specific version

PedsQL-Parent form. (Appendices 7A-E).

v) MBSRQ - Disordered eating behaviours, attitudes and body image concerns

vi) Rosenberg self-esteem scale

vii) Mood - CEDS -10 ; GAD-7

viii) The Adolescent decision making questionnaire (ADMQ)

ix) Raven’s Progressive matrices -non-verbal assessment of general intelligence