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International Journal of Child and Adolescent Health

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The health of our youth and lessons from national surveys

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Introduction

There are many potentially risky behaviors that youth can engage in. Some of them can have implications for both their well-being, their life prospects and for others in their environment. Smoking, drinking, sex, drugs, driving, violence are just some of the important issues that can have some important ramifications for the remainder of their lives. These risky behaviors have changed and will change over time and it is therefore important that society try to monitor trends and risks in order to prevent damage or at least minimize long term effects on the youth.

It is therefore important that the Youth Risk Behavior Surveillance System (YRBSS) was created, which monitors six categories of priority health-risk behaviors among youth and young adults: 1) behaviors that contribute to unintentional injuries and violence, 2) tobacco use, 3) alcohol and other drug use, 4) sexual behaviors that contribute to unintended pregnancy and sexually transmitted diseases (STDs), including human immunodeficiency virus (HIV) infection, 5) unhealthy dietary behaviors and 6) physical inactivity (1). YRBSS also monitors the prevalence of obesity and asthma. YRBSS includes a national school-based Youth Risk Behavior Survey (YRBS) conducted by CDC and state and large urban school district school-based YRBSs conducted by state and local education and health agencies (1).

The last report for 2010-2011 (1) is a summary from 43 state surveys and 21 large urban school district surveys conducted among American students in grades 9–12. This national 2011 survey indicated that many high school students are engaged in health-risk behaviors associated with the leading causes of death among persons aged 10–24 years in the United States. The results showed that during the 30 days before the survey, 32.8% of high school students nationwide had texted or e-mailed while driving, 38.7% had drunk alcohol and 23.1% had used
marijuana. 12 months before the survey, 32.8% of students had been in a physical fight, 20.1% had ever been bullied on school property and 7.8% had attempted suicide. Many high school students nationwide were engaged in sexual risk behaviors associated with unintended pregnancies and STDs, including HIV infection. Nearly half (47.4%) of students had ever had sexual intercourse, 33.7% had had sexual intercourse during the three months before the survey and 15.3% had had sexual intercourse with four or more people during their life. Among currently sexually active students, 60.2% had used a condom during their last sexual intercourse.

Youth are also engaged in behaviors associated with the leading causes of death among adults in the United States. During the 30 days before the survey, 18.1% of high school students had smoked cigarettes and 7.7% had used smokeless tobacco. During the seven days before the survey, 4.8% of high school students had not eaten fruit or drunk 100% fruit juices and 5.7% had not eaten vegetables. Nearly one-third (31.1%) had played video or computer games for three or more hours on an average school day.

Since 1991, when these surveys started, the results have helped public health professionals to try various intervention and preventive measures. These efforts have decreased the prevalence of many health-risk behaviors, like never or rarely wearing a seatbelt, riding with a driver who had been drinking alcohol, current frequent cigarette use and being currently sexually active. On the other hand the percentage of high school students who are obese increased during 1999–2011 and the percentage who drank three or more glasses per day of milk and who routinely used sunscreen decreased during this same period. In addition, among students who currently smoke cigarettes, the percentage who tried to quit smoking cigarettes decreased during 2001–2011. Emerging behavior patterns can be detected by examining temporal changes during 2009–2011. For example, encouraging changes during 2009–2011 include a decrease in the percentage of students who currently used alcohol and binge drank and an increase in the percentage of students who ate vegetables three or more times per day. Concerning changes during 2009–2011 include a decrease in the percentage of students who were taught in school about AIDS or HIV infection and an increase in the percentage of students who attempted suicide and currently used marijuana.

The data from such surveys are used for public health action and the trends can guide professionals in their field work to promote more effective prevention and school health programs to reduce risk and improve health outcomes among our young people. We still have work to do.

References

REVIEW ARTICLES
The self-management and transition to adulthood program
“UNC STAR₇”: Instruments and lessons from the field

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Abstract

The University of North Carolina’s Self-management and Transition to Adulthood withRx=therapies Program (UNC STAR₇) has gained experience since 2006. This manuscript describes the program’s evolution from a nephrology-centric intervention to addressing multiple-conditions in an institution-wide interdisciplinary program. We illustrate the lessons and insight informed by youth with chronic conditions/disabilities, parent, health provider and community partner perspectives across the continuum of health care transition (HCT). Specifically, lessons relate to program sustainability, including the importance of a dedicated program coordinator, inter and intra-institutional collaboration to validate tools that promote and assess patient self-management skills and HCT, strategies to improve youth, provider (pediatric and adult-focused) and parent communication, and the important role for peer volunteers (in person or through social media) are addressed. The UNC STAR₇ Program’s collaboration has produced IRB-approved tools that promote communication between youth with chronic conditions and providers, while outlining customized interventions based on patient’s level of knowledge and skill mastery. Two private foundations provided initial funding and it now has become an institution-wide collaborative funded primarily by the North Carolina Children’s Hospital. The UNC STARx partners include youth with chronic conditions and disabilities, families and researchers from several disciplines and institutions in our state, nation and the world. Our innovative program holds great promise and it already appears to improve health outcomes and quality of life for youth and their families (based on participation rate and user satisfaction both at ≥95%). Our lessons from the field may assist other institutions as they strive to improve adolescents’/young adults’ health outcomes through evidence-based and cost-effective interventions.

Keywords: Transition, health care transition, transition program, self-management, adolescence, chronic conditions, social media, parents, disabilities

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Introduction

Health care transition (HCT) is a dynamic, patient- and family-centered process that involves the purposeful, planned movement of adolescents and young adults with chronic physical and medical conditions from child-centered to adult-oriented healthcare systems (1-3). The consensus goal of HCT is for adolescents and young adults (youth) to successfully engage the adult healthcare system in order to receive high-quality, developmentally-appropriate health care services, thus maximizing their lifelong functioning, potential, and quality of life (3,4). Toward this end, the HCT process is deliberate and focused, meets the needs of an individual, and prepares an adolescent or young adult with a chronic illness to assume progressive increasing responsibility for the management of their health (3,5-7).

HCT planning ensures a smooth, uninterrupted, and coordinated transfer from pediatric to adult health care providers and services. Ideally, the HCT process is flexible, responsive, continuous, comprehensive, and well-coordinated, and is championed by a transition program and/or care providers that ensure appropriate HCT planning and support are provided (3,4,6,7). The recommended key components of an effective HCT program are: 1) a designated professional responsible for HCT coordination, 2) development of written HCT plans at the onset of adolescence and 3) formulation of a written portable medical summary ready at the time of transfer to adult providers (3,5-7).

Despite consensus recommendations that youth with chronic conditions benefit from HCT programs (3-7), barriers to the establishment of effective HCT programs still persist. Firstly, there is lack of agreement regarding a theoretical model to support transition, despite a few proposals of interest (8,9). By extension, there is lack of agreement about the identified targets of intervention and clinical outcomes to measure transition (10). Secondly, there is no consensus about which individual should serve as the HCT coordinator, the coordinator’s level of training, or the coordinator’s function. Thirdly, health provider compensation to carry out HCT services also remains a barrier. Additionally, HCT program funding is a critical barrier as most HCT programs are not supported by institutional budgets and thus must rely on external sources of funding.

In this paper, we describe our experience in launching our institution-wide HCT program: called the UNC STARx (Self-management and Transition to Adulthood with Rx=treatment). We share the lessons we have learned and the insight we have gained from working with youth, parents, and community partners. We also briefly describe the tools that we have developed, currently utilize, and continue to validate in order to guide youth with chronic medical conditions/disabilities, their families, and the health providers who serve them in the HCT process.

Program organization and sustainability

In 2006, with the enthusiastic support of adolescent/young adults with chronic conditions and their parents, the need for the interdisciplinary self-management and transition program was acknowledged and addressed. The initial impetus for this collaborative effort was triggered by anecdotal experience with survivors of pediatric-onset chronic kidney disease who had poor outcomes (loss of transplant, lost to follow up, or death) subsequent to their transfer to adult-focused health. In preparation for establishing a formal program at UNC, the founder and program director visited the transition programs of Dr. Alan Watson (Nottingham, UK) and Dr. Janet McDonagh (Birmingham, UK) and conducted semi-structured interviews with published experts in the field of transition (see acknowledgments). The purpose of these initial discussions was to explore organizational models, ascertain how programs were funded, determine how multidisciplinary, intra-institutional partners were identified/recruited, and identify available tools for assessing young adults’ progression in achieving readiness for transfer (see acknowledgments). Two distinct lessons derived from these exploratory visits informed our programmatic plans: 1) no validated tools were available for dissemination, and 2) funds to support a targeted transition program were difficult to secure.

It was clear that a distinct organizational advantage at UNC was that pediatric nephrology resides within the internal medicine nephrology
group. This embedded model provides pediatric nephrology with greater fiscal stability and shared clinic space, promoting collaboration between pediatric and adult providers. In addition, increased communication between UNC pediatric and adult nephrology providers engendered improved communication between external providers who either referred or received adolescent/young adult patients.

Initial funding for the STARx was through a three-year award from the K.B. Reynolds Charitable Trust, and following HCT consensus guidelines a full-time transition coordinator position was established. This position proved critical to achieving timely execution of readiness assessments and was instrumental in achieving patient-centered education and in promoting communication between community partners (teachers, support agencies), the health care provider, the patient and the parent(s). Ms. Kristi Bickford has a BA degree in Psychology and extensive experience working with children and adolescents in the judicial, social service, and mental health fields. She has been the sole transition coordinator since the inception of our program. Following the expiration of the initial grant support, bridge funding was secured from the UNC Departments of Internal Medicine and Pathology.

A grant from the Agency for Healthcare Research and Quality through the UNC Center for Education and Therapeutics, partly supported the development one of our tools, the STARx Survey; a self-administered questionnaire to assess transition readiness and disease management skills (11).

The UNC Kidney Center and the Department of Pediatrics partially funded the development of our second tool, the TRxANSITION Scale™ It is a provider-administered survey to measure the adolescent/young adult’s self-management skills and disease specific knowledge. The development of a parallel TRxANSITION Scale-Parent Version™ was partly funded by the Renal Research Institute. Dr. Maria Ferris had previously developed and used a medical passport, which was adapted to be used in the STARx Program started, and it is now known as the TRxANSITION Medical Passport™

Since 2010, the University of North Carolina Children’s Hospital Administration has provided funding for the program’s full time transition coordinator, providing important stability. This substantial financial support has facilitated the expansion HCT services to receiving care in other pediatric subspecialties, including: Gastroenterology, Rheumatology, Endocrinology, Hematology, and Pulmonology. Additional research manpower, in the form of a psychology graduate student, two medical students and a coordinator, has been achieved with awards from the Renal Research Institute and the American Society of Nephrology, supporting two one-year funding for two medical students and 20% of Dr. Ferris’ salary. In-kind donations from the UNC Kidney Center and the UNC Schools of Arts and Science, Public Health, and Nursing, as well as the Carolina Institute for Developmental Disabilities, the Center for Faculty Development and the Odum Institute are essential sources in our continued effort (administrative support, office space and research program). With a dedicated HCT coordinator and additional research personnel, over 300 are being followed longitudinally, including post-transfer to adult focused health care. For further detail on the program timeline, partners, tools and funding, please see Figure 1.

Patients served and staff/volunteers

Patients: Our program enrolls patients between the ages of 12-24 years who have been diagnosed with a chronic health condition for at least 6 months. Additional inclusion criteria include: taking at least one medication daily for the diagnosed chronic condition and the cognitive ability (as deemed by their providers) to understand and answer questions about their medical condition(s) and treatment. All patients that accept our invitation to participate in our program sign an IRB-approved consent permitting access to their medical and pharmacy records for longitudinal data collection. Patients and their parents are enrolled in person during a routinely scheduled clinic visit. During the clinic visit the majority of the tool administration and assessments are completed, followed by phone or online administered surveys when necessary). We currently have a 95% program enrolment rate with an equally high proportion of reported participant satisfaction in the program at 95%).
Program staff and volunteers: By in large, our most influential team members are the youth with chronic medical conditions and their parents who volunteer their time, knowledge, and suggestions, guiding the advancement in our work. The STARx team is multi-disciplinary and composed of paid staff, grant funded researchers, and volunteers. The medical director receives 20% salary support via grant funding and a fulltime transition coordinator whose salary is 100% supported by the UNC Children’s Hospital. We collaborate with professionals amongst various disciplines including: nursing (nurses and nurse practitioners), pharmacy, clinical psychology, developmental disabilities, education, social work, public health and recreational therapy. Furthermore, the UNC STARx Program is aided by the work of five diligent student researchers (two medical and one psychology graduate student whose positions are funded by research grants provided by the American Society of Nephrology; and two part-time pre-medical students funded by the Renal Research Institute). Our team is also composed of a cohort of diverse student researchers volunteering their time during summer breaks.

Tools to measure transition readiness

The STARx Transition-Readiness Survey: This questionnaire was a collaborative work utilizing valuable input from adolescents and emerging adults with various chronic medical conditions. The 18-question survey was developed through the use of patient focus groups, focused interviews, and cognitive interviews, including the “concurrent think-aloud” technique in which responses are probed extensively. This tool was created with supplemental input acquired from patient-graduates and existing patients of our pediatric renal program; information obtained from published check lists of transition skills; and interdisciplinary collaboration between students of the UNC School of Public Health (Department of Health Behavior/Health Education). Using the Stages of Change Model, the STARx survey was designed to longitudinally measure self-reported health care transition readiness and disease self-management skills. The STARx Transition-Readiness Survey includes self-reported knowledge of (1) disease diagnosis, (2) medications/treatment, (3) health insurance, (4) ability to make medical
appointments, (5) ability to use health resources and (6) disease self-management. This web-based tool is administered every 6-12 months and is undergoing validation in clinical and therapeutic camp settings (11). Most recently, we are comparing the performance of this survey among adolescents with chronic conditions to another self-administered tool (12). (See Figure 1).

The TRANSITION Scale™: The TRxANSITION Scale™ (trademark 2006, University of North Carolina) is a longitudinally designed tool used to assess and monitor the HCT process; and is readily accessible (web-based) and reproducible in clinical practice (Ferris et al in press Renal Failure). This scale produces a collective score using the following 10 transition related domains: Type of illness, Rx (medications), Adherence, Nutrition, Self-management, Issues of reproduction, Trade/school, Insurance, Ongoing support, and New health providers. The scale has been revised thrice to support and reflect the current structured interview format. It should be noted that administration of the scale not limited to health providers. Our program is an example of how people with limited to no medical knowledge or backgrounds can be trained to effectively administer this tool (reproducibility kappa score 0.76). The scale collects information through both, confirmation of attained knowledge and skill mastery claimed (i.e. the patient has to name his/her medication(s) to get credit for the answer) and patient self-report (13-16). This allows the health provider to commend the youth on their attained knowledge/skills and helps them provide developmentally-appropriate patient-education activities in the areas of low competency. The scale is administered every 6-12 months, monitoring progress in a de-identified web-based format.

Preliminary analysis of a cross-sectional pilot study revealed adolescents younger than 17 years had a significantly lower score than older teens and young adults, with those younger than 14 years having the lowest scores (13,14,16). This may reflect life experiences and time-varying development as the adolescent matures. Validation studies are underway to assess the instruments’ effectiveness in a longitudinal study design. Internal medicine and combined internal medicine-pediatrics fellows assume the care of transitioned patients when the youth achieve a TRxANSITION Scale™ score of > 80%.

The TRxANSITION medical passport™: This tool helps teach youth with chronic medical conditions about their disease and facilitates communication between health care providers in emergency rooms and clinic settings. This laminated, wallet-sized document contains the following patient-specific health information: medical diagnosis, current medication list (type, dosage, frequency, and purpose), drug allergies, and medical provider contact information. The TRxANSITION Medical Passport™ also includes the patient’s name, photograph (if they wish), emergency contacts, and their unique patient ID number. The medical passport is updated every 6-12 months to reflect their most current health and personal information. In an effort to evaluate retention and usability, patients are contacted and asked if they have their medical passport in their possession (17). To confirm that they do in fact have it, they are asked to read their ID number located in the upper right-hand corner of the card. User satisfaction and feedback from providers (in emergency departments and clinics throughout the state) has been enlightening.

Peer-support and on-line Facebook™: Our transition coordinator is the administrator of a Facebook™ page for some of the young adults who participate in our STARx program. She monitors communication between the invited members and proposes relevant, age-appropriate topics of discussion. This expansion into a social media forum has led the participants to discuss their challenges to self-manage their conditions, and finding the appropriate support systems. This platform encourages active communication among members and provides a non-threatening, non-judgmental environment. Youth share stories, coach one another, ask questions, and seek support. There have been several instances when a group member has been hospitalized and other members coordinate a visit to the hospital. Many of the young adult members of this group have said that they don’t feel comfortable posting status updates about their health on their personal Facebook™ pages. In contrast, our HCT Facebook™ page monitored by our transition coordinator provides an environment where they feel comfortable to post about their feelings (e.g.
being different from “healthy” peers, sadness about having a health condition, frustration with taking medications daily), struggles (e.g. medication side effects, special diets, wheel-chair dependence), and triumphs (e.g. hospital discharge, receiving a transplant, medication removed, etc.) related to their health. Table 1 depicts recommendations for health providers that the youth in our program have.

**Table 1. UNC STAR, Program Youth Recommendations to Health Providers**

1. **Customer service**
   **In the outpatient setting:**
   a. Everyone should have a smile to show they are happy to see you
   b. Good bed-side manners by providers
   c. All signage should be clear and visible (as in an airport) to navigate the system.
   d. Clean environment in the clinic but not smelling like a hospital
   e. A waiting room that is the “Apple™ stores of clinic”, airy, nicely designed, not cluttered
   f. Magazines that are up to date and today’s news-paper,
   g. Relaxing music in the background at low volume/having a fish tank
   h. Health message in posters, computer screens or TV monitors with nicely designed graphics with colors that are great to look at, almost artistic; surprising the consumer that they are actually health education messages
   i. Email system for staggered appointments with times that are respected.
   j. Paying co-pays up-front to stand in line at the check-in/out counter once
   k. Patient portal to access medical record

**In the in-patient setting:**
   l. Hospital gowns are not cool, they are demeaning and revealing
   m. Children’s wards prevents the youth from getting sleep (crying babies next door)
   n. Adult wards is also not appropriate and they would prefer an adolescent and young adult unit that caters to their unique needs and morbidities
   o. Being able to eat or drink on a timely basis if a potential procedure is cancelled

2. **Health care providers that**
   a. Direct the conversation to the adolescent and young adult
   b. Ask for the youth’s opinion
   c. Ask the parents to leave the room
   d. Reassure the youth that all conversations are private
   e. Inspire confidence and trustworthiness, as a friend. Youth patients often “don’t know what we don’t know” until they are faced with a question or having to explain it to someone else.
   f. Listen to the youth’s concerns
   g. Relates to young-adults interests by being up-to-date in music, movies, sports
   h. Encourage questions by the youth and help navigate the system
   i. Teach how to explain their condition to their peers
   j. Showing the awards the clinic or providers have received or the results of the research

3. **Continuous Quality Improvement**
   a. Individualized patient and parent education, re-education and re-training, particularly those patient who were diagnosed early in life
   b. Counseling about how to successfully self-manage their condition
   c. Meeting older patients serving as mentor/coaches or even examples of what not to do with tangible consequences (i.e. Somebody who lost a transplant due to no-compliance)

4. **Creating a patient health ambassador program:** Using the principle “You see something, you do something, you teach something”

5. **Getting a Health Care Transition Graduation Certificate**

6. **Ecological Aspects of Health**
   a. Secure individualized education plans and assistance with 504 Educational plans
   b. Participation in therapeutic camp
   c. Involvement in peer-support group
Recurring themes youth have taught us through personal and on-line conversations include:

- The importance that health providers have in their lives and sense of well-being.
- Providers can inspire trust particularly if they express confidence in the youth’s ability to manage their condition and lives. On the other hand, providers can also inspire distrust if the youth are treated without respect or their opinions are discounted.
- Youth…
  - like to be included in all conversations that affect their lives
  - actually hear what the health providers advise, but don’t necessarily agree at times
  - worry about the burden their diagnosis brings to their parents/siblings and family
  - like to have peer support and the ability to share “war stories” and advice from peers who are experiencing the same struggles they encounter (18)
  - would like having more relaxed communications with their providers as conversations expand to survival and life goals
  - want to be affirmed of their growing autonomy

Lessons from the parents of youth with chronic medical conditions

For youth with chronic medical conditions, parents assume a variety of roles that include care coordinator, medical expert, and patient advocate (19). Additionally, as their child develops through adolescence and acquires self-management skills, the role of a parent ideally transitions from that of a manager, to a supervisor, and then finally a consultant (20). Through their monitoring, supervision, coaching, and support of skill-development, parents play a significant role in HCT (8,9,21)

Initially, the UNC TRANSITION Scale™ was administered to patients in private, without their parent(s) present. About two years ago, our transition coordinator began to administer the scale to the youth in the presence of their family members, as long as the family members remain silent during the assessment. Due to time constraints and limited clinic space, she recognized that a parent’s non-participatory presence during assessment served as an excellent learning and teaching opportunity to both, the youth and the parent. By doing this, our HCT coordinator discovered that many parents did not know the level of skills their children possessed, or, worse yet; parents would mention that they themselves did not know the answer to many of the questions related to their child’s medical condition(s) and management. This was a very concerning finding, since parents are important facilitators of their children’s acquisition of medical knowledge and disease self-management. We considered this as one of the most valuable lessons from the field as this experience reinforced the need for a targeted educational intervention that is both patient- and family-centered.

As a direct result of this experience, the complement to the UNC TRANSITION Scale™ for Adolescents and Young Adults was expanded to include a parent version (22). This parent version serves as an assessment of a parent’s disease and medication knowledge of their child’s condition and as an additional proxy report for the youths’ self-management, medication adherence and other HCT-related skills mastery (23). In table 2 we have summarized the UNC TRANSITION Program parent recommendations for health providers.

Community partners and volunteers

We have partnered with Victory Junction, a camp located in Randleman, NC, providing year-round programming for children with chronic and life-threatening conditions and their families. Victory Junction has allowed the UNC Star Program to conduct summer research programs that include the deployment of web-based surveys to children and adolescents with a variety of chronic medical conditions who participate in this therapeutic camp (18,23). In-kind donations by Victory Junction have allowed an expansion of services to organize the annual Young Adult Weekend, serving adolescent and emerging adult patients with chronic medical conditions.
conditions. During this annual weekend, 16-24 year-old participants are able to engage in camp activities and teambuilding sessions, while learning about health care transition and disease self-management.

The UNC STARx Program has attracted the assistance of undergraduate, graduate and medical students from several institutions. Two of our students have received “abstract of the year awards” in international conferences (22,23) and summer students have secured funding from the NIH and private foundations. This year, two of our participating medical students each received a 12-month grant from the American Society of Nephrology to conduct research in the area of health care transition (14,22).

Table 2. UNC STARx Program Parent Recommendations to Health Providers

1. Customer service: Similar to the youth recommendations plus…

   **In the outpatient setting:**
   a. Have a care coordinator, particularly if multiple consultants are involved
   b. Psychological services should be offered as soon as the chronic diagnosis is made and presented to the family as an expected referral for all patients
   c. Schedule 2-4 appointments in one day to avoid losing work days
   d. Identify parent and patient support groups

   **In the inpatient setting**
   a. As much as possible be consistent with the rounding time, so that they can rest and are able to talk with the provider every day
   b. Have a multidisciplinary family meeting once per week to improve communication with all involved
   c. Having the same nurse care for their child to allow continuity
   d. Participate in holiday-related decorations or floor activities to be considered part of the team, improve the environment and get respite
   e. Getting blood work at 4:00 AM is not friendly, especially when it has been a rough night
   f. Try to do blood work from peripheral IV when possible to decrease veni-punctures
   g. Admission to the same floor whenever possible
   h. Minimize radiation exposure
   i. Have laundry-related services available for long-term admissions
   j. Being able to have your child use regular clothes and not the hospital gowns
   k. Have a parent tray of food

2. Their fears
   a. That their child will not be able to survive
   b. Who will assist their child manage their health conditions and their lives as they age
   c. Financial burden
   d. Strain in their marriage
   e. Losing their jobs
   f. Having enough time for their other children and themselves
   g. Keeping their sanity and optimism

3. Their need for continuous education on
   a. Their child’s diagnosis, especially if the diagnosis is early in life.
   b. Education material that is literacy- and culturally-appropriate
   c. Guidance on how to find community resources
Partnering with other HCT programs

The UNC STAR Program has also collaborated with the North Carolina Health and Transition Project, a grant by the Agency of Healthcare Research in Quality to the North Carolina Department of Health. Following the conclusion of the grant, we continued our state-wide collaboration by contacting other HCT programs and researchers outside of North Carolina. As a result, we co-founded what is now known as the International and Interdisciplinary Health Care Transition Research Consortium. This consortium holds monthly telecommunication conferences and has bi-annual face to face meetings, with the purpose of advancing the evidence in the field of HCT (22). This has allowed for formal research collaboration of our proprietary tools with Nationwide Children’s Hospital/The Ohio State University (pediatric and adult transplant programs), Carolinas Medical Center, the University of Michigan, Hospital Infantil de Mexico, and Universidad de Puerto Rico.

The (long) road ahead

Our program will continue to provide needed services while collecting longitudinal data and evidence on health care transition readiness and disease self-management. Innovation and program development will continue, driven by our patients’ experiences and what they teach us. Generalizability of these innovative tools and applications will come from collaborative studies with our committed present and future partners. Understanding and appreciation of the efforts of other practitioners and investigators in this field will continue to inform us and help us all develop the science of HCT. Of paramount importance will be defining cost-effectiveness of our efforts – the costs of failed transplants and unnecessary medical complications is all too evident to many but need to be assessed systematically and balanced against our HCT efforts and costs. Over time, evidence and best practices will emerge and be defined.

We will continue to recognize and honor the essential input of youth and their families who ultimately define how we can best serve their needs. Interdisciplinary collaboration among pediatric patients, team members and practitioners will further assist in tool refinement to assure general application. Our commitment to collaboration with other programs in North Carolina, the United States and countries around the world will continue to advance the evidence and knowledge in the field of health care transition. In the end, expanding our HCT program to those with varying medical conditions, and linking to innovative programs underway at other centers, will allow us all to develop useful and valid HCT-specific tools and reliable outcome measures to decrease morbidity/mortality of our youth with chronic health conditions/disabilities and to improve their health-related quality of life.

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*Published/field experts consulted prior to our program's inauguration.

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Self-management and transition

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Youth suicide prevention at grassroots

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Abstract

The suicide literature suggests that mental illness and in particular depression are the main causes of suicide. Worldwide government policies of addressing mental illness have been the main focus for suicide prevention, which coupled with a moratorium on reporting and public debate of suicide appears to deliver ineffective services. A prevention scheme that is based on intervention will be ineffective because intervention mainly occurs at or after an outcome such as incidence of an illness. Not everyone suffers from mental illness, and not everyone who suffers from mental illness will commit suicide. However, there is a growing body of literature that challenges the mental illness-suicide link. This paper argues that suicide is the result of a complex decision making process by individuals who live in communities and contribute to society. Therefore any interventions must be holistic and at grassroots level. The application of Kentucky University’s ‘stop youth suicide’ campaign to a New Zealand community is briefly discussed.

Keywords: Adolescence, suicide, prevention, New Zealand

Introduction

In spite of the large volume of literature on suicide the public health strategy on suicide prevention is still reliant on a medical model that treats suicide as a mental illness. There is however, confusion within the literature which is often due to poor study design and methodological flaws associated with human behaviour. Suicide data, in particular those based on psychological autopsy type investigations such as Beautrais (1-3), are often plagued with a high degree of bias. Given the current public mindset, helped by the medical model and the media, that depression causes suicide, the collection of data on suicide cases from friends and relatives after the event of suicide will be highly biased towards mental illness, as is the case with the Canterbury Suicide Project (1-3). Studies that fail to address the methodological issues
related to design, data collection and analysis will lead to misleading and conflicting conclusions. For example, Beautrais (1-3) used a psychological autopsy method and collected information about suicide cases from family and friends to conclude that mental illness causes suicide. Khan et al (4) claimed that antidepressants do not reduce suicide and may increase the risk of suicide, while, Hall et al (5) claimed that antidepressants reduces suicide rates.

The suicide literature also suggests a link between other health, social and environmental factors with suicide. For example, some studies suggest bereavement, e.g. (6-8), early childhood trauma, e.g. (9), socio-economic group and employment issues, e.g. (6), financial strain and negative life events, e.g. (10, 11) and so on as risk factors for suicide. Although, suicide prevention is very slowly and gradually taking notice of alternative medical models, nevertheless, in terms of policy development suicide prevention is still listed under mental health policy. Despite a move by WHO to increase awareness on mental illness which was taken up by some governments (e.g. UK’s no health without mental health policy document (12)), more of the same appears to be the main policy for suicide prevention. In other words, the policy documents recommend more mental health services to be made available to the public (13). In the meantime the suicide rates appear to maintain an overall upward trend with cycles where suicide rate trends may reverse for a short period of time. The response from the authorities has often been to praise mental health services during the cycle(s) when trends appear to be downwards, but when the trends reverse it is claimed that suicide is a very complex public health issue and depends on many social, economic and environmental variables which require further research. The lack of progress in suicide prevention appears to be related to budgeting, developing and carrying out “further research” as policy documents appear to suggest “further research” and further investment is often translated into more of the same, i.e. more investment into mental health services (13).

Furthermore, the problems with suicide prevention are exacerbated with the restrictions in the reporting of suicide in the media and public places such as schools and youth clubs which matter most. One main implication of banning discussions of suicide is for the suicide survivors (e.g. see (14)). The ban on an open discussion of suicide has effectively been to shut survivors out and restrict discussion of suicide with their counsellor, if they had one. It is obvious that there will be further complications such as the availability of skilled and culturally sensitive counsellors. This is an important issue when the suicide case is a young adolescent person survived by parents, siblings and friends.

In this paper we discuss the rationale for adopting a holistic approach to suicide prevention and in order to have an impact on future suicide rates emphasis should be placed on educating the young. The issues of interest will be illustrated through a real life application of a grassroots approach to youth suicide prevention.

Rationale

Over the years there has been more discussion in the literature about other non-medical risk factors for suicide (15-24) suggesting that a medical model alone will not be an effective form of treatment and prevention. Over the last decade or so, researchers and governments’ strategy policies appear to acknowledge the complexities of suicide, however, their action plans seem to divert from these complexities towards a medical model for both prevention and intervention (e.g. see (25, 26)), in other words governments’ action policy only offer more of the same (13).

In New Zealand, like other countries, there has been a long established view of the direction of causality from mental illness (specifically depression) to suicide. This has been achieved by the hasty reporting of so called research and in particular the media’s slant and uncritical reporting. In announcing a $6.4 million campaign to reduce the impact of depression, the New Zealand Government claimed “We know that up to 90% of suicides are caused by depression and that each year 500 New Zealanders are dying by suicide.” The Government further claimed “The World Health Organisation has predicted that by the year 2020, depression will be second only to cardiovascular disease, in contributing to the global burden of disease. We must tackle this problem head on and the National Depression Initiative will go a long way to achieving this objective.”

beatdepression]. This announcement is a reflection of the ineffectiveness of health and social policies in reducing cardiovascular disease.

The New Zealand Government’s suicide prevention strategy document (25) is testament to this confusion. The document attempts to demonstrate a move away from the medical model by including almost all other possible factors reported in the literature as potential contributors: from alcohol and drug abuse to bereavement, family break-ups, unemployment, educational and financial failure and so on. The strategy (25) is not clear as to how this wide range of contributory factors may relate to policy and therefore budget allocation. It is imperative that policy makers do not fall in the trap of attempting to achieve a perceived desired effect by symbolic manipulation of an outcome process, e.g. removing the ‘fail’ as an outcome in school exam. In other words, such a policy unwisely assumes that removing ‘fail’ from an education outcome will lead to positive adolescents. This is analogous to a policy that encourages people to move from their homes because most accidents happen at home.

The main point of concern that all of us (not just practitioners and researchers) must remember, is that at the centre of this decision making process there is a person. In the case of young adolescents, the individual has already gone through their own process of decision making by which time it is too late for any external influence/intervention. Time is a particularly important factor in preventing adolescent suicide due to the fact that the process of decision making takes place much more rapidly than in adults. In adolescents the risk of a complete suicide is heightened when there is immediate access to quick methods of killing (e.g. guns) following a ‘trigger’ event/factor. Conversely, this risk can be reduced as quickly when the access to means is denied or made difficult thus providing time for the young individuals to reflect on the trigger event whilst attempting suicide. This is not to say that some teenagers do not take time and plan to end their own lives. Although, these suicides may appear as sudden decisions, this does suggest a wish by the individual to be in the driving seat and is in control.

As reported earlier, most of the suicide cases had no psychiatric records suggesting that for these people the decision making process had been completed and executed before any “intervention” could be actioned. Clearly, in these cases not even a holistic treatment would have been effective because of the choice they made. However, such an approach may be modified and extended to understand individuals through an understanding of the society they live in, in order to influence the individual’s process of decision making. In medical treatments a “holistic” approach is often referred to as treating the person and not just the physical or emotional symptoms. Ventegodt and Merrick (27) suggest that we must, as holistic physicians and health practitioners, support and guide our patients through the dynamics of suicide. To understand the dynamics of human behaviour in the current age of an advanced information culture, the “holistic” notion must go beyond the individual and accept that decision making processes are influenced by many other processes such as social, economic, environment, media (28). Physicians on their own have little or no control over these dynamic processes.

The Good Life Approach (28) may be adopted to develop social and health policy actions incorporating possible influences from these processes.

As shown in Figure 1, the Good Life model assumes the individual as well as society are the central processes that are subject to influence from other processes. Some of these processes we know about and are related to human behaviour; politics, economy, education, public health and medicine, whilst others such as the environment are inter-related with human behaviour but we do not have complete control over them. The problem is that the dynamics of human behaviour may influence these processes in a conflicting and diverging direction to contradict and lead to adverse interactions between the processes.

Erroneous results and mis-conclusions from a biased and subjective assessment of suicide will have further ramifications for policy and treatment. For example, anti-smoking or anti-violence policies may be ineffective in the light of how politicians behave, and the media’s portrayal of a hero as a violent smoker who dabbles in risky behaviour.
Figure 1. An example of a conceptual holistic model of suicide.

The main points being presented here are:

a) The current list of risk factors for suicide and suicidal behaviour (e.g. see (25, 26)) suggests that suicide is a complex health and social issue that can affect anyone. In other words the whole population is at risk of suicide.

b) There are overlaps and conflicts in human behaviour leading to conflicting consequences in behaviour outcomes such as the interaction between entertainment media, social and health policies, and behaviour outcomes such eradicating family and sexual violence, reducing smoking rates, and preventing a suicide.

**Conceptualization**

It can be visualised from Fig. 1 that prevention actions based on a single model may not have an impact on suicide but will affect the parameters of other processes and can itself be affected by them. Such dynamic interactions may in fact produce outcomes in the opposite direction. For example, the emphasis by the medical model on mental illness may in fact help maintain the taboo status of suicide, and influence other health and social behaviour outcomes, e.g. social attitudes and perceptions of mental illness as the main cause of suicide and a lack of service uptake, see (17, 29). Furthermore, the generally upward trends since World War II in Figure 2 can be interpreted that such an approach of relying on a sustained application of a single model has not worked.

Surely, after so many decades of ‘more of the same’ it must be time to follow a different direction and adopt a more collaborative approach. However, bearing in mind the conceptual model in Figure 1, we must first try and understand not just suicide but human behaviour. Second, any new direction and approach must take account of the residual effects of health and social policies on behaviour. For example, it will not be easy to reverse the effects on policy development of the well-established view in the public mind set that mental illness causes suicide.
Youth suicide prevention

As suggested above, risk factors for suicide are many and cover many aspects of society. The literature on suicide, e.g. (25, 26), suggests a large number of variables from depression to trauma, bereavement, unemployment, marriage break up, poor health, drug and alcohol abuse, poor nutrition, childhood events and so on may cause suicide. A pragmatic translation of the literature is that the general population is at risk of suicide. This interpretation actually makes sense and reinforces that suicide cannot be explained by one discipline or a model. Suicide is a process of decision making. Suicide prevention policy development should allow a multidisciplinary approach to include input from members of the public. However, in most countries the policy development for suicide prevention and intervention has been a top-down approach where governments develop mental health strategy documents with respective policy action documents in order to allocate and distribute resources. As discussed elsewhere (13), strategy documents and policy actions are often translated into mental services which the public are told they need. In other words there is no input from the public about what they really need and what they really want.

It is evident that suicide prevention and intervention must start with a willingness from the public to take part in (31). In order to achieve this, the direction of policy development must be reversed. That is, prevention and interventional policies must be holistic, and to be holistic they must be developed at the grassroots.

Community-based actions are not new phenomena. The University of Kentucky’s “stop youth suicide” Campaign (http://stopyouthsuicide.com) started in 2001 because the coroner was concerned to see so many young suicide cases. His approach was without presumption and simple. He approached the adolescent medicine department at the University of Kentucky and asked the question ‘what can we do to reduce youth suicide? The “stop youth suicide” campaign began with the knowledge and understanding of adolescents and therefore their communities. That is, we must understand or gain insight into the young persons who engage in suicide or suicidal behaviour before assuming mental illness. Through such an approach we can then gain insight into the society and communities of these young people. Within a year the “stop youth suicide” Campaign had enlisted community workers,
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politicians, schools, teenagers themselves (32). The Campaign has been successful in reducing youth suicide rates from around 19 to fewer than 12 per 100,000 and attributes this success to the involvement at grassroots. The Campaign has brought about law changes including gun-safety, public discussion of suicide, and suicide education programmes at schools. Most of these programmes are longitudinal and are an integral part of the curriculum to maintain continuity.

The New Zealand experience

As mentioned in the background, New Zealand aligns itself with Western democracies on suicide. Despite acknowledging the multidimensional risk for suicide, the prevention and interventional strategies are top-down and based on a medical model. Internationally, New Zealand’s suicide rate is high. In 2010, 522 people died as a result of suicide. The national suicide rate is 11.5 per 100,000 people (http://www.health.govt.nz/publication/suicide-facts-deaths-and-intentional-self-harm-hospitalisations-2010). Youth suicide is of particular concern in New Zealand. Suicide rates for young people are high, with deaths between the ages of 15 and 24 making up 23% of all suicides in the Waikato region. Suicide is the second most common cause of death for young people. Between 2002 and 2006, over a quarter of deaths in the Waikato region for people aged 15-19 were due to suicide.

In New Zealand, Waikato Institute of Technology (Wintec) funded a proposal in 2009/10 to run youth suicide prevention. Wintec is a tertiary education provider with a strong commitment to the community it serves. The workshops were facilitated by the Chair of Kentucky’s ‘Stop Youth Suicide campaign’ (32).

A programme of four workshops targeting communities that had been identified with high rates of youth suicide and a public lecture was hastily put together.

During these workshops the extent of community despair and frustration caused by suicide and its politics became more evident. Despite the high level of frustration with the politics of suicide most frontline service providers and those affected by suicide demonstrated a strong passion about suicide prevention and wanted to talk about it. In New Zealand, like most Western countries, there is a moratorium on a public discussion of ‘method’ of suicide in particular within the media. Unfortunately, the moratorium has been abused and misinterpreted by many including some employers to shut staff down. Some attendees reported that their employer had threatened them with legal action and termination of contract for attempting to discuss with other staff how best they could contribute to suicide prevention in the workplace. It is not comforting to know that the majority of these organisations were educational establishments. Despite limited publicity the workshops were well attended.

Workshop evaluations were 100% positive and demonstrated a very strong demand for a community-based strategy. The workshop evaluations also suggested a strong demand for more details of workshops providing skills training. At least one community set up a support group made up of volunteers. The media showed interest, too, but the workshops did not get much air time due to an unfortunate major mine disaster with many fatalities in New Zealand around the same time as the workshops. However, one of the key messages was that we cannot keep suicide a secret and must talk about it otherwise our youth could make uninformed decisions about their understanding of suicide based on secretive rumours.

Due to the feedback and demand for training, in association with participating communities, and through a Fulbright Specialists Grant, advanced training workshops were offered in 2011. Wintec’s community alliance consisted of many frontline health and social services groups including Waahi Whanui, Huntly Community Advice, Raukura Waikato Social Services, mental health awareness forum or the Maori Women’s Welfare League, South Waikato District Council, Raukawa Iwi and Te Puna Oranga (Māori Health Service) Waikato District Health Board (DHB), Population Health Service of the Waikato DHB, Safe Kawerau Kids Injury Prevention Project (SKKIPP) and Rangatahi group for Kawerau. The Fulbright grant was supplemented with local communities’ financial support and a major grant from Trust Waikato to cover expenses. These workshops were run during the latter part of November 2011. There were more communities who
had joined the first group of communities which stretched from Thames (North Waikato), central and South Waikato, and an interest group in Christchurch (in the South Island). Needless to say it was a punishing schedule but a rewarding one. Quite unexpectedly, a number of interventions occurred during these workshops. Although, the workshops were designed for the health professionals (including social workers, counsellors, health promoters, GPs, psychiatrist and mental health workers), attendance was open to the public with an interest in youth suicide prevention. Some had attended the workshop as a last resort so that perhaps they could find the help they were looking for which was not forthcoming from the services in their own community.

Multi-agency help as per their expressed needs of the persons was organised immediately following the workshops through the suicide prevention liaison agents who were available at every workshop. Those who simply were happy to discuss their issues and to vent off frustration with lack of services or a failure of the authorities to listen, help was offered and coordinated by counsellors and social workers who happened to be in the same room attending the workshops. A lack of communication between the various service providers themselves, and the communities they serve is an artefact of the top-down model.

The communities that were involved with the workshops have now joined forces and have regular contact with each other to share information and action plans, and to support each other and share scarce resources where there are overlaps. Most of the communities have now set up support groups made up of mostly volunteer parents, concerned individuals, suicide survivors (parents who have lost to suicide). These groups do not see themselves as frontline suicide prevention workers but as a buffering force, to be a ‘non-threatening’ and approachable resource for young people or anyone to feel comfortable to contact and talk about their issues. The groups have collated a list of resources including emergency phone numbers to crisis, national suicide prevention, mental health services and other local services that may be appropriate.

The groups have no funds nor have they any resources to operate effectively. However, armed with a knowledge of their community and a passion to prevent suicide have adopted a strategy of simple actions that could have a major impact on the outcome. For example, talking about the evils of suicide, providing a cell phone help-number for people to contact, taking a chance and start a conversation with people at any opportunity e.g. at the bus stop or in the park. Simple steps like talking to people have already helped some people in the community who had otherwise been contemplating suicide. The irony is that, social contact and community involvement is an integral human behaviour that appears to have been eroded to such an extent that it is being taught as though it is a new discovery.

As explained earlier, this may be the result of residual health, social and economic policies (see Fid. 1). However, without any resources even the simple steps can become a major problem and could take months if not years to organise. As an example, one group recognised a community need for youth to contact the group but found organising a cell phone very difficult. Although, it was relatively easy to get hold of a handset which was donated by a local resident, getting mobile service providers on-board to donate air time has not come to fruition despite its success and local relevance and the cost is being borne by the group. The group has already received calls from local youths seeking help.

Amongst other success it appears that suicide is beginning to lose its taboo stature and is being discussed and debated at a community level. In 2012, Lifeline Aotearoa (www.lifeline.org.nz) launched a three month television campaign on Maori TV called ‘start the conversation today- Me timata te korero i tenei ra!’

**Conclusion**

A top-down approach coupled with a lack of communication between support service agencies is often ineffective and has very little effect on the outcomes for which the services are designed in the first place (13, 33). Within a top-down policy formation, the authorities become less receptive to community input. For example, it is reported that the Associate Health Minister was to chair a meeting of media, mental health professionals and researchers
early this year to update the guidelines (http://www.stuff.co.nz/the-press/news/4550480/ Anger-over-missing-voice). There is no mention of communities or victims/survivors of suicide in this statement of intent. Such groups were mentioned in a non-specific way by a spokesman for the Associate Health Minister that family and friends would be able to participate in the meetings this year, after an uproar by suicide survivors.

Relevant and effective policy actions can be developed through the depolitisation of research and science so that collaboration can occur more fluidly within and between the various agencies in conjunction with the communities at grassroots level. By engaging the community and the public at the beginning of the process of decision making will help make policy actions more relevant and effective. At the time of writing, the author received a report from one of the communities that through engaging the public a young teenager intervened and prevented a potential suicide of another adolescent by turning up at their doorstep.

In the context of a grassroots approach, the role of the experts would be to critique the available research collaboratively and not in competition. It must be remembered that every policy action will have a multi-dimensional reaction on behavioural outcomes (Figure 1). We must avoid a situation where society and communities are defined by individualism, thus, eroding the most intrinsic of human behaviour, which is keeping in contact and looking out for friends and neighbours and other members of the community.

References


Attention deficit hyperactivity disorder: Neuropsychologic and pharmacologic aspects

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Abstract

Attention deficit hyperactivity disorder (ADHD) is noted in 3-9% of children and adolescents by American research, three times more commonly in males than females; it is found in 3%-5% of adults with equal male to female ratios if the diagnostic criteria are based on the DSM. The neuropsychiatric etiology of ADHD was suspected from early on so that significant research was aimed at elucidating its neuropsychological deficits. Impairments in attention, impulse control, and motor activity -the condition's core deficits- are well documented in neuropsychological studies. So are the beneficial effects of medication for ADHD which have been unambiguously supported by hundreds of studies in the expert academic literature. While stimulants are the most effective therapeutic agents, non-stimulants also play an important role. Theoretical constructs linking molecular neurotransmitter actions to neuroanatomical macro structures and cognitive and behavioral findings have found solid empirical confirmations. Although medication related cognitive improvements appear to be supported only in short term studies, it is recommended that ADHD be actively treated, as patients with this condition can show serious long term disabilities that go beyond academic failure, and overall clinical improvements are strong and the agents prescribed relatively safe.

Keywords: Attention deficit hyperactivity disorder, psychiatry, behavior

Introduction

Few conditions in the mental health field have shown a closer link to neuropsychological constructs than the Attentional Disorders. From the word "attention", prominently listed in the current Diagnostic Statistical Manual of Mental Disorders (DSM-IV-TR) (1) nomenclature of "Attention Deficit Hyperactivity Disorder (ADHD)" and recent sophisticated neurotransmitter findings, to previous descriptions such as "minimal brain dysfunction", the disorder has
been associated with neuropsychiatric substrates throughout its history (2).

ADHD is noted in 3% to 9% of children and adolescents by American research, three times more commonly in males than females; it is found in 3%-5% of adults with equal male to female ratios if the diagnostic criteria are based on the DSM (3). Clinicians in European countries tend to use criteria based on the International Classification of Diseases in which the condition is called "attention-deficit/hyperkinetic disorder", and estimate a much lower prevalence for ADD/ADHD (4). However, various studies from different countries based on similar diagnostic criteria confirm the widespread prevalence of ADHD (5,6). In 2006, 5 million individuals in the United States were prescribed psychostimulant medications, the most commonly recommended ADHD agents. 3.5 million between ages 3 to 19 years, and 1.5 million between ages 20 and 64 years (3).

**ADHD core features**

The DSM-IV-TR presents a detailed list of symptoms and criteria for arriving at a diagnosis. Core features include attention dysfunction along with variable degrees of hyperactivity and impulsivity that interfere with day to day functioning (1,7). This disorder is a lifelong condition with persistence from childhood and adolescence into adulthood in approximately up to 66% of those diagnosed with ADHD in childhood (2). Sometimes, ADHD is not diagnosed until adolescence or adulthood. Inattention in childhood may evolve into difficulty sustaining attention, paralyzing procrastination, and severe disorganization skills in teens or adults. The impulsivity of childhood may persist manifesting in adults as severe impatience characterized by frequent losing one’s temper, quitting or losing jobs, or ending relationships. The classical hyperactivity of childhood is observed less commonly in the older populations and may evolve into an inner restlessness, excessive talking, and/or self-selection of jobs that mask ADHD symptomatology (8).

ADHD is considered a neurobehavioral disorder with abnormalities in various neurotransmitter systems, mainly dopaminergic and noradrenergic (9-11). Neuroimaging (i.e., PET scans) and genetic studies further suggest that dopamine transporter dysfunction (6) appears to be implicated in the pathophysiology of ADHD. Heritability is about 75% with at least seven genes involved in ADHD: DRD4, DRD5, DAT, DBH, 5-HTT, HTR1B, and SNAP25 (12). Current research is attempting to identify different types of attentional dysfunction based on what areas of the brain are involved and then using specific medication to correct or moderate the identified defects; these areas include the cortex (prefrontal and parietal), brain stem (reticular formation), thalamus, basal ganglia, cingulate gyrus, and limbic structures (amygdala-hippocampus) (13). It is hoped that this brain mapping may allow more specific ADHD medications in the future.

**Current psychopharmacologic practices**

There are over 70 years of research noting that medication can ameliorate ADHD symptoms in children, adolescents, and adults (9). Drugs used for treatment include US Food and Drug Administration (FDA) approved stimulant and non-stimulant agents as well as other various non-FDA approved agents.

**FDA approved agents**

*a. stimulant agents*

Hundreds of research studies on patients with ADHD have established the beneficial effects of stimulant medications in all ages: children, adolescents, and adults (3,14-17). Approximately 75% or more of those with ADHD achieve some benefit (9) and the utilization of medication has become a standard part of management for these patients by many clinicians. A comprehensive study was sponsored by the National Institute of Mental Health (NIHM) in the United States; this research was named the NIMH Collaborative Multisite Multimodal Treatment Study of Children with Attention-Deficit/Hyperactivity Disorder, Combined type (or the MTA study) (18,19). The MTA study posed 3 questions. How do long-term medication and behavioral treatments compare with one another? Are there additional benefits when they are used together? What is the effectiveness of
systematic, carefully delivered treatments versus routine community care? In this study, 579 children with ADHD Combined Type, aged 7 to 9.9 years at study entry, were randomly assigned to 14 months of treatment with: rigorous medication management; intensive behavioral treatment; the 2 combined; or standard community care (delivered by community providers who in two thirds of the cases treated patients with medications). Seventy-four percent of the MTA Study subjects in the medication management group received methylphenidate immediate release (MPH IR) 3 times per day with an average dose of approximately 31 mg/d, which was well tolerated overall. Because of ethical concerns about the duration of the trial, a placebo or sham treatment control group was not included; the community care group served as the comparator arm. Although all groups showed considerable reductions in symptoms with time, there were significant differences between the 4 groups. For core ADHD symptoms, children in the combined treatment and medication management groups showed significantly greater improvement than those given intensive behavioral treatment and community care. However, the combined treatment offered no significantly greater benefits than medication management alone for core ADHD symptoms. The MTA results validated the clinical experience that children who largely adhere to a well-titrated regimen of stimulants continue to benefit significantly for at least 14 months.

Methylphenidate preparations

MPH, the stimulant most commonly prescribed for patients with ADHD since its production started in 1957, is a sympathomimetic agent with mild central nervous system (CNS) stimulant properties. Preparations are available for racemic dl-MPH as well as the single d-MPH isomer. Its beneficial effect on attention span dysfunction results from blocking the presynaptic dopamine transporter in the CNS striatal and prefrontal areas, leading to rise in extracellular dopamine (20). It also causes a blockade of the CNS norepinephrine transporter in the norepinephrine system. Stimulant medication therapeutic actions include reduced motor restlessness (i.e., less gross/fine motor movement), reduced impulsivity, reduced hyperarousal, enhanced concentration and less aggressive and/or antisocial behavior. There is no correlation between weight of the patient and optimal MPH dose, and plasma levels of MPH are not useful. A number of tools, some of which are listed in table 1, are used to assess treatment effectiveness and include patient/family interviews, parent ratings, school grades or reports, and others. These instruments are helpful to monitor the efficacy of any type of ADHD therapy. Various IR or short acting preparations of MPH had been popular until recently, when a number of longer-acting products were developed. All these agents are listed in table 2.

There is only one "head to head" study comparing agents (21), so the absence of comparison data at this time makes the selection of the most appropriate agent truly a veritable blend of art and science (9). The process of identifying the best agent for specific patients is addressed later in this chapter. Reasons for failure of MPH to be effective are listed in table 3 and its side effects in table 4.

<table>
<thead>
<tr>
<th>NAME</th>
<th>MAIN FEATURES</th>
</tr>
</thead>
<tbody>
<tr>
<td>Conners Scales</td>
<td>Available in Parent, Teacher, Adolescent Versions Long, Short, and Abbreviated (10 item) Forms <a href="http://www.mhs.com">www.mhs.com</a></td>
</tr>
<tr>
<td>ADHD Rating Scale-IV</td>
<td>Based on the DSM-IV 18 symptoms, School and Home versions available. <a href="http://www.guilford.com">www.guilford.com</a></td>
</tr>
<tr>
<td>SKAMP</td>
<td>Brief 10 item version for Teacher or Observer <a href="http://www.adhd.net">www.adhd.net</a></td>
</tr>
<tr>
<td>CBCL</td>
<td>Not ADHD specific but one of the oldest and most studied tool. Multiple informant versions <a href="http://www.aseba.org">www.aseba.org</a></td>
</tr>
<tr>
<td>Brand name (in USA)</td>
<td>Dosage form</td>
</tr>
<tr>
<td>---------------------</td>
<td>-------------</td>
</tr>
<tr>
<td><strong>Active ingredient: d,l.methylphenidate</strong></td>
<td></td>
</tr>
<tr>
<td>Ritalin; Generic form available</td>
<td>Scored tablets: 5,10,20 mg</td>
</tr>
<tr>
<td>Methyl</td>
<td>Scored tablets: 5,10,20 mg; chewable tablets: 2.5,5,10 mg; oral solution: 5mg/ml, 10 mg/10 ml</td>
</tr>
<tr>
<td>Ritalin SR</td>
<td>Sustained release tablets: 20 mg</td>
</tr>
<tr>
<td>Metadate ER</td>
<td>Extended release tablets: 10, 20 mg</td>
</tr>
<tr>
<td>Methylin ER</td>
<td>Extended release tablets: 10, 20 mg</td>
</tr>
<tr>
<td>Metadate CD</td>
<td>Extended release capsules: 10, 20, 30 mg. Can be sprinkled</td>
</tr>
<tr>
<td>Ritalin LA</td>
<td>Long acting capsules: 10,20,30,40 mg; can be sprinkled</td>
</tr>
<tr>
<td>Concerta</td>
<td>Capsules: 18,27,36,54 mg; do not split or chew or crush</td>
</tr>
<tr>
<td>Daytrana</td>
<td>Transdermal patch: 10,15,20,30 mg</td>
</tr>
<tr>
<td><strong>Active ingredient: d. methylphenidate</strong></td>
<td></td>
</tr>
<tr>
<td>Focalin</td>
<td>Scored tablets: 2.5, 5, 10 mg</td>
</tr>
<tr>
<td>Focalin XR</td>
<td>Extended release capsules: 5, 10 mg; can be sprinkled</td>
</tr>
</tbody>
</table>
### Table 3. Reasons for failure of Methylphenidate

- Inaccurate diagnosis
- Comorbid disorders that overshadow the ADHD
- Medication doses that are too high or not high enough
- Medication is diverted to others in or outside the family
- Intolerable medication side effects
- Medication is used as a drug of abuse for its euphoric effects
- Patient and/or family not accepting of medication
- Patient does not respond to MPH but does to other stimulants or alternative medications
- Patient does not respond to medications of any kind


### Table 4. Potential Side Effects of Stimulant Drugs

- Headache*
- Nausea/vomiting*
- Anorexia*
- Insomnia (delayed onset of sleep)

**Weight loss**

**Moodiness (irritability)**

- Tachycardia
- Palpitations
- Sudden cardiac death
- Increase in blood pressure
- “Unmasking” of Tourette Syndrome
- Rebound phenomenon

**Reduced seizure threshold**

**Irritability/ restlessness**

**Emotional lability**

**Appearance of psychosis or psychotic features**

**Growth retardation (at higher doses, over longer times, in those with short stature or slow axial growth)**

**Skin rash (rare)**

*Commonly seen side effects*


### Amphetamine preparations

The description of beneficial effects of amphetamine (AMP) on hyperactivity and inattention date back to 1937 (22). The amphetamines are non-catecholamine, sympathomimetic amines that act as CNS stimulants. Their putative mechanism of action involves reuptake blockade of neurotransmitters (dopamine and norepinephrine) into presynaptic neurons, as well as an increased release of those neurotransmitters into the synaptic cleft (20). Amphetamines are available as dextroamphetamine sulfate (the dextro isomer of d,l
amphetamine sulfate) or as mixed amphetamine salts (dextroamphetamine plus levoamphetamine) as well as lysdexamfetamine, a prodrug formulation of d-amphetamine. The potential adverse effects of amphetamines are the same as of MPH (see table 4). Available amphetamine products are listed in table 5.

### Table 5. AMP preparations

<table>
<thead>
<tr>
<th>NAME/FORMULATION</th>
<th>DOSE</th>
<th>STARTING</th>
<th>MAXIMUM DOSE</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>SHORT ACTING</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Adderall</td>
<td>5, 7.5, 10, 12.5, 15,</td>
<td>3-5y: 2.5 mg q.d</td>
<td>40mg.</td>
</tr>
<tr>
<td>(Mixed AMP salts)</td>
<td>20, 30 mg tab</td>
<td>&gt;6y: 5 mg q.d.</td>
<td></td>
</tr>
<tr>
<td>Dexedrine</td>
<td>5 mg cap</td>
<td>3-5y: 2.5 mg q.d</td>
<td>40mg.</td>
</tr>
<tr>
<td>(d-AMP)</td>
<td></td>
<td>&gt;6y: 5 mg q.d.</td>
<td></td>
</tr>
<tr>
<td><strong>LONG ACTING</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Dexedrine Spansule</td>
<td>5, 10, 15 mg cap</td>
<td>&gt;6y: 5-10mg q.d.</td>
<td>40mg.</td>
</tr>
<tr>
<td>Adderall XR</td>
<td>5, 10, 15, 20, 25,</td>
<td>&gt;6y: 10 mg q.d.</td>
<td>30mg;</td>
</tr>
<tr>
<td>(Mixed AMP salts XR) sprinkled</td>
<td>30 mg cap</td>
<td>contents can be</td>
<td></td>
</tr>
<tr>
<td><strong>PRODRUG</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Vyvanse</td>
<td>20, 30, 40, 50, 60,</td>
<td>&gt;6y: 20mg q.d.</td>
<td>70 mg</td>
</tr>
<tr>
<td>(LDX)</td>
<td>70 mg cap</td>
<td>contents can be dissolved in liquid</td>
<td></td>
</tr>
</tbody>
</table>

### Contraindications for stimulant use

Unless stated otherwise, it is assumed that any medication will have as a contraindication sensitivity to that medication or any of its ingredients. Patients with significant levels of anxiety, inner tension, or psychomotor agitation should generally not be on psychostimulants. Other contraindications include glaucoma, psychosis, and hyperthyroidism. Due to significant comorbidity with substance abuse disorders, the field has taken a fresh look at the traditional contraindication of drug and alcohol dependence although it is still present on the labels (9). Because of potential cardiovascular side effects, stimulants should not be used in patients with uncontrolled hypertension, symptomatic cardiovascular disorder (i.e., angina, heart failure), serious structural cardiac abnormalities, cardiomyopathy, and serious heart rhythm abnormalities.

The use of stimulants in the presence of motor tic disorder or Tourette's syndrome is relatively contraindicated along with a history of epilepsy. Stimulants should not be combined with monoamine oxidase inhibitors since this combination can lead to a hypertensive crisis. Therefore, two weeks should be allowed between prescribing a stimulant and discontinuing a monoamine oxidase inhibitor. Mixing a stimulant with a tricyclic antidepressant may lead to sudden death from cardiac arrhythmias in rare cases. MPH can interfere with the metabolism of some anticonvulsant drugs, such as phenytoin and phenobarbital.

### Side effects of stimulants

Adverse effects of stimulants, some of which are transient, can be reduced if the patient starts with a low dose and slowly increases the dosage to
maximize benefit. Nausea or emesis that may occur with stimulants often improves if the medication is taken with meals. Dizziness occurs in some patients and is worse with short-acting stimulants versus long-acting types. If dizziness occurs, dehydration or blood pressure changes may be responsible and need to be treated as necessary. Headaches may develop while taking stimulants and this may be related to peak plasma levels or related to drug withdrawal. A change to a different formulation may provide symptomatic relief. The use of stimulant medication does not appear to increase the risk of substance abuse, although it is important to be cognizant of potential stimulant diversion and prescribe longer acting formulations that are less preferred in patients with drug dependence histories (23).

The phenomenon of stimulant related delayed growth remains controversial and seems to be, in part, related to appetite suppression with decreased caloric intake (24).

It appears to be a transient effect, and most children eventually seem to attain expected adult height. However, youth on stimulants who are not growing properly need careful supervision. If the appetite is blunted while on stimulants, a number of measures can be taken, including taking food when the stimulant wears off (as in the evening), using high-caloric foods or nutritional supplements, taking the patient off stimulants when not in school (such as during vacation or on weekends), and trying other non-stimulant ADHD medications (9).

Tolerance may develop in some patients receiving high stimulant doses. Management involves tapering off the stimulant and trying a different ADHD medication. Rebound can develop in which increased ADHD symptoms (i.e., irritability, sadness, and excitability) develop as the stimulant effect wears off. This can be managed by giving a smaller immediate-release dose in the afternoon or changing to a sustained release product. Stimulants may interfere with sleep and this side effect tends to diminish with time. In addition to stimulant side effect, the patient with sleep disturbances should be carefully evaluated for other causes of sleep disturbances (25).

Administering the last dose of the day earlier, eliminating or reducing the last dose of the day, or the use of a long-acting preparation are some of the strategies that may help with sleep problems. Pharmacological options for sleep problems in children are limited. Drugs such as tricyclic antidepressants, alpha2 agonists [i.e. clonidine, guanfacine], trazodone, and melatonin have been used. However, potential complications of combination of these drugs with stimulants must be carefully considered, in particular regarding antidepressants. Recent data suggests that combinations with melatonin (26) and guanfacine XR (27) are safe.

ADHD is found in 50% to 75% of patients with Tourette Syndrome (TS) and TS may become apparent in some children or adolescents after starting stimulant drugs. Research does not suggest that stimulant medications cause TS and the presence of tics is a relative, not absolute contraindication to stimulant medication. Patients with both ADHD and TS may be given both stimulant medications (if effective) and anti-tic medication (such as risperidone, haloperidol, or pimozide). If the tics are worsened by the stimulant drugs, other ADHD medications may be tried that do not typically worsen tics such as guanfacine and atomoxetine.

Because of reports of serious cardiovascular adverse events in recent years, the FDA has required that a strong warning be placed on the label of stimulant drugs. Before starting a patient of any age on a stimulant drug a careful cardiovascular screening is recommended with the goal of identifying those at risk for serious underlying cardiovascular disease and adverse events related to stimulant use (28).

**How to monitor patients on stimulants**

In cases of long term use of stimulants, periodic complete blood count (with differential and platelet count) is recommended. Height and weight should be monitored routinely in pediatric patients, and any significant slowing should prompt further evaluation and possible discontinuation of the stimulant medication.

Blood pressure and pulse should be checked as both values can increase with stimulant treatment. The use of rating scales is recommended to aide in the periodic assessment of therapy efficacy.
b. Non stimulant agents

Atomoxetine

Atomoxetine is a selective inhibitor of norepinephrine reuptake. Its actions include the blockade of the presynaptic norepinephrine and dopamine transporter in the prefrontal cortex (29). The efficacy of atomoxetine has been documented in many short and long term studies in children and adults (30). Full therapeutic effect can take up to 4 weeks to develop. It can be used in those not wishing to take a stimulant, where stimulant or other medications are ineffective, or in patients with anxiety symptoms. Table 6 shows the main features of the preparation. The duration of atomoxetine effect is 18-24 hours.

Table 6. FDA approved non stimulant preparations main features

<table>
<thead>
<tr>
<th>NAME/FORMULATION</th>
<th>DOSE FORMS</th>
<th>STARTING DOSE</th>
<th>REMARKS</th>
</tr>
</thead>
<tbody>
<tr>
<td>Strattera</td>
<td>10, 18, 25, 40, 60,</td>
<td>&lt;70 kg: 0.5mg/kg/day. Increase up to 1.2mg/kg/day not faster than every three days. Can be given in 2 divided doses.</td>
<td>Max daily dose=100mg or less than1.4mg/kg. Higher doses have not shown greater efficacy.</td>
</tr>
<tr>
<td>(Atomoxetine)</td>
<td>80, 100 mg cap</td>
<td></td>
<td>In CYP 2D6 poor metabolizers or with 2D6 potent inhibitors, titrate dose after 4 weeks of initial dose if symptoms fail to improve</td>
</tr>
<tr>
<td>Intuniv</td>
<td>1, 2, 3, 4 mg</td>
<td>1mg at bedtime, then increase by 1mg per week up to 4 weeks.</td>
<td>Max daily dose=4mg. However, if tolerated, doses up to 0.12mg/kg may provide additional benefit.</td>
</tr>
<tr>
<td>(Guanfacine extended release)</td>
<td></td>
<td></td>
<td>Do not crush or chew.</td>
</tr>
<tr>
<td>Kapvay</td>
<td>0.1 &amp; 0.2mg</td>
<td>0.1mg at bedtime, may increase by 0.1mg daily at weekly intervals</td>
<td>Max daily dose = 0.4mg.</td>
</tr>
<tr>
<td>(Clonidine extended release)</td>
<td></td>
<td></td>
<td>Do not crush or chew.</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Upon d/c, ↓ by 0.1mg every 3-7 days to prevent withdrawal.</td>
</tr>
</tbody>
</table>

Table 7 lists potential adverse effects. Atomoxetine has been associated with an increased risk of mydriasis, and should not be used in patients with narrow angle glaucoma. Due to reporting of several cases of severe liver injury, the manufacturer’s package insert was modified in December 2004 to recommend baseline liver function tests with periodic monitoring. Patients should be monitored for an increased risk of suicidality due to reports of increased risk of suicidal ideation and behavior as atomoxetine carries an FDA black box warning similar to that for antidepressants. Drug-drug interactions can occur with inhibitors of the cytochrome P450, 2D6 isoenzyme, including selective serotonin reuptake inhibitors.

Guanfacine XR

Guanfacine is a selective alpha 2A adrenoreceptor agonist. An extended branded release formulation (GXR), was approved by the FDA in 2009 for the treatment of ADHD in children ages 6-17 years. It appears that guanfacine strengthens prefrontal cortex (PFC) regulation of attention and behavior by directly stimulating postsynaptic alpha 2A adrenoreceptors in that region. Controlled short term studies as well as open label studies of up to 24 months duration concluded that GXR was effective and safe as monotherapy. These studies also found that GXR improves both hyperactive as well as inattentive symptoms (31).
The side effect profile is considered mild with a preponderance of sedation which attenuates with continued use. Because guanfacine is a hypotensive agent, researchers followed its cardiovascular effects in detail in both the controlled and open label studies and results were similar across subject populations. Mild decreases in blood pressure and heart rate were noted which tended to normalize with continued treatment.

In clinical settings, it would be prudent to obtain baseline and follow up readings of blood pressure and pulse. Research did not show weight loss or delayed growth and some patients experienced the opposite. Commonly reported side effects include abdominal pain, dizziness, dry mouth, and constipation. GXR does not carry a black box warning. It is contraindicated in patients showing sensitivity to guanfacine. Discontinuation should take place over time because while this was not observed with GXR, there are reports that immediate release a2 agents can cause rebound hypertension. It is recommended that dosing be titrated upwards slowly and based on a mg/kg method. Improvement can be seen in some cases at the second week of treatment (9).

**Clonidine XR (Kapvay)**

Clonidine is another a2 agonist that was approved as an extended release formulation in October 2010 for the treatment of ADHD in those aged 6-17 years. This agent, like guanfacine, was originally approved for the treatment of hypertension and has been used off-label for ADHD for many years. Dosage is initiated at 0.1mg daily at bedtime and can be titrated up to a maximum of 0.4mg daily (two divided doses) at weekly intervals. Side effects most commonly reported include sedation, fatigue, irritability, nightmares, constipation, and dry mouth. Due to the potential for bradycardia/hypotension, patient’s heart rate and blood pressure should be monitored at baseline, after dosage increases and periodically thereafter. Due to the risk for rebound hypertension, abrupt withdrawal should be avoided (no more than 0.1mg decrease every 3-7 days).

**Non FDA approved agents**

Over the years, clinicians have searched for alternatives to the traditional stimulant treatments. A few agents that were found to be effective to some degree have not been approved by the FDA. Due to their effects on central neurotransmission, antidepressant agents were among the first options researched. For instance, multiple controlled and open label studies showed that imipramine and desipramine are effective for ADHD symptoms. However, they appear to improve behavioral problems more than cognitive deficits. Despite their efficacy, they are rarely used today due to concerns regarding cardiovascular toxicity (9). Bupropion considered to be a safer antidepressant from the cardiovascular perspective, has shown efficacy in controlled ADHD studies as well (32) and can be considered a second line agent. It works by inhibiting dopamine and norepinephrine reuptake into the presynaptic neuron. At higher doses, bupropion is associated with an increased seizure risk. In contrast to the tricyclics and bupropion, the SSRI antidepressants have not shown efficacy in ADHD. Modafinil, a wake-promoting agent with actions similar to amphetamine and methylphenidate, showed efficacy in ADHD (33). Nonetheless, the FDA rejected its approval because of concerns regarding Stevens Johnson syndrome, reason for which it is not often recommended. Clonidine is a presynaptic, central-acting alpha2-adrenergic agonist that is used by some clinicians to
manage ADHD symptoms, though it may take 4 to 6 weeks to achieve full benefit and is less effective than stimulants (34,35). Abrupt discontinuations can result in severe rebound hypertension, cerebrovascular accidents and sudden death. Blood pressure should be monitored for hypotension and rebound hypertension. Clonidine is used as an alternative or adjunctive medication to MPH. It is often given with MPH to treat the insomnia related to MPH.

Linking psychopharmacologic neurophysiology and pathophysiology

A brief outline of current thinking regarding the pathophysiology of ADHD is helpful in understanding the potential remedial role that pharmacological agents play. The cognitive and behavioral impairments experienced by ADHD patients can be viewed from a unifying neuropsychological perspective as representing deficits in executive functions (EF). These functions encompass higher order cognitive tasks such as organizing, prioritizing, focusing, sustaining effort, managing frustration, utilizing working memory, monitoring and self-regulating, as well as certain aspects of behavior and emotion (36). The literature shows that the neuronal substrate for these functions is located in the PFC and its connections to other cortical and subcortical structures and that anatomical as well as neurochemical integrity are instrumental for healthy EF. For instance, dopamine (DA) and noradrenaline (NA) are essential to PFC function and a growing body of evidence suggests that normal PFC activity is attained when NA/DA availability reaches an optimal level. Either too much or too little catecholaminergic presence can result in PFC dysfunction (37). DA and NA appear to exert different actions at the cortical level. While NA strengthens network connections, sometimes referred to as increasing "signal", DA seems to weaken unnecessary connections or decrease "noise". Not surprisingly, all the agents with demonstrated efficacy in improving ADHD symptoms are believed to improve catecholaminergic transmission. As mentioned, stimulants increase synaptic cleft DA and NA by inhibiting their intracellular reuptake; atomoxetine blocks the NA transporter resulting in higher synaptic levels of both NA and DA; and guanfacine selectively blocks post synaptic alpha 2a receptors thus mimicking increased levels of NA (37).

Neuropsychological outcomes: Positive and negative

Because stimulant medications exert a primary effect on the DA system by preventing catecholamine reuptake it is not surprising that the most heavily researched neurological regions in ADHD are those that have inputs and outputs which affect the DA system. These regions are the PFC, basal ganglia, and cerebellum. This is logical given that these same areas are also involved in executive functioning, a core cognitive vulnerability in individuals with ADHD.

The PFC and basal ganglia are the primary targets of two ascending dopamine pathways, the neocortical and nigrostriatal pathways (38). The cerebellum, especially the posterior-inferior lobules of the cerebellar vermis, is also a target of DA projection from the ventral tegmental area (39). There are also reciprocal connections between the PFC, basal ganglia, and cerebellum via the pons, dentate nucleus and thalamus (40). The cerebellar vermis also has projections to the ventral tegmental area and locus ceruleus, affecting the turnover of DA and NA in the basal ganglia (41). In sum, there is much connectivity between these regions, permitting feed-forward and feedback loops.

Stimulant medications reduce unwanted ADHD symptoms (hyperactivity) and increase desired symptoms (attention), in both individuals with ADHD as well as those without ADHD (42,43). Investigators found that non ADHD children who received MPH showed improved response inhibition and memory, and healthy adults who were administered stimulants displayed improved attention, vigilance, and working memory (44). Thus, a positive response to a stimulant medication is not diagnostic of ADHD. These cognitive benefits appear to be mediated not only by DA stimulation but also by NA release (45).

A great deal of research has been centered on studying the cognitive effects of stimulants which has focused more on short-term treatment effects rather than long term effects. The methodologies utilized varied greatly in the doses prescribed, length of
Attention deficit hyperactivity disorder

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The selection of a specific starting agent is not guided by its neuropsychological effects because as noted above, all agents improve core ADHD deficits alike. The decision of which agent to use is based on the assessment of individual patient needs and the pharmacodynamic/pharmacokinetic properties of a particular medication (9), as follows. Before beginning pharmacotherapy, it is important to record baseline measures to help determine the safety and feasibility of treatment. More specifically,
information should be obtained from a recent physical examination that includes blood pressure, heart rate, and growth rate. Also, parents and teachers can complete pretreatment symptom rating scales or if this is not possible, a clinical estimation of baseline severity can be made. It is essential to discuss target symptoms to determine improvement, and carefully review possible adverse effects with the patient and family. Despite guidance from specialty medical associations, the multiplicity of agents available and the variety of patient clinical presentations call for a true blending of art and science in order to tailor the choice of medication to individual patient circumstances. It is normally recommended that treatment be started with an FDA approved agent but should it be a stimulant or a non-stimulant? Unless specific contraindications exist, stimulants are the favored first choice because of their high degree of efficacy for core ADHD symptoms, rapid onset of action, ease of use, and generally benign side effect profile. Non stimulants could be used first if there is patient/caretaker preference, patient/caretaker substance abuse (due to diversion or abuse concerns), comorbidity, prior stimulant failure, or recent intolerance to stimulant side effects.

Longer acting preparations are the best first option for children and adults, for several reasons. First, once daily administration affords the patient full day symptom coverage in school, afterschool activities, homework, and evening family time. In addition, by virtue of the ease of following a once/day regimen, these agents may improve adherence. Unquestionably, they eliminate the need to involve school nurses, and they potentially are less likely to be abused. In general, the longest acting preparation that induces no side effects or side effects that are deemed acceptable to the patient is the one preferred. On the other hand, children under 6 are usually started on short acting preparations because they are more sensitive to dose dependent adverse effects and long acting agents are not available in low enough strengths. However, once a safe dose of an IR formulation has been established, conversion to a longer acting agent maybe considered.

While AMP was the first described agent to treat ADHD, concerns about its illicit use led the way for MPH to become more frequently prescribed. Nonetheless, in the past few years, AMP has regained considerable popularity. There have been several studies comparing AMP with MPH formulations that show differences in effectiveness and side effect profiles but these differences are not clinically meaningful enough to dictate choice of one type over another. It is important to understand that both types of stimulants have demonstrated high efficacy. When one fails, the other kind could be recommended next in order to increase overall treatment effectiveness to 80%. Usually, clinicians tend to become comfortable with one stimulant type they start patients with and use the other if the first trial fails. For example, a clinician may recommend Concerta but switch to Vyvanse if there are problems or vice versa. In special circumstances, such as children who cannot swallow pills, physicians may recommend one of the various preparations described in Tables 2 and 5 that do not require ingesting an intact pill.

For treatment of naive patients, the rule of thumb is to start with the lowest possible stimulant dose and to monitor side effects and efficacy every few days. If parent/teacher rating scales show inadequate improvement and there are few significant side effects, it is reasonable to increase to the next dose level. This strategy can continue until either the desired effect is reached or intolerable side effects appear. In general, doses can be titrated upwards until improvements in rating scale scores of 40-50% are obtained.

In cases where the patient is not improving and has side effects, the first step is to discontinue the initial stimulant and switch to the other type, or switch to a non-stimulant. There are no evidence based data that preferentially support continuation with either strategy after a first treatment fails. If the main issue is intolerance to stimulant side effects, then switching to a non-stimulant is preferred. There is evidence that adding a non-stimulant to stimulant therapy potentiates the effectiveness of the overall regimen; thus, combination therapy is another accepted strategy. However, if there is no improvement after two ADHD treatments, a diagnostic reassessment is necessary. For instance, is there comorbidity with affective disorder, anxiety disorder, or substance abuse? Can adherence be clearly ascertained? Are there psychosocial stressors that require resolution?
Only a small minority of patients will not respond to FDA approved treatments, either as monotherapy or in combination. Therefore, if there is little or no improvement, a diagnostic reassessment is mandatory. In the absence of diagnostic issues, non FDA approved treatments can be entertained. On the other hand, these have yielded lower effect sizes than approved agents. A trial of behavior therapy for which there are evidenced based data of effectiveness should also be presented to the family. If medication is preferred by caretakers, a trial of bupropion, modafinil, or tricyclics can be entertained as long as appropriate informed consent is obtained.

The need for continued treatment should be reevaluated periodically, as some patients may no longer require pharmacotherapy. In order to avoid disruptions in school function, treatment should generally be maintained through the academic year. On the other hand, it is important to have school input when assessing the need for continued care. Thus, a reasonable strategy is to taper first and finally discontinue treatment near the end of the year. For adolescents, it is important to maintain treatment until final examinations are taken. By the end of the year, teacher input is still available but final grades are not jeopardized as there is time to reinstitute treatment if the patient relapses off medication. Regarding medication use during the summer, for non-stimulants, unless the goal is to reassess need for ongoing care, it is not advisable to stop treatment because it may take several weeks to return to therapeutic success.

Weekend holidays are impractical for the same reason. With respect to stimulants, if a patient becomes symptomatic without them, routine discontinuation on weekends is not recommended. However, in cases in which there is notable growth delay, drug holidays have been recommended as a strategy to allow for "catch up" growth. Routine summer discontinuations are no longer recommended since symptom relapse often occurs in the absence of medication. On the other hand, if growth delay is a concern or the patient prefers stopping, summer discontinuation should be considered.

Conclusion

The neuropsychiatric etiology of ADHD was suspected from early on so that significant research was aimed at elucidating its neuropsychological deficits. Impairments in attention, impulse control, and motor activity -the condition's core deficits- are well documented in neuropsychological studies. So are the beneficial effects of medication for ADHD which have been unambiguously supported by hundreds of studies in the expert academic literature. While stimulants are the most effective therapeutic agents, non-stimulants also play an important role. As described above, theoretical constructs linking molecular neurotransmitter actions to neuroanatomical macro structures and cognitive and behavioral findings, have found solid empirical confirmations. However, medication related improvements appear to support only short term gains (50) and just while patients remain under carefully monitored treatment conditions (68). Plausible reasons exist for the apparent lack of scientific proof in documenting long term academic gains and further research is needed in this respect. Nonetheless, because of the strong beneficial effects in alleviating current symptomatology and the relative safety of the agents used, the clinical psychiatric community strongly recommends that ADHD be appropriately treated, as patients with this condition show very serious long term disabilities that go beyond academic failure (69).

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Attention deficit hyperactivity disorder


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ORIGINAL ARTICLES
Upper-air observation indicators predict outbreaks of allergies among elementary school children: Integration of daily environmental and school health surveillance systems in Pennsylvania

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Abstract

Objectives of this study are to determine if a relationship exists between occurrence of allergies among elementary school children and daily upper-air observations (temperature, relative humidity, dew point, mixing ratio) and to derive a mathematical model that predicts allergies. Using an ecological study design, school health records of 168,825 students in elementary schools enrolled in “Health eTools for Schools” within 49 Pennsylvania counties were analyzed. Data representing allergy occurrences were originally recorded by school nurses as the type of treatment given to a student during a clinic visit on a particular day. Daily upper-air measurements from ground level to the 850mb pressure level, covering a radius of 800 kilometers around Pittsburgh, PA, were obtained. Wilcoxon Two-Sample test was used to identify associations. A Generalized Estimating Equation model was used to predict the occurrence of more than 13 cases, the daily mean for 2008-2010. Results showed that the surveillance of allergies among school children in Pennsylvania has increased over these three years. The primary occurrence of allergies among school children was in August-September, followed by December and April, while the lowest was in January and May. Annual averages of upper-air observations were significantly different between seasons (p<0.02). Upper-air temperature, dew point, and mixing ratio above their three-year mean values were significantly associated with occurrence of allergies (p<0.011). In conclusion, monitoring of upper-air observation data over time can be a reliable means for predicting outbreaks of allergies among elementary school children. Such predictions could help parents and school nurses implement effective precautionary measures.

Keywords: Temperature, relative humidity, dew point, mixing ratio, allergies, school health records, Pennsylvania
Introduction

Hay fever, respiratory allergies, food allergies, and skin allergies are the main types of allergies among children in the US. Percent of children with diagnosed hay fever in the past 12 months is 9.5% (7.1 million), while 11.5% (3.4 million) of children reported with respiratory allergies. In addition, 4.6% (9.4 million) of children in the US had food allergies in the past 12 months, while 12.6% of children reported with skin allergies (1). Seasonal allergies are fairly common in children older than five years old. According to the American Academy of Allergy, Asthma, and Immunology, about 10-15% of school-age children have seasonal allergies (2). According to CDC, about 10% of children under 17 years had suffered from hay fever, 12% from respiratory allergies, 5% from food allergies, and 13% from skin allergies in the past 12 months (3). There is some evidence that more than 10% of children were sensitized to pollen and a high proportion of the children sensitized only to pollen were also sensitized to other inhalant allergens later. Technically, an allergen is a non-parasitic antigen capable of stimulating a type-1 hypersensitivity reaction in atopic individuals (4). The most common allergens are pollen, dust, food, insect stings, animal dander, mold, medications, and latex. Most humans mount significant Immunoglobulin E (IgE) responses only as a defense against parasitic infections. However, some individuals mount an IgE response against common environmental antigens (4).

Seasonality of allergies (5,6) and their association with asthma (7) are well-known phenomena. Atopic eczema and allergic rhinitis were found to be higher in the period September–May. Some evidence support that non-summer warmth and urban air pollution (8), probably mediated through exposure to common allergens, such as dust mites, are possible risk factors for allergies in school-aged children (9). The highest frequencies of IgE reactivity to food were found in the group of children sensitized to several types of pollen (10).

Seasonal allergy symptoms are commonly experienced due to pollen in summer, fall, or spring, when certain trees or grasses pollinate. The season of pollination depends on the type of tree or grass. As an example, grasses such as Bermuda, timothy and orchard pollinate in the summer, while some trees such as oak, elm, and maple pollinate in the spring. Grass allergy is generally linked to hay fever because their symptoms and causes are somehow similar to each other. Symptoms include rhinitis, which causes sneezing and a runny nose, as well as allergic conjunctivitis, which includes watering and itchy eyes (2). Also, depending on the season, the symptoms may be more severe. The immune system has strong influence on seasonal allergies, since it reacts differently to diverse allergens like pollen. Meteorological factors are very important for the occurrence of pollen grains in the air. Dry and hot weather speeds up maturation and the loosening of pollen grains from anthers, and the concentration of pollen grains is considerably higher than in cold and wet weather (11). It has been found that the temperature has a positive correlation with pollen count, while relative humidity has an inverse correlation with the pollen count in the atmosphere. The total daily rainfall also has a negative correlation (11). Wind and thunderstorms are also accelerating the process of pollen release, especially in spring and summer months (12).

The current study investigated was undertaken to determine if a relationship exists between occurrence of allergies among school children, based on school health services records and routine upper-air variables, such as mixing ratio, relative humidity, temperature, and dew point. Mixing ratio is the mass of water vapor per unit mass of dry air, while relative humidity is the partial pressure of water vapor in air, given as a percentage of the saturated vapor pressure under the same conditions. Air temperature at which condensation first begins is the dew point, another measure of humidity. Although temperature and relative humidity at ground surface level have been considered in allergy studies, neither dew point nor mixing ratio have been linked with allergies or used for prediction of allergy outbreaks. The concept of relative humidity is complex. The amount of humidity is relative to the temperature available to do the work of evaporation, and can fluctuate even if no change occurs in the actual amount of water vapor per unit mass of dry air (mixing ratio). Therefore, dew point and mixing ratio provide the best assessments of humidity as it relates to allergy outbreaks.

The atmospheric variables examined in this study are upper-air observations. Upper-air observations
This study involved analysis of existing de-identified student health record information pertaining to allergy occurrences that was routinely collected and aggregated in the eTools data management system by school nurses.

**Purpose of the Study**

1. To determine whether associations exist between allergies among elementary school students and upper-air observation parameters (relative humidity, dew point, actual mixing ratio, and temperature) in Pennsylvania
2. To determine if a mathematical model can be developed to estimate and predict the daily burden of allergies based on upper-air observations for the purpose of inferring future policy and programmatic initiatives

**Methods**

Ecological study design was adopted in order to understand the relationship between daily occurrence of allergies in a “whole population” of elementary school students and daily measurements of upper-air observation parameters (16). In the ecological design, which investigates group-level variables, a geographical region can be analyzed in a cross-sectional manner (once or repetitively) to investigate the variation in a health-related variable (e.g., mean blood pressure, hospitalizations for allergies, and homicide rates) and its associations with regional characteristics (e.g., salt intake, air pollution, handgun laws, and drug policies) (16).

Two categories of group-level variables are found in epidemiological study designs. The first is aggregate variables; summary measures of individual characteristics (e.g., per capita income). These variables demonstrate a distinction between individual-level and group-level characteristics, because the group-level measure is inferior to (is a weaker measure than) the individual-level measure. The second is integral variables; group-level variables that are not summary measures of individual-level variables (e.g., weather, air pollution, and laws).
These variables do not have corresponding individual-level values and can only be investigated at the group-level. Since upper-air variables in the current study are integral variables, ecological study design is the most appropriate analytic approach.

An ecological design also has the advantageous ability to control for individual-level variability while at the same time addressing influences at the regional-level. In addition, this study design enables researchers to include all the students of the enrolled elementary schools in the study sample, contrary to a study design in which each student with an allergic condition serves as his/her own control and excludes other students (16). Moreover, extracting daily upper-air data from existing environmental databases and retrieving computerized daily health data from existing repositories, such as eTools, is inherently cost-effective in that it requires a very low level of effort.

**Study population**

School districts located in 49 of the 67 counties in Pennsylvania participated in eTools. From 2008 to 2010, enrolled school districts received eTools services for 168,825 elementary school students. These students constituted the study population. All eTools services for participating school districts were subsidized by the funders of eTools (the Highmark Foundation) and covered costs of utilizing eTools through a three-year period. School districts that opted into eTools had to meet five requirements in order to receive a fully paid subscription service: (1) Make a three year commitment to use the portal, (2) Increase the amount of instructional time spent on nutrition education to 75 minutes per marking period, (3) Provide increased opportunities for physical education and physical activity through age appropriate instruction, (4) Participate in in-service training and professional development offerings that enhance use of the portal, and (5) Participate in an annual evaluation of eTools effectiveness. Pennsylvania schools that met participation criteria were eligible to be covered under the subsidy program during the three-year period and were considered for participation on a first-come, first-served basis.

Therefore, all students attending the 1,100 schools in participating school districts were represented by eTools. At the individual level, the sole participation eligibility requirement was to be a student with a health record in an elementary school that utilized eTools. Student records from these schools were excluded if they contained incomplete or inaccurately entered health record data. In addition, no race-, ethnicity-, or income-based bias existed in the enrollment of school districts, schools, or students in eTools. All of the above factors are important in respect to generalizability of study results to elementary school students at the state level or beyond the state level (16).

**Data collection**

Within the 49 Pennsylvania counties, 168,825 records of elementary school students were identified for this study. Data on allergies were originally noted in records maintained by school nurses as the type of treatment given to a student on a particular day. Treatment options for school health nurses were based on the prescribed medication provided for the student. For purposes of this study, having allergy was defined as “any case managed with antihistamines.” In fact, school nurses recorded the trade name of all the medications administered, which were then later categorized into functional groups (i.e., antihistamines, analgesics, etc.). It was assumed that the treatment option noted by a school nurse correctly represented the disease.

Data analyzed for this study were provided to the authors by InnerLink, Inc. which had custodial responsibility under a common Statement of Understanding and Service Level Agreement with all participating school systems. Data pertaining to total use of antihistamine medications at the school level was unavailable. Likewise, demographic characteristics of students in each school or school district were not included in the eTools database and, therefore, were unobtainable. The school year in Pennsylvania usually begins in August, ends in June, and typically includes an extended winter break. Therefore, surveillance data were commonly unavailable for the last three weeks of June, all of
July, the first three weeks of August, and the second half of December every year.

According to Pennsylvania State regulations, each school entity (e.g., school district) must have a written policy to allow for the possession and self-administration by school-age children of medications and the prescribed medication to be administered thereby in a school setting (17). The policy under this section shall require a child of school age that desires to possess and self-administer medications in a school setting to demonstrate the capability for self-administration and for responsible behavior in the use of medications. The physician, certified registered nurse practitioner, or physician assistant shall state whether the child is qualified and able to self-administer the medication. A written request is also required from the parent or guardian to the effect that the school entity complies with the order of the physician, certified registered nurse practitioner, or physician assistant (17). Because of these regulations, which rely on developmentally-appropriate restrictions, self-administration of medications for allergies, while being allowed on an individual basis at any age, is less likely to occur among elementary school students. The number of visits by middle school and high school students to a school health nurse’s office, therefore, may not accurately represent the number of allergy occurrences. Hence, only data from elementary school students’ records were included in this study.

All US school districts, including those in Pennsylvania, must collect and maintain all student records, including health records, in accordance with provisions of the federal Family Educational Rights and Privacy Act (FERPA). Regardless of whether a school is in a contractual arrangement with Innerlink, school nurses must maintain proper records safeguards; therefore, participation in eTools created no added burden for nurses in participating schools. FERPA regulations also give states the flexibility to share data for the purpose of ensuring that taxpayer funds are invested wisely in programs as long as students’ personal information is properly safeguarded (18). This study involved analysis of existing de-identified student health record information pertaining to allergy attacks that was routinely collected and aggregated in the eTools data management system by school nurses who followed all FERPA safeguards. A common contract with InnerLink holds school districts responsible for maintaining the privacy, confidentiality, and integrity of all data, systems, and intellectual property related to eTools. InnerLink requirements affirmed that all school districts adhere to the FERPA regulations of 1974. Upper-air observation data were utilized for this study, for three reasons: (1) they are closely correlated with surface weather observations; 2) upper-air observations are following the same protocol as common for all locations in Pennsylvania, so a single value can be used for the entire statewide; 3) no study has tested the association and usefulness of upper-air observations in allergy research. The upper-air data used in this study were downloaded from the Wyoming University web site (13). Measurements were obtained from the ground level to the 1500-meter level (which is equivalent to 850 mb pressure). These upper-air observation values cover an area with a radius of about 800 kilometers, around Pittsburgh, PA (Figure 1).

Figure 1. Map of Pennsylvania and Surrounding States Depicting Coverage Area of Upper-Air Observation Data, Which is Equal to a Radius of 800 km Around Pittsburgh.
As the coverage area includes the whole state of Pennsylvania, the geographical distribution of schools within the state did not affect study results. For each day of the three years (2008-2010) the measured values at time 12Z were obtained for analysis. The Z-time is the basis for synoptic meteorology, which requires collection of all measurements at the same time every day and, thereby, produces a snapshot of the state of the atmosphere worldwide. The 12Z time in the United States is 6 a.m. in January (Eastern Standard Time) and 7 a.m. in July (Eastern Daylight Time).

This particular time was selected because 7 a.m. is closer to the usual time when students travel to school and are exposed to outdoor climatic factors. Due to this, any difference between the outside air temperature and the air temperature in the school is irrelevant. The variation of upper-air measurement values over the day is very small; the range of upper-air temperature over a day is less than 5°F (13).

Analysis

Descriptive statistics were used to summarize the mean changes of allergy cases throughout years. Two ratios were created: (1) daily mean allergy cases to annual average of allergy cases and (2) daily mean of allergy cases to number of schools enrolled. The first ratio was employed to study relationships between upper-air observation factors and allergies, and the second ratio was used to study the pattern of allergy occurrences over years. A nonparametric test, the Wilcoxon Two-Sample test, was used to compare means of first ratio that correspond to low and high groups of upper-air observations (with cutoff at three year median). Chi Square test was used to identify associations between the relative humidity (with cutoff at relative humidity = 50%) and occurrence of allergies.

The Generalized Estimating Equation (GEE) model was used to predict the probability of occurrence of cases greater than or equal to 13 (a cutoff value equal to the 2008-2010 mean). The repeated subject (cluster) in the model is the “matched date.” For example, March 8th in 2007, 2008, 2009, and in 2010 is a subject. GEE needs at least 100 clusters to study 5-12 exploratory variables; however, a great deal of confidence is assured with 200 clusters, (19, 20) the circumstance in the current study. “Logit” link function on binary distribution was used on a binary dependent variable. “P” represents Daily Allergy Cases ≥ 13 and “1-P” represents Daily Allergy Cases < 13. The independent variables were the upper-air observation variables.

Human subjects approval statement

This study was approved by the Indiana University Bloomington Institutional Review Board, Bloomington, Indiana, United States.

Results

Offices of school health nurses in Pennsylvania had 259,951 visits of elementary school students for various health problems during the three-year period 2008-2010 (Table1). This was equal to 40.9% of total student visits (preK-12) for the period. The treatment option in more than 60% of these occasions was either analgesics (30.7%) or Attention Deficit Hyperactivity Disorder drugs (30.0%). Antihistamines were given in 1.61% of occasions, which reflected the occurrence of this disease or disease exacerbations among students of all grades.

A gradual increase of allergy cases was observed from 2008 to 2010, both in elementary schools and in schools with higher grades (Table 2). This is partially explained by the increase in the number of schools participating in the allergy surveillance system.

The total number of schools (elementary, middle, and high schools) increased from 2008 to 2009, with a slight decrease from 2009 to 2010. However, a boost from 0.85 to 1.77 (208% increase) in the ratio of daily average of allergy cases to number of schools (preK-5) partially explained the real increase in allergy prevalence among school children, because that particular increase is not influenced by an increase in the number of schools participating in the allergy surveillance system. It may, however, be influenced by increased reporting of school nurses,
Table 1. Student Visits to Offices of School Nurses for Various Types of Treatments in Pennsylvania, preK-12 and preK-5, during 2008-2010, and Daily Means for the Period

<table>
<thead>
<tr>
<th>Disease</th>
<th>No. of Visits by preK-12</th>
<th>No. of Visits by preK-5</th>
<th>% of Visits by preK-5</th>
<th>Daily Mean preK-5</th>
<th>Daily Median preK-5</th>
<th>Daily St Dev preK-5</th>
</tr>
</thead>
<tbody>
<tr>
<td>ADHDs</td>
<td>190,992</td>
<td>110,833</td>
<td>58.00%</td>
<td>194</td>
<td>188</td>
<td>99</td>
</tr>
<tr>
<td>Analgesics</td>
<td>195,449</td>
<td>38,079</td>
<td>19.50%</td>
<td>67</td>
<td>66</td>
<td>36</td>
</tr>
<tr>
<td>Anti-asthmatics</td>
<td>39,185</td>
<td>27,123</td>
<td>69.20%</td>
<td>48</td>
<td>45</td>
<td>27</td>
</tr>
<tr>
<td>Anti-diabetics</td>
<td>65,361</td>
<td>26,440</td>
<td>40.50%</td>
<td>46</td>
<td>45</td>
<td>25</td>
</tr>
<tr>
<td>Gastrointestinal</td>
<td>60,318</td>
<td>22,601</td>
<td>37.50%</td>
<td>40</td>
<td>40</td>
<td>21</td>
</tr>
<tr>
<td>Antibiotics</td>
<td>27,070</td>
<td>15,585</td>
<td>57.60%</td>
<td>27</td>
<td>25</td>
<td>21</td>
</tr>
<tr>
<td>Other Psychotropics</td>
<td>22,135</td>
<td>9,121</td>
<td>41.20%</td>
<td>16</td>
<td>16</td>
<td>9</td>
</tr>
<tr>
<td>Antihistamines</td>
<td>8,546</td>
<td>4,185</td>
<td>49.00%</td>
<td>7</td>
<td>6</td>
<td>6</td>
</tr>
<tr>
<td>Anticonvulsants</td>
<td>8,838</td>
<td>3,461</td>
<td>39.20%</td>
<td>6</td>
<td>6</td>
<td>3</td>
</tr>
<tr>
<td>Anti-inflammatories</td>
<td>18,189</td>
<td>2,523</td>
<td>13.90%</td>
<td>4</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>Total</td>
<td>636,083</td>
<td>259,951</td>
<td>40.9%</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Table 2. Visits to School Health Nurses Due to Allergies as Reported by School Health Nurses in Pennsylvania, 2007-2010

<table>
<thead>
<tr>
<th>Year</th>
<th>Number of Schools</th>
<th>Avg. of Allergy Daily Visits (preK-5)</th>
<th>Ratio of [Daily Cases/Schools] for the Year</th>
</tr>
</thead>
<tbody>
<tr>
<td>2008</td>
<td>471</td>
<td>4 (SD=3)</td>
<td>0.85</td>
</tr>
<tr>
<td>2009</td>
<td>675</td>
<td>7 (SD=5)</td>
<td>1.04</td>
</tr>
<tr>
<td>2010</td>
<td>621</td>
<td>11 (SD=8)</td>
<td>1.77</td>
</tr>
</tbody>
</table>

since any surveillance system takes a few years to reach the full functional capacity. Geographical differences in new school enrolment may also have influenced this 208% increase. Differences between daily means of allergy cases reported from elementary schools in each year (2008, 2009, and 2010) were statistically significant (p<0.001; Kruskal-Wallis test). This statistical significance is true for both the daily mean and the ratio of daily cases to annual average (p<0.004).

Use of antihistamines among school children as reported by school health nurses has an almost identical pattern in each year during 2008-2010 (Figure 2). The peak of antihistamine use lies in the period from late August to early September, although there are noticeable increases in December (early winter) and in April (early spring) too. The lowest use of antihistamine use is reported in January and in May (Figure 2). It should be considered that the last three weeks of June, whole month of July, and first three weeks of August have no surveillance due to summer vacation, and the second half of December has no reporting due to winter break. Differences between daily means of allergy cases reported from elementary schools in each season were statistically significant (p<0.001) according to the Kruskal-Wallis test. This significance is not only true for the daily mean, but also true for the ratio of daily cases to annual average (p<0.001). As winter has the lowest number of cases, it was considered the baseline for number of allergy cases in odds ratio estimates. The summer season compared to winter had 17 times higher tendency of exceeding the daily mean of allergy cases (7 cases), which was followed by fall (2.6 times higher), and spring (2.1 times higher). In other words, 68% of days in summer exceeded the daily mean of allergy cases for three years, followed by fall (38%) and spring (35%). Upper-air temperature peaks in July (hot) and...
Figure 2. Antihistamine Use Among preK-5 Students (Ratio of Weekly Mean to Annual Mean), 2008-2010.*

* No data available for the period between the 25th and 34th week of the year due to summer vacation; No data available for the last (52nd) week of the year due to winter break.

Figure 3. Fluctuation of Weekly Mean of Upper-Air Temperature (Celsius), 2008-2010.

has its minimum in January (cold). None of the annual means of four upper-air observations showed differences between years according to the Kruskal-Wallis test.

There were significant differences between temperature means for each season (p<0.001), with the highest in summer, followed by spring and then fall (Figure 3). Similarly, upper-air dew point peaks in July (wet) and reaches its minimum in January (dry). Significant differences existed between seasons (p<0.001), with the highest in summer, followed by spring and then fall (Figure 4). Significant differences between mixing ratio means for each season were also statistically significant (p<0.001), with the highest in summer, followed by spring and fall.

Variation in upper-air relative humidity is complex and it’s difficult to identify a specific pattern (Figure 5). Differences between relative humidity means for each season were statistically significant (p<0.02), with the highest in summer, followed by winter and then fall. The lowest relative humidity was recorded in spring.
Figure 4. Fluctuation of Weekly Mean of Upper-Air Dew Point (Celsius), 2008-2010.

Figure 5. Fluctuation of Weekly Mean of Relative Humidity (Percent), 2008-2010.

Table 3. Comparing Means of Allergy Cases Ratio\(^\text{a}\) by Low/High Classes of Upper-air Observations, 2008-2010

<table>
<thead>
<tr>
<th></th>
<th>N</th>
<th>Mean Of Ratio (^\text{b})</th>
<th>SD</th>
<th>Wilcoxon Test</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Dew Point (^c)(°C)</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>DWPT &gt; -3.42</td>
<td>296</td>
<td>1.125</td>
<td>0.849</td>
<td></td>
</tr>
<tr>
<td>DWPT &lt;= -3.42</td>
<td>272</td>
<td>0.887</td>
<td>0.675</td>
<td>Pr &lt; 0.0001</td>
</tr>
<tr>
<td><strong>Mix Ratio (^d)(g/kg)</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>MIXR &gt;4.36</td>
<td>236</td>
<td>1.181</td>
<td>0.902</td>
<td></td>
</tr>
<tr>
<td>MIXR &lt;=4.36</td>
<td>332</td>
<td>0.886</td>
<td>0.647</td>
<td>Pr &lt; 0.0001</td>
</tr>
<tr>
<td><strong>Temperature (^e)(°C)</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Temp &gt;2.92</td>
<td>305</td>
<td>1.130</td>
<td>0.851</td>
<td></td>
</tr>
<tr>
<td>Temp &lt;=2.92</td>
<td>263</td>
<td>0.878</td>
<td>0.666</td>
<td>Pr &lt; 0.0006</td>
</tr>
</tbody>
</table>

\(^a\) Allergy Cases Ratio = Daily Cases / Annual Average.
\(^b\) The cutoff values are three-year median values for dew point, mixing ratio, and temperature.
The Wilcoxon two-sample test was used to determine the significance of association between allergy cases reported from elementary schools during three years (2008-2010) and each upper-air observation indicator (Table 3). The ratio of daily allergy cases to annual average was utilized for analysis instead of using the absolute number of daily allergy cases to minimize the effect of increase in allergy reporting over three years. The ratio of allergy occurrence has statistically significant associations with all four upper-air observation indicators. Cut-off points for dew point, temperature, and mixing ratio were considered as the median values (for the three-year period) of each variable: -3.42, 4.36, and 2.92, respectively. When the upper-air dew point was higher than its median value, the occurrence of allergy cases was higher and this difference was statistically significant (p<0.0001). Similarly, a higher number of cases reported with a higher value of upper-air mixing ratio (p<0.0001). Finally, when the upper-air temperature was higher than its median value, a higher number of allergy cases were reported (p<0.0006).

The cut off for relative humidity (50%) was obtained using guidelines from the Mayo Clinic and American College of Allergy, Asthma, and Immunology (ACAAI) (21, 22). The Chi-Square test revealed that relative humidity had no significant association with occurrence of allergy cases. The Chi-Square test revealed that season, mixing ratio, and interaction of temperature with relative humidity are important in determining whether or not the number of allergy cases is greater than the daily mean of allergy cases for the particular year.

Finally, using the GEE model, the following equation was adopted for determining the probability of having ≥ 13 cases (three-year mean + one standard deviation) on a day:

\[ y = a_0 + a_1 x_1 + a_2 x_2 + a_3 x_3 + a_4 (x_4 * x_3) \]

\[ \log \frac{P}{1-P} = -4.3212 - 0.2685 (T) - 2.4288 (MR) - 0.1012 (RH) - 0.074 (DP * MR) \]

As an example, if the upper-air temperature, upper-air mixing ratio, upper-air relative humidity, and upper-air dew point temperature are 12°C, 5 g/kg, 55%, and 5°C respectively on a particular day, the probability (P) of having more than 13 cases of allergies within the surveillance system on that day is 64%.

**Discussion**

The surveillance of allergy among school children in Pennsylvania has improved during the last four years in two aspects: the school enrollment in the surveillance system and the disease reporting by school health nurses, a proven, reliable data source (23). The increased exposure to allergens and changes in other socioeconomic and sociodemographic factors among school children may be the main reasons for an increase in allergies in Pennsylvania. The finding of the current study that peaks (main outbreaks) of allergy occurrence were reported in August-September and in April was compatible with the previously stated evidence from empirical studies. However, having the highest prevalence in the summer months may be associated with characteristics of pollen that cause allergic symptoms (2).

Annual averages of upper-air observations (temperature, relative humidity, dew point, mixing ratio) did not differ between years. As explained previously, a higher temperature (greater than the three-year median) is associated with occurrence of more allergies among Pennsylvania school children. However, this study considered only the upper-air temperature, not the surface-level ambient temperature. Similarly, a higher upper-air dew point was found to be related to the occurrence of more allergies. In addition, a higher upper-air mixing ratio was associated with occurrence of more allergies. The
review of literature found no record of these latter two associations. It is important that all three associations were considered in isolation during the analysis, rather than assessing their interaction with each other or with any other variable, such as relative humidity, air pollution, or pollen. The upper-air relative humidity showed no association with occurrence of allergies at its median value cut off, although the upper-air relative humidity ≥ 50% was significantly associated with allergies. As discussed previously, the concept of relative humidity is complex because relative humidity is relative to the amount of energy (measured by temperature) available to do the work of evaporation, and it can be changed without having any change in the actual amount of water vapor in the air (absolute humidity). Therefore, dew point and actual mixing ratio in conjunction with temperature provide a better assessment of humidity, which is more relevant to allergies.

Put another way, the routinely measured and publicly available upper-air indicators provide a good estimate and a reliable tool for forecasting allergy burden on the school health system today or on a future day. This output of analysis with GEE is based on a three-year mean of allergies (13 cases) and does not restrict the utilization of the above equation beyond interpolation. Therefore, the extrapolation for forecasting is also realistic given the current analysis, based on the average of allergies for the 2008-2010 period.

Limitations

Apart from decreased accuracy that results from using group averages and ignoring individual level variations, a risk of "ecological fallacy" occurring also exists, which would be the erroneous interpretation that specific children with allergies in the group share the characteristics of the study sample. In prediction of incidence, it is inappropriate to infer that a specific child with an allergy has an X% probability of experiencing an allergy attack on a particular day. However, it is possible to interpret that there is an X% probability of more than N number of allergy occurrences in the study sample on a particular day (16). In addition, there is a possibility that other allergy triggers, such as pollen, air pollution, and respiratory infections, may confound the relationship between upper-air variables and allergy occurrences.

Allergy surveillance in schools is not being conducted during winter break and summer vacations, as well as during weekends and school holidays. The relatively fewer data available for the summer season due to school vacation may somewhat distort the relationships caused by unequal representativeness across seasons.

In addition, it is difficult to exclude the possibility that some students who experience worsening of symptoms at night or early in the morning did not attend the school so their allergy attacks are not included in school health records. It was also impossible to estimate the number of students with respiratory symptoms who did not receive medications in school or who received medication that was not administered by a nurse as some elementary school students may have taken allergy medications without informing the school nurse. Therefore, we cannot exclude the possibility that use of antihistamine medications as recorded by school nurse somewhat under-represented the occurrence of allergy symptoms at school. Unavailability of antihistamine medications usage data at school level as well as absence of data on demographic characteristics (e.g., ethnicity, income) of students in each school or school district were also limitations.

The number of schools using eTools during 2007 was relatively low and, therefore, student data from that year were not included in some of the analyses. The number of schools using eTools changed each year with some schools dropping off and others joining, causing fluctuations in the total number of available student data records. Additionally, each year some students were leaving their school or school district. Nevertheless, the total number of student data strings provided for any one year was sufficiently robust, as was the number of data strings available for multi-year comparisons, to generate reliable results.

Both respiratory and skin allergies may have an association with upper-air variables and both can also be caused by food allergies. Unfortunately, no mechanism exists for distinguishing respiratory and skin allergies from food allergies, because school nurses did not specify the type of allergy associated with treatments they provided. Therefore, we cannot exclude the possibility that a distortion of the
relationship between upper-air indicators and respiratory and skin allergies occurred due to the inclusion of food allergies in the analysis. Most likely, a causal relationship between upper-air observations and occurrence of food allergy symptoms does not exist; however, the seasonality of some food allergies is an observed phenomenon possibly caused by seasonal fluctuations in sunlight and perhaps vitamin D (24).

Finally, as we cannot exclude the confounding effect of pollen on a relationship between climatic factors and allergies, another study will be conducted utilizing the same data sources to evaluate the combined effect of pollen in combination with climatic factors on allergies.

Conclusion

The surveillance of allergies among school children in Pennsylvania increased over three years in two aspects: school enrollment in surveillance system and the allergy reporting by school health nurses, a proven reliable source. The primary occurrence of allergies among elementary school children was in August-September, followed by April, although the highest overall prevalence was reported in summer, followed by fall. The lowest incident of allergies was reported in winter. Annual averages of upper-air observations (temperature, relative humidity, dew point, mixing ratio) were significantly different between seasons. Upper-air temperature, dew point, and mixing ratio above their three-year mean values were significantly associated with occurrence of allergies, although upper-air relative humidity $\geq 50\%$ was not.

Monitoring of upper-air observation data (temperature, dew point, and actual mixing ratio) over time can serve as a reliable means for predicting increased occurrence of allergies among elementary school children. The new mathematical model derived from statistical integration of routine environmental observations and school health records may be used to scrutinize the complexity of allergic diseases as a dynamic outcome determined by multiple environmental parameters. It is also possible to assess the risk for future allergy outbreaks based on fluctuation analysis of a long time series of atmospheric function.

Prediction of allergy outbreaks is important for children diagnosed as having allergies, and their household members can take more preventive measures to avoid allergic conditions, regardless of the severity of allergic condition. In addition, being informed of a possible allergy outbreak on a particular day or week, teachers will be able to pay more attention to early identification of allergic reactions among children in the classroom. Being informed of a possible allergy outbreak, doctors and nurses in emergency rooms or in family practices can take extra preparations and utilize resources more efficiently to serve an increased number of allergy patients. With accurate prediction, the school health system can also play a major role by effectively reallocating both human and physical resources as well as by notifying teachers and children with allergies to take extra precautions and identify allergic reactions very early. Mass media and local media can also play an important role in all of these aspects. Results of the current study can be used to inform similar programming at the national level and in other states. Monitoring of upper-air observation data over time can serve as a reliable means for predicting outbreaks of allergies among elementary school children and for taking more effective precautionary measures.

Acknowledgments

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References

Allergy and schools


Mandate HOPHSCwS. Early Intervent 2008;36.


Health risk and deviant behaviors among undergraduate students at an academic institute in Israel

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Abstract

The purpose of this study was to examine the prevalence of health risk behaviors (such as cigarette and hookah smoking, alcohol consumption and marijuana use), and deviant and delinquent behaviors (such as theft, property damage, drug abuse, cheating on exams and various driving violations) among undergraduate students at an academic institute in Israel. The novelty of this study is its investigation of a broad variety of health risk and deviant behaviors as a whole among undergraduate students, and the understanding of their contribution to predicting cannabis use. This study used a structured, self-reported anonymous questionnaire dealing with health, welfare and risk behaviors. The questionnaire was distributed among 1,574 undergraduate students at a large academic institute in Israel. The mean age of the sample subjects was 27 (SD=6.64). The findings demonstrate that approximately one fourth of the students reported cheating on exams. Additionally, around one fourth reported smoking marijuana and over one third of the drivers reported not stopping at a stop sign. All of these behaviors were found in higher frequency among males. The considerable prevalence of these behaviors among undergraduate students raises the question: In their eyes, are these behaviors considered a social norm or a deviance?

Keywords: health risk behaviors, deviance, cannabis use, cheating on exams, delinquency, undergraduate students

Introduction

Health risk behaviors are voluntary behaviors which lead to negative outcomes from a health perspective. A negative health outcome could be an injury, an illness or death. However, these behaviors could also have negative and problematic social outcomes for their implementer (1). The Problem Behavior Theory (PBT) explains that these behaviors are a product of an integration of risk factors which raise the probability of involvement in risk behaviors by

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providing a model for problematic behavior, broadening the possibilities of involvement in other risky behaviors, and magnifying the personal vulnerability of problematic behaviors. The model also introduces resilience factors which reduce the probability of involvement in risk behaviors by providing a model of positive social behaviors, by means of social and personal supervision and control, as well as a supportive social environment. Both risk and protective factors are present in all of our social and personal systems (2). According to this theory, health risk behaviors are related to each other and have a clustering effect.

Illegal drug use is a common behavior among young-adults including undergraduate students. Cannabis products (marijuana and hashish) constitute the most common drug in general and among undergraduate students in particular (3). A comprehensive study conducted in Israel on behalf of the Israel Anti Drug and Alcohol Authority (IADA) in 2003 examined undergraduate student’s attitudes towards drug use as well as drug use rates in a representative sample (N=6,965) from twelve higher education institutes. Over 40% of the students reported experiencing illegal drug use. Close to one third of the students (30%) reported illegal drug use within the last year. Cannabis was found to be the most common drug used amongst the illegal drugs (4).

Excessive alcohol consumption is a growing phenomenon in the Israeli society. Studies in the field show an increase in excessive alcohol use and an expansion of the phenomenon in the various alcohol dimensions such as binge drinking and drunkenness. Binge drinking is defined as drinking five or more servings of alcohol within a few hours- that is, in one event. In research literature it is considered an extremely dangerous behavior, in which under the influence of such quantity of alcohol, judgment and response capabilities are significantly impaired (1, 5). Epidemiological data from various studies shows a significant increase in this behavior in recent years. Ezrahi, Rosiner, Nirel & Bar-Hamburger (6) reported an increase in beer drinking among young-adults aged 18-40 as well as a rise in reported drunkenness.

Cigarette smoking was also examined among young-adults in several studies, and has proved to be a problematic risk behavior among adolescents (7). More than one third of the sample (37.6%) aged 18-40 reported smoking cigarettes in 2009 (6), a lower incidence in comparison to 2005 (41.0%). Youth aged 18-24 reported smoking cigarettes at a higher frequency than the frequency in both of the older age groups (25-34 and 35-40) examined. The prevalence of male smokers (47.2%) was much higher than the prevalence of female smokers (28.0%). Approximately half of the student sample reported that they did not smoke or have ever smoked in the past. About 38% reported smoking cigarettes, and about a quarter reported smoking regularly (4).

Hookah (water-pipe) smoking is a health risk behavior which has expanded in Israel over the last decade and a half from the prevalence of zero to that which is higher than that of cigarette smoking among adolescents (1, 5, 8). Hookah experiencing prevalence stood at 37.7% of Israeli youth while cigarette experiencing prevalence stood at 27.7%. A study conducted on a representative sample of youth in Israel in 2002 found that those who smoke a hookah have a higher incidence of involvement in other risk behaviors in comparison to those who do not smoke hookahs, such as: suffering injuries, involvement in violence, involvement in risky sexual behaviors, cigarette smoking, alcohol consumption and drug use. The study findings indicate that it is important to view the behavior of hookah smoking among adolescents in Israel as a health risk behavior associated with the consumption of addictive substances and as a gateway for experiencing more serious risk behaviors (8). A different survey conducted in 2008, in the Arab sector, among adolescents in the city of Taybeh found an even higher incidence where 37.1% report smoking a hookah regularly- 55.0% among males and 17.4% among females. The probability of hookah smoking increased among undergraduate students with low academic aspirations and smoking parents (9). A survey conducted by the Anti-Drug and alcohol Authority also found that 27.0% of the adolescents and approximately 17.0% of the adults reported hookah smoking within the past month (6).

Academic dishonesty is an additional risk behavior commonly found among undergraduate students, which is attributed to copying and cheating on examinations, copying homework assignments and plagiarism of academic tasks (see for example: 10, 11). Subjects tend to view academic dishonesty as a
Health risk and deviant behaviors

normative behavior which is not considered immoral, but stress that this does not mean that students perceive this behavior as appropriate (10). With respect to gender differences, there are no consistent study findings which stand out. Some studies found that males copy on exams at a higher rate than females, while others found no significant gender differences (12).

Driving/moving Violations – the Israeli driver, especially the young driver, drives with a sense of immunity from traffic accidents, despite the high incidence, in practice, of involvement in road Accidents. Although young drivers are at the peak of their physical and mental power, their involvement in accidents is particularly high. The reason for this is most likely a combination of several factors: lack of experience (and therefore limited driving skills), underestimation of risk, overexposure to driving in dangerous situations (night driving, driving in a state of fatigue, driving after drinking alcohol, etc.), and an internal need as well as social pressure to demonstrate "masculinity" by taking risks while driving (13).

In international literature, significant gender differences were found with respect to driving. On average, males more than females, tend to drive faster, pass other cars more often, are more involved in drunken driving offenses and generally take more risks. Males are also more likely than females to be involved in serious car-accidents, especially accidents caused by traffic offenses such as speeding, driving under the influence of alcohol, etc. (13, 14). It was also found that Israeli men spend more hours driving and have a higher self-evaluation and higher self-confidence than women (13).

In summary: In this section we have listed various health risk and deviant behaviors among undergraduate students and young-adults in Israel: Illega drug use, excessive alcohol consumption, cigarette smoking, hookah smoking, academic dishonesty and driving violations. Some of these behaviors (excluding driving violations and academic dishonesty) have been generally examined, especially among children and adolescents; e.g., in a study of the HBSC in Israel, headed by Dr. Yossi Harel-Fisch et al. (5), but few comprehensive studies have been conducted on these topics among undergraduate students. With respect to hookah smoking, for instance, we have found no studies which have been conducted among undergraduate students. The importance of examining these behaviors, as a whole, is derived from the conclusions of the Problem Behavior Theory mentioned above, which led us to examine the combination of these behaviors since the factors contributing to one risk behavior may also be explanatory factors for a different risk behavior.

Study objective

Our research goals of the current study are to examine the prevalence of various risk and deviant behaviors among undergraduate students. The study seeks to answer the following questions with reference to existing literature: Will risk behaviors be found in high frequency among undergraduate students? Are risk and daring behavior patterns more common among male students than among female ones? And, is it possible to predict cannabis use among those who exhibit other risk, daring or deviant behaviors?

Based on the literature review conducted, the hypotheses derived from the research questions are: The prevalence of males involved in risk, daring and deviant behaviors will be higher than the prevalence of females who report it. Additionally, as the PBT theory had determined, various risk behaviors will present in clusters. Risk behaviors will be found in high frequency among the undergraduate students examined, and cannabis use can be predicted by examining use of other health risk and deviant behaviors.

Methods

Research tools: This study is based on a structured, self-reported anonymous questionnaire which was completed by undergraduate students at a large academic institute in Israel. The study questionnaire was based on two main sources: First, the CU (2003) Personal and Social Development Questionnaire, created by Professor Jessor (15) for the examination of risk and well-being behaviors of college students at the University of Colorado, Boulder, USA; Second, the Israeli Health Behavior in School-aged Children (HBSC) study, the Israeli part of a collaborative Cross-National Study headed by the WHO (1). Our
complete questionnaire included questions on different topics as detailed: various socio-demographic questions; self-perceptions; self-esteem and body-image; psychosomatic symptoms; stress; social support; social relationships; academic studies; religion and security; excitement and daring behaviors; nutrition, diet and eating habits; exercise; dental hygiene; sexual behavior; cigarette smoking habits and smoking cessation; hookah smoking; alcohol consumption; reckless driving, and drug abuse. The questionnaire constructed for this study was mainly composed according to the American questionnaire used and was adapted to the student population in Israel. Due to the large quantity of topics presented in the questionnaire and due the desire to not excessively burden the students, the questions were divided into two columns. The most important core questions of each subject were asked in both columns, but different issues were expanded on in each of the columns. Column A expanded on issues of smoking, alcohol, drugs and driving. Column B expanded on issues of education, excitement seeking, eating habits, sexual behavior, religion and security. Each questionnaire column distributed comprised 16 pages.

Population and sample: A total of 1,574 undergraduate students participated in the study, representing 36% of all registered undergraduate students enrolled in an academic institution in Israel. The study was conducted in three faculties (Health, Nature and Social sciences) with their deans’ approval. No sampling was, in fact, conducted in this study. Instead, all students present in the classroom who had agreed to complete the questionnaire participated in the study. The surveyors entered all classrooms in the three faculties. The response rate for the questionnaire stood at 93.5%. Of these, 768 completed column A questionnaire, 770 completed column B questionnaire, and 36 students were the pilot group for this study. The sample included 1028 females and 566 males, the average age of the sample was 27 (SD = 6.64). After logic cleaning and cleansing of the data file from significant multiple or missing values, the sample included 1519 subjects.

Research procedure: All students present in the classrooms received the questionnaires within the classroom. Overall the coverage percentage of the sample was 36.3% of students in the sampled departments. The questionnaire was distributed among the students during classes that they attended during April - May, 2009. Overall the surveyors entered approximately 70 classrooms. Questionnaire completion lasted, on average, 20-30 minutes. The three department heads of the faculties participating in the study helped coordinate the classrooms including the number of students attending, the lecturers and the study topic in order to arrange for the most convenient dates for distributing the survey, for the lecturers, the students and the research team. A telephone conversation was conducted between the principal investigator and the various lecturers in order to explain the study and its goals. Considerable cooperation was noted from the lecturers with respect to the completion of the study. Each meeting that was arranged by the principal investigator with a lecturer was followed by an additional reminder telephone call by the surveyor the day before entering the classroom. The surveying team received detailed instructions on how to carry out the questionnaires in the classrooms. Students were told that they do not have to complete the questionnaire if they are not interested in doing so.

Variables: the dependent variables in this study are health risk behaviors, driving violations, deviant behaviors and delinquency. These variables were tested against the independent variables: gender, age, ethnicity, religious background and family income. In addition, in order to examine the odds ratio, indexes were created for driving offenses variables as well as for deviation and delinquency (variable and index details in Appendix 1).

Results

Table 1 presents the dependent variables in the study according to gender. The findings are presented in the table in percentages with standard deviations appearing in parentheses. The table indicates the prevalence of the subject sample according to reports on daring behaviors, health risk behaviors and driving offences. Overall it can be seen that among the deviant behaviors reported, reports on academic dishonesty are highest (25.1%). Of the reported driving offences, reports of speeding are most common (72.9%). With respect to all of the risk and deviant behaviors specified in the table, there is a
higher prevalence of males in comparison to females in reporting these behaviors. The biggest gaps between genders were found in the category of binge drinking (42.7% and 17.4% respectively) and in the category of speeding (80.7% and 68.2% respectively).

Table 2 presents the results of predicting the probability of experiencing and regular smoking of cannabis, i.e., what are the chances of, for example, a male to smoke marijuana in comparison to a female. When the safety margin starts at a point greater than 1, the result is significant, and the smaller the range between two points is - the better the result is. Most of the odds ratios values presented in the table are significant (except for deviation and delinquency and ecstasy experiencing – with cannabis experiencing).

The table reveals strong predictors in the areas of: socio-demographic characteristics, driving offenses, deviation and delinquency and health risk behaviors. The table demonstrates that the odds of an undergraduate student to experiment with cannabis are higher if they are males (1.5 times higher) in comparison to females, older (1.9 times higher) in comparison to younger, single (almost twice as high) in comparison to married, and more secular (more than 5 times as high) in comparison to more religious. In addition undergraduate students of Ashkenazi (or Eastern European) decent are more likely to experiment with cannabis (1.72 higher) when compared to students of a Sephardic or Ethiopian decent, and those with a high family income are 1.6 times more likely to experiment with cannabis when compared to those with a low family income. The driving offense index also demonstrates that the probability of experiment with cannabis is 2.5 times higher among students whom have committed driving offenses than among those who have not committed any driving offenses. The examination of all risk behaviors shows that hookah smoking experience raises the probability of a student to experiment with cannabis (by more than 10 times) or use them regularly (more than 11 times).

### Table 1. Distribution of study measures by gender (percentages; ±SE)

<table>
<thead>
<tr>
<th>Measure list</th>
<th>N</th>
<th>Total</th>
<th>Females</th>
<th>Males</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Deviation and Delinquency</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Academic dishonesty</td>
<td>1302</td>
<td>25.1 (0.82)</td>
<td>24.1 (0.75)</td>
<td>27.1 (0.94)</td>
</tr>
<tr>
<td>Shop lifting</td>
<td>1308</td>
<td>3.1 (0.34)</td>
<td>2.1 (0.26)</td>
<td>5.0 (0.46)</td>
</tr>
<tr>
<td>Property damage</td>
<td>1308</td>
<td>3.4 (0.33)</td>
<td>1.8 (0.19)</td>
<td>6.6 (0.50)</td>
</tr>
<tr>
<td>Drug sale or practice</td>
<td>1306</td>
<td>3.0 (0.42)</td>
<td>2.3 (0.35)</td>
<td>4.3 (0.53)</td>
</tr>
<tr>
<td>Theft of something valuable</td>
<td>1308</td>
<td>1.3 (0.21)</td>
<td>0.7 (0.14)</td>
<td>2.5 (0.31)</td>
</tr>
<tr>
<td>Hitting someone who said something I did not like</td>
<td>1308</td>
<td>3.7 (0.35)</td>
<td>2.5 (0.21)</td>
<td>6.2 (0.53)</td>
</tr>
<tr>
<td>Not stopping at a stop sign</td>
<td>1107</td>
<td>35.3 (0.87)</td>
<td>33.1 (0.79)</td>
<td>38.7 (0.97)</td>
</tr>
<tr>
<td>Failure to keep distance</td>
<td>1102</td>
<td>57.8 (0.98)</td>
<td>54.8 (0.85)</td>
<td>62.6 (1.12)</td>
</tr>
<tr>
<td>Driving after drinking alcohol</td>
<td>1102</td>
<td>27.5 (0.84)</td>
<td>20.2 (0.65)</td>
<td>39.1 (1.04)</td>
</tr>
<tr>
<td>Speeding</td>
<td>1100</td>
<td>72.9 (1.34)</td>
<td>68.2 (1.22)</td>
<td>80.7 (1.42)</td>
</tr>
<tr>
<td>Driving through a red light</td>
<td>1104</td>
<td>8.2 (0.45)</td>
<td>6.9 (0.38)</td>
<td>10.2 (0.55)</td>
</tr>
<tr>
<td>Driving after using marijuana</td>
<td>1103</td>
<td>6.4 (0.55)</td>
<td>3.2 (0.36)</td>
<td>11.4 (0.75)</td>
</tr>
<tr>
<td>Not always wearing a seatbelt when a friend drives ¹</td>
<td>567</td>
<td>13.6 (0.57)</td>
<td>10.4 (0.44)</td>
<td>18.8 (0.74)</td>
</tr>
<tr>
<td>Not always wearing a seatbelt when I drive ¹</td>
<td>563</td>
<td>5.0 (0.41)</td>
<td>3.3 (0.30)</td>
<td>8.0 (0.56)</td>
</tr>
<tr>
<td><strong>Driving Offences</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hookah smoking at least once a week</td>
<td>1192</td>
<td>7.5 (0.70)</td>
<td>4.1 (0.56)</td>
<td>13.3 (0.85)</td>
</tr>
<tr>
<td>Regular daily cigarette smoking ²</td>
<td>341</td>
<td>22.9 (0.83)</td>
<td>19.9 (0.80)</td>
<td>27.3 (0.87)</td>
</tr>
<tr>
<td>Alcohol binge drinking ²</td>
<td>495</td>
<td>28.5 (1.09)</td>
<td>17.4 (0.69)</td>
<td>42.7 (1.38)</td>
</tr>
<tr>
<td>Getting drunk within the last month ²</td>
<td>525</td>
<td>24.8 (0.91)</td>
<td>20.3 (0.69)</td>
<td>30.5 (1.12)</td>
</tr>
<tr>
<td>Any cannabis smoking experience</td>
<td>1265</td>
<td>25.3 (0.78)</td>
<td>22.5 (0.73)</td>
<td>30.5 (0.86)</td>
</tr>
<tr>
<td>Smoking cannabis once a week or more in the last month ²</td>
<td>429</td>
<td>9.1 (1.27)</td>
<td>6.0 (1.11)</td>
<td>13.6 (1.45)</td>
</tr>
<tr>
<td>Experiencing ecstasy ¹ ²</td>
<td>199</td>
<td>7.5 (0.75)</td>
<td>6.2 (0.29)</td>
<td>9.3 (1.10)</td>
</tr>
<tr>
<td>N</td>
<td>---</td>
<td>---</td>
<td>1000</td>
<td>519</td>
</tr>
</tbody>
</table>

¹Questions asked only in column A.
²filtered questions (from the sample of drivers or from those whom have experienced cannabis).
While the examination of ecstasy experiencing did not come out significant when compared with experiencing with cannabis (most likely due to the small number of students who reported it), the probability of a person whom has experienced ecstasy to use cannabis regularly is very high (more than 12 times higher) and is clearly significant in comparison to students who have not experienced ecstasy. The findings in the table do show that the essence of drug use in its whole is similar, and that the prospect of students who smoke, drink, get drunk or use ecstasy to experience and use cannabis as well, is high.

The table indicates that the independent variables show a higher probability for regular cannabis use to be preceded by other risk behaviors, than a one-time experience with it. This is especially noticeable with respect to the driving offenses index (2.50 versus 4.06) and ecstasy experiencing (5.68 versus 12.69). In other words, students who commit driving offences and experience cannabis are more likely to be regular cannabis users than those who experience cannabis only once. The table also shows that the deviance and delinquency index does not considerably increase the likelihood of students to experience cannabis.

### Discussion

This study examined risk and deviation behavioral patterns among undergraduate students at a large academic institution in Israel. A major query arising, concerns the prevalence of these behaviors, and whether, due to their high frequency, they should be defined as a deviation or whether these behaviors are considered to be a social norm among the students. It was found that cheating on exams was reported by approximately one quarter of the students (25.1%) in
comparison to few positive answers to the other questions pertaining to: shoplifting (3.1%), property damage (3.4%), sale of or dealing drugs (3.0%), theft of something valuable (1.3%) and hitting someone for saying something I did not like (3.7%). It may therefore be assumed that cheating on exams is not considered by students as a deviance, but is perceived as a common and legitimate enough behavior in comparison to the other deviant behaviors presented.

An analysis of the driving offenses index shows quite an interesting picture. Of the eight questions in this index, two offenses were answered at a very high rate. These were: Driving at an excessive speed (72.9%) and failure to keep distance (57.6%). It is apparent from this data that these two offenses are perceived as a normative behavior among most students. Two additional questions which were found to be “mainly normative” pertain to not stopping at a stop sign (35.3%) and driving after consuming alcohol (27.5%). It was interesting to see that the lowest prevalence was received in questions about not wearing a seat belt, driving through a red light and the use of marijuana while driving. From this, we can conclude that these behaviors are considered to be a deviation among the students, and the majority of them do refrain from executing them. In other words, it seems that among the students in our sample, not wearing a seat belt in a car is perceived to be more of a deviant behavior than driving after drinking alcohol or speeding. It is possible that the requirement to wear seatbelts, which was implemented in recent years, was internalized and accepted by the Israeli public. Therefore, it seems that it is possible to change deviant behavioral norms if an emphasis is put on preventing these behaviors, along with conducting campaigns for their prevention and using various law enforcement methods against those conducting them.

Another interesting finding pertains to the differences observed between the genders in this study. The study findings showed an unequivocal trend regarding differences in risk and deviant behaviors between the genders. The prevalence of males in all of the behaviors examined in the study was higher than the prevalence of females reporting these behaviors. The greatest disparities between the genders were found in the issues of binge drinking and of speeding. A gap of more than double exists between the genders on the issue of frequent cannabis use (13.6% among males compared to 6.0% among females) and binge drinking (42.7% and 17.4% respectively). The frequency of cannabis use and these differences between the genders correlates with previous findings presented in the literature with respect to drug use, as shown by Ezrati et al. (6; 12.3% of the males vs. 5.5% of the females). The large gaps between the genders are also expressed in the issue of alcohol consumption both in our study and in the work of Ezrati et al., (6; 73.5% of the males vs. 54.9% of the females). Additionally, the frequency of cigarette smoking and gender differences are similar both in the literature examined (4, 6) and in our study. The various daring and deviant behaviors examined also proved to be unfavorable towards the males. With respect to cheating on exams, no consistence stood out in the research literature pertaining to gender differences. Some studies found that males copy on exams more frequently than females, while others found no significant gender differences (12). The findings of this study do not shed new light on the issue and do not show significant differences between the genders in this respect. While, cheating on exams / homework was found to be higher among males in this study, the differences reported were insignificant (27.1% vs. 24.1% respectively). On the issue of driving offenses, however, clear differences emerged between the genders, as found in international literature. Studies have shown that males tend to drive on average faster than females. They also pass cars more often, are involved in more drunk driving offenses and generally take more risks than females. Males are also more likely than females to be involved in serious accidents, especially accidents caused by traffic offenses, such as speeding and driving under the influence of alcohol (13, 14). The current study findings support this data. The prevalence of males was higher than that of females in all driving offense examined (i.e. not stopping at the stop sign, failure to keep a distance, the combination of drinking and driving, cannabis smoking and driving, speeding, driving through a red light and not wearing a seat belt). The price paid by women in a patriarchal society is clear, however even the men pay the price - the price of risk. Males tend to take part in risk behaviors more than females in many fields - as is
clearly evident in the present study, among others, in order to prove the superiority of the male gender.

Accordingly, and in order to determine whether a behavior is a deviation, we must examine the practices of a society in a given a time and place. If the behavior violates the practice, rule, law or norm acceptable it is a deviation. Drug use is considered a deviation in the Israeli society, the behavior deviates from the customary rules of conduct in the Israeli culture and by law is defined as illegal. However, students report that drug use is part of the young-adult culture in Israel and that to them, it is not considered a deviance, on the contrary, this is the acceptable norm and those who deviate from it experience peer pressure at times. Cannabis use is illegal in Israel and yet many believe that this law should be changed (16). For example, Bar - Hamburger (4) found that 25% of his sample reported that they are in favor of changing the law pertaining to the legalization of cannabis use, 42% of the students expressed their opinion that the law prohibiting its use should stay as it is, and the rest - 33% were indecisive. Many of the students who reported using drugs in practice favored legalizing their use. In general, young-adults and students do not perceive the use of cannabis products as a deviant or negative behavior (for example: 4, 16), and many of them do not attribute health risk to cannabis (6).

The data obtained in this study helps base the understanding of the reasons for the change observed in the extent of drug abuse among students and also gives a better understanding as to the characteristics of students who use drugs, while relating them to additional risk patterns. In addition, another unique importance of this study is that it presents, in a comprehensive manner, abundant information about various risk behaviors, beyond drug abuse, and in various aspects – behaviors which have a clear and significant relationship between them.

The study findings also try to explain cannabis smoking by means of different variables. The most significant variables for explaining experiencing marijuana are: a religious background, driving offenses, and health risk behaviors - especially hookah smoking. The probability of students experiencing cannabis were 5.4 times higher among the less religious students in comparison to the more religious ones; 2.5 times higher among students who also commit driving offenses; and more than 10 times higher among students who smoke a hookah. The deviance and delinquency index as well as the ethnic origin did not come out significant in the analysis.

The current study adds confirmation the Problem Behavior Theory (2) which shows that relationships exist between the different risk behaviors - cannabis use vs. driving offense, deviation and delinquency, hookah and cigarette smoking, alcohol binge drinking, and experiencing ecstasy. Strong causal and significant relationships were found for all of these in our study. According to the PBT, experiencing and using cannabis are explained by the strengthening of risk factors and the weakening of resilience factors in the personal and social environment. Indeed in our study, as expected, when the risk factors increased, so did the odds of students to experiment and use cannabis regularly. It seems that the content world of smoking and alcohol use considerably affect the likelihood of students to smoke cannabis.

This study has several limitations. First, the study is based on students whom are present in the classroom rather than on all students registered in the various programs. This may have a moderating effect on the degree of their involvement in risk and deviant behaviors. Second, despite the questionnaire being anonymous, the fact that it was distributed in an academic institute may have had a moderating effect on the subjects' responses as they may have feared for impact on their academic record. If these influences exist, it should be presumed that the scope and the severity of risk and deviant behaviors examined in this study are lower than in reality.

Overall, this study is a pioneering study which is meant to be used as a pilot of a larger study which will include a representative sample of students from a number of leading academic institutions in Israel and later, internationally as well.

**Acknowledgment**

We would like to thank the academic institution where this research was conducted, and to the Israeli Anti-Drugs Authority for the funding assistance and for its support; The students for their willingness to contribute to this research and for their patience in completing the questionnaire; Professor Jessoor, from
the University of Colorado, Boulder, for his contribution in guidance and theoretical instruction as well as for allowing us to use his research questionnaire and finally we want to thank Mrs. Yael Shaked for her comments and ideas.

Appendix 1: Variable details

The health risk behaviors examined in this study are hookah smoking, cigarette smoking, alcohol consumption, marijuana smoking and ecstasy use. The Measure of hookah smoking at least once a week was built from the variable of hookah smoking frequency: "If you smoke a hookah, how often do you smoke a hookah these days?". The answer values to this question were: 1. I do not smoke. 2. Less than once a week. 3. At least once a week but not every day. 4. Every day. This measure included subjects who replied values 3 and 4. For the examination of regular daily cigarette smoking - subjects were asked to indicate whether the statements are applicable for them. This measure was based on the statement: "I smoke regularly and consistently throughout the day". The answer values to this question were: 1. Yes. To some extent. 3. No. This measure included subjects who replied value 1. The binge drinking measure was based on the question: "In the last month, how often did you drink five or more alcoholic drinks when drinking?" and the drunkenness measure was based on the question: "In the last month, approximately how many times did you actually get drunk?". The answer values to these questions were: 1. Never. 2. Once. 3. Two - three times. 4. Once a week. 5. Five to seven times. 6. Twice a week. 7. More than twice a week. Subjects replying values of 2 to 7 were included in these measures. The measure of cannabis smoking experience was based on the question: "Have you ever tried marijuana/ hashish?" Answer values were: 1. No, never. 2. Yes, once. 3. Yes, more than once. This measure included subjects who replied values 2 and 3. Smoking marijuana once a week or more was based on the question: "Over the past month, how often have you used marijuana/ hashish?". The values ranged from 1 never to 7 every day. This measure included values 4-7 from once a week to daily. Ecstasy use experience was based on the question "Have you ever used the following drugs? If so, please indicate how many times you have used each drug during the last month." The values were: 0. No. 1. Yes, and an option of putting down the number of times they had used in the last month.

The driving offenses indexes were based on a series of questions as detailed: "Over the past month, how often did you: 1. pass a stop sign without coming to a complete stop? 2. Drive too close to the car in front of you? 3. Drive after drinking at least one whole bear, a glass of wine or something similar? 4. Drive more than 20 kilometers per hour above the speed limit? 5. Drive through a red light? 6. Drive after using marijuana?" The answer values to these questions ranged from 1. Never to 5. Ten times or more. Subjects replying answer values 2 (once or twice) to 5 (ten times or more) were included in these measures. Two additional measures on the use of seat belts were based on the questions: "When you are a passenger in a car that a friend is driving, do you use your seat belt?" And "Do you wear a seat belt when you drive?" The answer values for both questions ranged from 1. Always to 5. Almost never. Subjects replying answer values 2 (almost always) to 5 (almost never) were included in these measures.

Daring, deviant and delinquent behavior indexes were based on a series of questions as detailed: "Over the past month, how often did you: 1. Cheat on exams or homework? 2. Shop lift? 3. Caused damage or marked public or private property on purpose? 4. Sold or dealt drugs? 5. Stole something valuable such as a Palm pilot, a backpack, or a wallet from someone? 6. Hit someone because you did not like what they had to say?" Values for these questions ranged on a scale from 1. Never to 5. 5 times or more. Subjects replying values 2 (once) to 5 (twice or more) were included in these measures.

Independent variables: gender (male, female), The age category variable - determined by year of birth (age group distribution was determined by the median value - born in 1984 - distributing the sample to young people – up to age 26, and from age 26 onwards - adults). The variable of ethnicity was based on the question: "What ethnic background best describes you?". This question had eight response values as follows: 1. Ashkenazi/ Western Europe; 2. Spain/ Mizrahi. 3. Eastern Europe/ The Soviet Union / Russia. 4. Ethiopia. 5. Arab Israeli 6. Druze. 7.
Bedouin. 8. Other. In the construction of the measure, categories were created for Jewish – those who replied values 1 to 4, and non-Jewish – those who replied values 5 to 7. The marital status variable included the categories 1. Single, 2. Single living with a partner. 3. Married. 4. Separated. 5. Divorced. 6. Widower. The Analysis included students from the categories 1 + 2 as single, and Category 3 - married. The family income variable was based on the question: "What is your family’s average monthly income?" Response values were: 1. Less than 7,000 NIS. 2. Between 7,000 NIS and 9000 NIS. 3. Between 9,000 NIS and 13,000 NIS. 4. Between 13,000 NIS and 17,000 NIS. 5. Between 17,000 NIS and 25,000 NIS, and 6. Over 25,000 NIS.

Odds ratio analysis indexes: Religiosity index (α = 0.85) consisted of five questions as follows: 1. How important is it for you to be able to rely on what religion teaches when you have a problem? 2. How important it for you to believe in God, a higher power or a creator? 3. How important it for you to depend on your religious beliefs as a guide to everyday life? 4. How important it for you to be able to turn to prayer when you deal with personal problems? And Question 5 - How many times did you attend synagogue or other religious services during the last month? In questions 1-4 the students were asked to mark their answer from four values on a scale ranging from “very important” to "not important at all". In the fifth question they were asked to list the number of times from - 1.Never to 7. Eight times or more. For the creation of a secular - religious index, the five questions were put together and their values were divided to two according to the average value.

The driving offenses index (α = 0.61) consisted of eight questions which asked the respondent to mark frequencies within the last month on a scale of five responses ranging from “never” to "10 times or more", for the questions: 1. Not stopping at a stop sign 2. Not keeping a distance 3. Driving after drinking alcohol. 4. Speeding. 5. Driving through a red light 6. Driving after using marijuana 7. Not wearing a seat belt when a friend drives. 8. Not wearing a seat belt when I drive. For index creation purposes, these eight questions were put together, and the values were divided to 0 - no offense, and 1 - one or more offense.

The deviation and delinquency index (α = 0.73) consisted of five questions in which the subjects were asked to select, within the past month, how often, on a scale of five responses, ranging from “never” to "5 times or more", have they: 1. Shop lifted. 2. Caused property damage. 3. Sold or dealt drugs 4. Stole something valuable. 5. Hit someone because they did not like what they said. For index creation purposes, these five questions were put together and the values were divided to 0 – none of these behaviors, and 1 – at least one of these behaviors. The "cheating on exams" variable was omitted from the index because it lowered the reliability of items with results of under 0.6.

References


Health risk and deviant behaviors


Adult perceptions of youth mental health issues in a Canadian Province

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1 University of Calgary, Department of Community Health Sciences, Canada
2 Alberta Centre for Child Family and Community Research, Canada
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Abstract

Although 15% of Canadian youth experience mental health problems, barriers to disclosure and treatment exist. Objective: This population-based study aimed to assess public opinion about the prevalence of mental illness among youth, treatment for mental illness, and comfort interacting with youth with mental health problems. Study Group: A random sample of adults residing in Alberta Canada. Methods: Chi-square tests and t-tests were used to understand responses by demographics. Logistic regression was used to determine factors predictive of comfort in interacting with youth with moderate mental health problems. Results: Twenty percent were able to correctly identify the prevalence of youth mental health problems. Over 50% stated that they believed that <10% of youth with mental health problems received treatment. Approximately 70% of the sample reported they would be comfortable interacting with youth with moderate mental health problems in work, school, social and community settings. Consistent predictors of comfort interacting with youth with moderate mental health problems included: being between the ages of 18-24, high school completion, Caucasian ethnicity, and annual household income >$40,000/year. Conclusions: There are meaningful gaps in Albertans understanding of the prevalence of youth mental health issues, but the majority of adults would be comfortable interacting with youth with moderate mental health problems in work, school, social and community settings. Increased public awareness about the prevalence and detrimental impact of youth mental health issues may help policy makers allocate resources to effective screening and treatment for youth with mental health concerns.

Keywords: Mental health, children and youth, stigma, literacy, social distance

Introduction

Adequate levels of mental health literacy (‘the knowledge and beliefs about mental disorders which aid their recognition, management or prevention’(1))
in the population is important for several reasons. First, it is estimated that in the course of a lifetime, almost everyone will either come into contact with a person with a mental health problem or will develop a mental health problem (1). Second, poor mental health literacy may delay treatment as people are unable to identify the signs and symptoms of mental health problems or be unable to clearly communicate these symptoms to care providers (2). As the majority of mental health problems begin before the age of 24 (3), understanding the public’s knowledge of mental health problems in adolescents is crucial as this sets the context in which policy is developed, clinicians are trained and individuals seek care (4). Furthermore, an Australian study found that when dealing with mental health issues, youth (aged 15-25) were most likely to turn to family and friends for assistance before seeking out professional help (3). Therefore, it is important that members of the general public are able to recognize the signs and symptoms of mental health problems and are able to direct individuals to appropriate sources of care.

Poor mental health literacy is believed to contribute to public stigma towards individuals with mental health problems. This in turn can lead to social distancing (‘the desire to avoid contact with a particular group of people’ (5)) from individuals with mental health problems which can further impact an individual’s ability to seek and receive treatment and successfully integrate into society (6). While the desire for social distance from adults with mental health issues has been widely reported on in the literature, the desire for social distance from children and youth afflicted with mental health problems is less clearly understood (5). A 2009 review of social distance from individuals with mental health problems concluded that social distance should routinely be measured as part of national health surveys as an indicator of public stigma and the impact of public health campaigns to reduce stigma towards individuals with mental health problems (5).

This study aimed to assess the mental health literacy of the general population in relation to the prevalence of moderate mental health problems in youth, and to assess their desire for social distance from youth afflicted with moderate mental health problems.

Methods

English-speaking men and women who were at least 18 years of age and were residing in Alberta Canada at the time of contact were involved in this population-based study. Participants were recruited through a random-digit dialling technique targeting landlines and cellular phones. If an individual was contacted on their cellular phone, they were given the opportunity to provide an alternative number for a scheduled call back. Potential participants were contacted up to 10 times at various times of day. Interviews took approximately 30 minutes to complete. Prior to beginning the questionnaire, participants were informed that their participation in this research was completely voluntary, that their individual responses would be kept confidential, and that they could end the interview at any time. An overall response rate of 21.2% (1203/5667) was obtained for this survey and on average it took 3.9 call attempts to complete an interview. This study was approved by the Arts, Science and Law Research Ethics Board at the University of Alberta.

Questionnaire

The Alberta Survey is conducted annually by the Population Research Laboratory at the University of Alberta to understand public opinion on issues with relevance to public policy. Community groups, researchers and governmental organizations have the opportunity to add a group of questions to this survey each year.

To understand mental health literacy and a desire for social distance, respondents were asked the following 5 questions regarding their perceptions about youth mental health issues along with questions related to respondent demographics:

1. Generally, what percentage of youth between the ages of 15 to 19 do you think have some kind of mental health problem? (Open Ended)
2. Generally, what percentage of children between the ages of 12 to 14 do you think have some kind of mental health problem? (Open Ended)
3. What percentage of those between the ages of 12 to 19 with a mental health problem receive treatment? (Open Ended)

4. At what age do you think a mental health problem can develop? (Response options: before or after birth (up to 12 months), early childhood (13-59 months), childhood (5-9 years), puberty (10-13 years), teens (14-19 years), early adulthood (20-24 years), adulthood (=25 years), any age)

5. How comfortable do you think you would feel in the company of a child or youth between the ages of 12-19 who has a moderate mental health problem in the following settings? (Response options: very uncomfortable, uncomfortable, neutral, comfortable, very comfortable)
   a. Work
   b. School
   c. Social setting (i.e. family gathering or party with friends or work colleagues)
   d. Community setting (i.e. sports, recreational activities, or church)

The following definition of a moderate mental health problem was provided to survey respondents upon request: An individual with a moderate mental health problem exhibits chronic and pervasive behaviours that interfere with the functioning and safety of the individual and other individuals around him/her. Typically a moderate mental health problem is characterized by a number of maladaptive behaviours, such as: an inability to establish or maintain satisfactory relationships with peers or adults; a general mood of unhappiness or depression; inappropriate behaviour of feelings under ordinary conditions; continued difficulty in coping with the everyday situations in spite of remedial intervention; physical symptoms or fears associated with personal, work or school problems; difficulties in accepting the realities of personal responsibility and accountability; and/or physical violence toward other persons and/or physical destructiveness toward the environment.

Data were collected between May and July 2010 using a computer-assisted telephone interview (Ci3 WINCATI, Sawtooth Software).

Statistical analysis

This analysis was completed using Stata SE version 11 and significance was set at p<0.05. Descriptive statistics were used to describe the characteristics of study respondents. Categorical variables were expressed as frequencies and percentages with 95% confidence intervals (CI). Four multivariable logistic regression models were used to determine what demographic variables (marital status, employment, education, age, ethnicity, annual household income) were significantly associated with comfort in interacting with youth with moderate mental health problems in various settings (coded as very comfortable/comfortable vs. neutral/uncomfortable/very uncomfortable). All variables were initially entered into the model, the variable with the highest p-value was purposively removed from the model until all remaining variables had a p-value of <0.05.

Results

This questionnaire was completed by a total of 1203 individuals. Approximately equal numbers of men and women participated in the survey (Table 1). The majority of respondents: lived in a city, were married or in a common law relationship, were employed full-time, had completed post-secondary education, had an annual household income = $80,000, were Caucasian, and did not currently have children residing with them in their homes (Table 1).

Respondents are reflective of the Alberta population as captured by the 2006 Canadian census (7) in terms of gender and ethnicity (Table 1). Respondents tended to have completed a higher level of education, have a higher income and be older than the average Albertan (Table 1).

Perceptions regarding the prevalence of youth mental health issues

Approximately 20% of respondents correctly identified that 11-20% of youth between the ages of 12 and 19 years suffer from mental health problems; and many respondents believed that mental health
problems influenced fewer than 10% of youth (Table 2). On average, 11% of respondents correctly identified that 21-30% of youth aged 12-19 with mental health problems receive treatment for these issues (Table 2). Slightly over half of respondents believed that no more than 10% of youth with mental health problems received treatment for these problems. Approximately a third of respondents correctly identified that mental health problems can develop at any age, and only 2.0% of respondents believed that mental health problems could not develop until adulthood (Table 2).

Table 1. Respondent characteristics

<table>
<thead>
<tr>
<th>Variable</th>
<th>Survey Respondents N (%, 95% CI)</th>
<th>2006 Canadian Census: Alberta Population (7) %</th>
</tr>
</thead>
<tbody>
<tr>
<td>Location</td>
<td></td>
<td></td>
</tr>
<tr>
<td>City</td>
<td>774 (64.4, 61.7 to 67.1)</td>
<td>---</td>
</tr>
<tr>
<td>Town/Village</td>
<td>238 (19.8, 17.6 to 22.1)</td>
<td></td>
</tr>
<tr>
<td>Rural Area</td>
<td>189 (15.7, 13.7 to 17.8)</td>
<td></td>
</tr>
<tr>
<td>Gender</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>598 (49.7, 46.9 to 52.5)</td>
<td>50.0</td>
</tr>
<tr>
<td>Female</td>
<td>605 (50.3, 47.5 to 53.1)</td>
<td>50.0</td>
</tr>
<tr>
<td>Marital Status*</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Married/Common Law</td>
<td>855 (71.4, 68.8 to 73.9)</td>
<td>64.8</td>
</tr>
<tr>
<td>Single/Divorced/Separated/Widowed</td>
<td>343 (28.6, 26.1 to 31.2)</td>
<td>35.2</td>
</tr>
<tr>
<td>Employment Status**</td>
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<td></td>
</tr>
<tr>
<td>Employed Full-Time</td>
<td>666 (60.1, 57.2 to 62.9)</td>
<td>Employment rate: 70.9%</td>
</tr>
<tr>
<td>Employed Part-Time</td>
<td>164 (14.8, 12.7 to 16.9)</td>
<td>---</td>
</tr>
<tr>
<td>Retired</td>
<td>227 (20.5, 18.1 to 22.8)</td>
<td>Unemployment Rate: 4.3%</td>
</tr>
<tr>
<td>Unemployed</td>
<td>52 (4.7, 3.4 to 5.9)</td>
<td></td>
</tr>
<tr>
<td>Highest Level of Education Completed</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Did not complete high school</td>
<td>96 (8.0, 6.5 to 9.6)</td>
<td>23.4</td>
</tr>
<tr>
<td>Completed high school</td>
<td>240 (20.1, 17.8 to 22.4)</td>
<td>26.2</td>
</tr>
<tr>
<td>Some post-secondary</td>
<td>137 (11.5, 9.7 to 13.3)</td>
<td>---</td>
</tr>
<tr>
<td>Completed post-secondary</td>
<td>584 (48.9, 46.0 to 51.7)</td>
<td>45.1</td>
</tr>
<tr>
<td>Post-graduate degree</td>
<td>138 (11.5, 9.7 to 13.4)</td>
<td>5.3</td>
</tr>
<tr>
<td>Median Age Group***</td>
<td>51.0</td>
<td>36.0</td>
</tr>
<tr>
<td>Ethnicity</td>
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<tr>
<td>Caucasian</td>
<td>1021 (84.9, 82.8 to 86.9)</td>
<td>86.1</td>
</tr>
<tr>
<td>Other</td>
<td>182 (15.1, 13.1 to 17.2)</td>
<td>13.9</td>
</tr>
<tr>
<td>Median Personal Income</td>
<td>$50,000 to 54,999</td>
<td>$43,964</td>
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<tr>
<td>Children Reside in the Home</td>
<td></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>805 (67.1, 64.5 to 69.8)</td>
<td>---</td>
</tr>
<tr>
<td>Yes</td>
<td>394 (32.9, 30.2 to 35.5)</td>
<td></td>
</tr>
</tbody>
</table>

* Census results for marital status are for individuals age 20.
** Census results for employment are for individuals age 15 and older.
*** Census results are for all Albertans, while survey participants had to be at least 18 years of age.

Comfort interacting with youth with moderate mental health problems

Approximately two-thirds of respondents reported that they would be comfortable or very comfortable interacting with youth with moderate mental health problems in work, school, social and community settings (Table 3). Only 10% of respondents reported that they would be uncomfortable or very uncomfortable interacting with youth with moderate mental health problems in work, school, social and
community settings (Table 3). The proportion of respondents who reported being comfortable/very comfortable interacting with youth with moderate mental health problems was slightly less for social and community settings than it was for work and school settings.

Age and ethnicity were significant predictors in all models examining comfort interacting with youth with moderate mental health problems (Table 4). Consistently, individuals who were 18-24 years old and of Caucasian ethnicity were more likely to report being comfortable or very comfortable interacting with youth with moderate mental health problems. Annual household income was a significant predictor in the models examining comfort in work, social and community settings (Table 4).

Table 2. Respondent beliefs about youth mental health issues (n=1139)

<table>
<thead>
<tr>
<th>Variable</th>
<th>N</th>
<th>% (95% CI)</th>
</tr>
</thead>
<tbody>
<tr>
<td>What percentage of children between the ages of 12-14 do you think have some kind of mental health problem?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>0-10%</td>
<td>476</td>
<td>46.5% (43.5 to 49.6)</td>
</tr>
<tr>
<td>11-20%*</td>
<td>204</td>
<td>19.9% (17.5 to 22.4)</td>
</tr>
<tr>
<td>21-30%</td>
<td>151</td>
<td>14.8% (12.6 to 16.9)</td>
</tr>
<tr>
<td>31-40%</td>
<td>60</td>
<td>5.9% (4.4 to 7.3)</td>
</tr>
<tr>
<td>41-50%</td>
<td>71</td>
<td>6.9% (5.4 to 8.5)</td>
</tr>
<tr>
<td>&gt;50%</td>
<td>61</td>
<td>6.0% (4.5 to 7.4)</td>
</tr>
<tr>
<td>What percentage of youth between the ages of 15-19 do you think have some kind of mental health problem?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>0-10%</td>
<td>358</td>
<td>34.7% (31.7 to 37.6)</td>
</tr>
<tr>
<td>11-20%*</td>
<td>229</td>
<td>22.2% (19.6 to 24.7)</td>
</tr>
<tr>
<td>21-30%</td>
<td>149</td>
<td>14.4% (12.2 to 16.6)</td>
</tr>
<tr>
<td>31-40%</td>
<td>102</td>
<td>9.9% (8.1 to 11.7)</td>
</tr>
<tr>
<td>41-50%</td>
<td>73</td>
<td>7.1% (5.5 to 8.6)</td>
</tr>
<tr>
<td>&gt;50%</td>
<td>122</td>
<td>11.8% (9.8 to 13.8)</td>
</tr>
<tr>
<td>What percentage of youth between the ages of 12-19 with a mental health problem receive treatment?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>0-10%</td>
<td>495</td>
<td>50.2% (47.0 to 53.3)</td>
</tr>
<tr>
<td>11-20%</td>
<td>115</td>
<td>11.7% (9.6 to 13.7)</td>
</tr>
<tr>
<td>21-30%*</td>
<td>110</td>
<td>11.1% (9.2 to 13.1)</td>
</tr>
<tr>
<td>31-40%</td>
<td>54</td>
<td>5.5% (4.0 to 6.9)</td>
</tr>
<tr>
<td>41-50%</td>
<td>114</td>
<td>11.6% (9.6 to 13.5)</td>
</tr>
<tr>
<td>&gt;50%</td>
<td>99</td>
<td>10.0% (8.2 to 11.9)</td>
</tr>
<tr>
<td>At what age do you think a mental health problem can develop?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Before or after birth (up to 12 months)</td>
<td>159</td>
<td>14.0 (11.9 to 16.0)</td>
</tr>
<tr>
<td>Early childhood (13-59 months)</td>
<td>199</td>
<td>17.5 (15.3 to 19.7)</td>
</tr>
<tr>
<td>Childhood (5-9 years)</td>
<td>207</td>
<td>18.2 (15.9 to 20.4)</td>
</tr>
<tr>
<td>Puberty (10-13 years)</td>
<td>101</td>
<td>8.9 (7.2 to 10.5)</td>
</tr>
<tr>
<td>Teens (14-19 years)</td>
<td>65</td>
<td>5.7 (4.4 to 7.1)</td>
</tr>
<tr>
<td>Early adulthood (20-24 years)</td>
<td>12</td>
<td>1.1 (0.5 to 1.6)</td>
</tr>
<tr>
<td>Adulthood (25+ years)</td>
<td>10</td>
<td>0.9 (0.3 to 1.4)</td>
</tr>
<tr>
<td>Any age*</td>
<td>386</td>
<td>33.9 (31.1 to 36.6)</td>
</tr>
</tbody>
</table>

* correct response.
Table 3. Comfort interacting with youth aged 12-19 with moderate mental health problems in various settings (n=1174)

<table>
<thead>
<tr>
<th>Variable</th>
<th>Work Setting N (% 95% CI)</th>
<th>School Setting N (% 95% CI)</th>
<th>Social Setting N (% 95% CI)</th>
<th>Community Setting N (% 95% CI)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Very Uncomfortable</td>
<td>55 (5.0, 3.7 to 6.3)</td>
<td>40 (4.1, 2.8 to 5.3)</td>
<td>30 (2.6, 1.7 to 3.5)</td>
<td>30 (2.6, 1.7 to 3.5)</td>
</tr>
<tr>
<td>Uncomfortable</td>
<td>66 (6.0, 4.6 to 7.5)</td>
<td>62 (6.3, 4.8 to 7.8)</td>
<td>63 (5.4, 4.1 to 6.7)</td>
<td>55 (4.7, 3.5 to 5.9)</td>
</tr>
<tr>
<td>Neutral</td>
<td>214 (19.6, 17.2 to 21.9)</td>
<td>197 (20.0, 17.5 to 22.5)</td>
<td>225 (19.2, 16.9 to 21.4)</td>
<td>222 (18.9, 16.7 to 21.2)</td>
</tr>
<tr>
<td>Comfortable</td>
<td>305 (27.9, 25.2 to 30.6)</td>
<td>267 (27.2, 24.4 to 29.9)</td>
<td>352 (30.0, 27.4 to 32.6)</td>
<td>350 (29.9, 27.2 to 32.5)</td>
</tr>
<tr>
<td>Very Comfortable</td>
<td>453 (41.4, 38.5 to 44.4)</td>
<td>417 (42.4, 39.3 to 45.5)</td>
<td>504 (42.9, 40.1 to 45.8)</td>
<td>515 (43.9, 41.1 to 46.8)</td>
</tr>
</tbody>
</table>

Table 4. Significant predictors of comfort interacting with youth with moderate mental health problems in various settings

<table>
<thead>
<tr>
<th>Variable</th>
<th>Work Setting (n=828) OR (95% CI)</th>
<th>School Setting (n=730) OR (95% CI)</th>
<th>Social Setting (n=875) OR (95% CI)</th>
<th>Community Setting (n=876) OR (95% CI)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age Categories</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>18-24</td>
<td>Reference</td>
<td>Reference</td>
<td>Reference</td>
<td>Reference</td>
</tr>
<tr>
<td>25-34</td>
<td>0.26 (0.08 to 0.80)</td>
<td>0.67 (0.31 to 1.44)</td>
<td>0.31 (0.10 to 0.96)</td>
<td>0.19 (0.05 to 0.68)</td>
</tr>
<tr>
<td>35-44</td>
<td>0.31 (0.10 to 0.93)</td>
<td>0.58 (0.28 to 1.21)</td>
<td>0.52 (0.16 to 1.62)</td>
<td>0.26 (0.07 to 0.91)</td>
</tr>
<tr>
<td>45-54</td>
<td>0.28 (0.09 to 0.84)</td>
<td>0.48 (0.24 to 0.98)</td>
<td>0.30 (0.10 to 0.90)</td>
<td>0.20 (0.06 to 0.71)</td>
</tr>
<tr>
<td>55-64</td>
<td>0.25 (0.08 to 0.76)</td>
<td>0.41 (0.20 to 0.83)</td>
<td>0.28 (0.09 to 0.84)</td>
<td>0.17 (0.05 to 0.61)</td>
</tr>
<tr>
<td>65+</td>
<td>0.21 (0.07 to 0.64)</td>
<td>0.29 (0.14 to 0.61)</td>
<td>0.22 (0.07 to 0.69)</td>
<td>0.13 (0.03 to 0.45)</td>
</tr>
<tr>
<td>Annual Household Income</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt;$39,999</td>
<td>Reference</td>
<td>Not included in final model</td>
<td>Reference</td>
<td>Reference</td>
</tr>
<tr>
<td>$40,000-$79,999</td>
<td>2.00 (1.17 to 3.40)</td>
<td></td>
<td>2.27 (1.35 to 3.83)</td>
<td>1.77 (1.03 to 3.03)</td>
</tr>
<tr>
<td>≥ $80,000</td>
<td>2.25 (1.36 to 3.71)</td>
<td></td>
<td>2.37 (1.44 to 3.89)</td>
<td>1.85 (1.08 to 3.18)</td>
</tr>
<tr>
<td>Ethnicity</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Caucasian</td>
<td>Reference</td>
<td>Reference</td>
<td>Reference</td>
<td>Reference</td>
</tr>
<tr>
<td>Other</td>
<td>0.49 (0.32 to 0.76)</td>
<td>0.56 (0.38 to 0.83)</td>
<td>0.48 (0.31 to 0.73)</td>
<td>0.43 (0.27 to 0.66)</td>
</tr>
<tr>
<td>Highest Level of Education</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Completed</td>
<td>Not included in final model</td>
<td>Reference</td>
<td>Reference</td>
<td>Not included in final model</td>
</tr>
<tr>
<td>High School Incomplete</td>
<td>2.25 (1.25 to 4.03)</td>
<td>1.63 (0.85 to 3.13)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>High School Complete</td>
<td>2.29 (1.22 to 4.29)</td>
<td>1.86 (0.92 to 3.77)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Post-Secondary Incomplete</td>
<td>2.27 (1.34 to 3.85)</td>
<td>1.99 (1.09 to 3.63)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Post-Secondary Complete</td>
<td>2.49 (1.31 to 4.75)</td>
<td>2.02 (1.00 to 4.11)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Post-Graduate Degree</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Marital Status</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Married/Common Law</td>
<td>Not included in final model</td>
<td>Not included in final model</td>
<td>Not included in final model</td>
<td>Reference</td>
</tr>
<tr>
<td>Single/Divorced/Separated</td>
<td></td>
<td></td>
<td></td>
<td>0.64 (0.44 to 0.93)</td>
</tr>
<tr>
<td>Widowed</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

In all models, a positive association was observed whereby the higher the annual household income the more likely individuals were to report that they were comfortable/very comfortable interacting with youth with moderate mental health problems. Education was a significant predictor in the models examining comfort in school and social settings (Table 4). In both scenarios, individuals who had not completed high school were the most likely to report being uncomfortable interacting with youth with moderate mental health problems. Marital status was only a significant predictor in the model examining comfort in a community setting (Table 4), where it was noted that individuals who were single, separated, divorced or widowed were significantly less likely to report being comfortable interacting with youth with moderate mental health issues (OR=0.64, 95% CI: 0.44-0.93).
Discussion

Mental health literacy in this sample appears to be low, as only 20% of respondents were able to correctly identify that 11-20% of youth (aged 12 to 19) suffer from mental health problems and only 11% of respondents were able to correctly identify that 21-30% of youth aged 12-19 with mental health problems receive treatment for these issues. Additionally, only one third of respondents were able to correctly identify that mental health problems can develop at any age. Generally, respondents did not believe that youth with mental health problems were receiving the treatment that they need. This has important implications for government policy as it may indicate public confidence in Alberta’s publicly funded health care system in regards to youth with moderate mental health problems could be improved.

Most respondents reported that they would be comfortable or very comfortable interacting with youth with moderate mental health problems in work, school, social and community settings indicating a low desire for social distance from youth with moderate mental health problems. Consistent predictors of comfort included: age 18-24, completion of high school, Caucasian ethnicity, and annual household income =$40,000/year.

While direct comparison with other studies is difficult due to the differing nature of how questions were asked, respondents in this survey appear to be more willing to interact with individuals with mental health issues. A 2006 US study found that the majority of survey respondents did not want to work or socialize with individuals with mental health problems (4), while only 10% of respondents in this study reported feeling uncomfortable or very uncomfortable interacting with youth with mental health problems. Consistent predictors of comfort included: age 18-24, completion of high school, Caucasian ethnicity, and annual household income =$40,000/year.

In conclusion, these results indicate strong public support for social inclusion and connectedness to youth with mental health conditions, while also highlighting gaps in knowledge about the prevalence of youth mental health conditions. Finally, the public
correctly identified that it is only the minority of youth who receive treatment for these conditions. Additional treatment or intervention options for youth with mental health conditions would address a gap already identified by the public, and may improve outcomes for youth and their families.

Acknowledgments

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References


Acceptability of HPV vaccine among young adolescent girls in Uganda: Young people’s perspectives count

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2PATH, Seattle, Washington, United States of America

Abstract

Previous research on human papillomavirus (HPV) vaccine acceptance has focused largely on parental acceptability. Adolescents are the target population and adolescence is a phase associated with increased independence. Understanding adolescents’ perspectives regarding vaccine acceptance is therefore critically important. Objective: This paper presents young adolescent girls’ perspectives on acceptability of HPV vaccine after a two-year demonstration project. Methods: We explored acceptability of HPV vaccine among girls aged 10 to 15 years during 2008 and 2009. Acceptability was qualitatively defined as the girls’ willingness or reluctance to be vaccinated and to complete all three doses. Twenty-seven focus group discussions were conducted with girls who completed all three doses and 17 with those who did not. Girls were purposively sampled from areas where vaccine uptake was either high (greater than 90%) or low (less than 70%). Results: Girls independently made decisions and took actions that resulted in their vaccination or non-vaccination. Key influencers of their’ acceptability were: their understanding of cancer, concerns about their future as mothers; understanding of the vaccinations; fears of the consequences of being vaccinated or not; their experiences with the first dose; and their understanding of the eligibility criteria for vaccination. Conclusion: Adolescents demonstrate an independent ability in deciding to be vaccinated or not. As this group is the suggested population to receive this vaccine, preparing them for vaccination becomes critical in helping them make informed decisions. Adequate preparation can foster acceptance of HPV vaccine among girls and eventually influence the success of a national HPV vaccination program.

Keywords: Human papillomavirus, HPV vaccine, acceptability, adolescents, girls

Introduction

Cervical cancer is the third most common cancer in women globally, with an estimated 530,000 new cases in 2008. It is the second most frequent cancer in
women between 15 and 44 years of age in developing countries. High-risk regions include Eastern and Western Africa, where the age-standardized rate (ASR) is greater than 30 per 100,000 and it remains the most common cancer in women in Eastern Africa (1).

In Uganda, cervical cancer is the most frequent cancer among women (1). Current estimates indicate that every year 3,577 women are diagnosed with cervical cancer and 2,464 die from the disease. Approximately 74% of invasive cervical cancers are attributed to human papillomavirus (HPV) types 16 and 18 (2). Cost-effectiveness models have suggested that introduction of HPV vaccines could significantly reduce incidence and mortality of cervical cancer in low-resource settings like Uganda (3).

As the World Health Organization (WHO) continues to recommend routine HPV vaccination to be included in national immunization programs (4), acceptability of the vaccines remains key to the success of the program. Generally, factors for considering introducing HPV vaccine include: the country’s disease burden; infrastructure, affordability, and cost-effectiveness of vaccination; cultural acceptability of the vaccine; and political will, among others (5).

Previous research on acceptability of HPV vaccine has shown high acceptability of the vaccine by parents for their children, college students, and health workers (6–10). While acceptability of the vaccine by parents for their children is important, there is a dearth of literature on the perspectives of younger adolescents with regards to HPV vaccination (11). Given that young adolescents are the population targeted by HPV vaccine (4), more attention should be paid to their acceptance of the vaccine.

The Ministry of Health in Uganda and PATH, an international nonprofit organization, implemented an HPV vaccination demonstration project to assess vaccine coverage, feasibility, cost, and acceptability of HPV vaccine among key stakeholders, including adolescent girls eligible for the vaccinations (12). The project was implemented from 2008 to 2009 through the Uganda National Expanded Programme on Immunization (UNEPI), in partnership with local government authorities of the two districts of Ibanda and Nakasongola. Approximately 10,000 girls were vaccinated in the two districts.

This paper presents results on an assessment of acceptability of HPV vaccine among young adolescent girls in Uganda. The findings can inform our understanding of younger adolescents’ acceptability of the vaccine and the factors underlying their acceptance, which will be important for the future rollout of the program in Uganda and elsewhere in Africa.

Methods

A cross-sectional qualitative study design was adopted that included fully, partially, and non-vaccinated girls aged 10 to 15 years. Using data from UNEPI on HPV vaccine uptake in 17 sub-counties in the two districts, three sub-counties with high coverage of 90% and above and two others with lower coverage of 70% and less were purposively sampled. In each of the sub-counties sampled, two schools were randomly selected. In each school, one focus group discussion was conducted with 10 to 12 girls who were eligible for HPV vaccination. In the sub-counties that had high coverage, the focus group discussions involved fully vaccinated girls. In the sub-counties with lower coverage, the focus group discussions were with partially or non-vaccinated girls. Due to the high coverage in both districts, it was difficult to convene the same number of focus group discussions of fully vaccinated as those with partially and non-vaccinated girls. In the end, 27 focus group discussions were held with fully vaccinated girls and 17 focus group discussions with partially and non-vaccinated girls (Table 1).

In all, a total of 44 focus group discussions were conducted over a period of two years involving 422 girls drawn from the two districts of Ibanda and Nakasongola that participated in the demonstration project. The focus group discussions with the girls explored vaccine acceptability and reasons for being fully, partially, or not vaccinated at all; their preparation for the vaccinations; their experiences with the vaccination exercise; and their role in deciding whether to be vaccinated or not. Acceptability of the vaccine was qualitatively defined as the girls’ willingness and/or reluctance to be vaccinated and to complete all three doses.
As a secondary outcome, we were also interested in the girls’ perspectives and the extent to which they portrayed their agency. Agency was defined as the adolescents’ capacity or ability to decide and act on what they consider to be in their interest. In analysis, we extracted the children’s voices that we have included in the text. In some measure, this portrays the girls as social actors and attributes competence rather than incompetence to them (13). Girls were encouraged to discuss their experiences in the language that they were most comfortable expressing themselves in. The discussions were recorded and later transcribed and translated into English. Key themes and sub themes were identified through textual data analysis and a coding scheme was constructed (14, 15). Atlas.ti software was used to facilitate data management and analysis.

Parental written consent was obtained for girls to participate in the study. Verbal assent was taken from the girls at the time of data collection. The study was approved by ethics committees in Uganda and the United States.

Results

Girls in the focus group discussions explained their reasons for acceptance and/or reluctance to be vaccinated and the actions that they took as individuals to ensure that they were fully vaccinated or not. In the sections that follow, we present the reasons given by the fully vaccinated girls for accepting to be vaccinated and those given by the partially or non-vaccinated girls for refusing to complete their doses or be vaccinated at all.

Reasons for vaccination

Discussions with the fully vaccinated girls revealed that the majority understood HPV vaccine as a prevention of cancer. According to the girls, cancer is a disease that is very painful, has no cure, and kills. A few mentioned cases of people whom they knew who had died of cancer as the following extracts illustrate:

My uncle died of cancer, they tried everything but there was no cure…

My aunt who had cancer died a very painful death.

According to the fully vaccinated girls, the idea that cancer could be prevented was a relief, especially because prior to this, the only thing they knew about cancer was that it killed. This influenced their willingness to be vaccinated as illustrated by the following:

People say that cancer has no cure but the health worker told us that this cancer which they were vaccinating against could be prevented, so I was very happy because it meant that if I got vaccinated I would not die of cancer.

Girls perceived the vaccinations as a way to protect themselves against a disease that had no cure. To them this was an opportunity which they did not want to miss:

When you get a chance you use it.

If you do not use an opportunity you may not get another one.

The majority of the fully vaccinated girls also reported that they had decided to complete all three doses because they feared that if they were not fully vaccinated they would not get the full protection, which meant they could still get cancer and die a painful death. The idea that those that got the cancer died a painful death was a recurrent theme in both districts and emerged as an important consideration for the girls:

Table 1. Study populations and sample sizes for HPV vaccine acceptability study, Uganda

<table>
<thead>
<tr>
<th>Study population</th>
<th>Sample, year 1</th>
<th>Sample, year 2</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Girls fully vaccinated</td>
<td>7 focus group discussions</td>
<td>20 focus group discussions</td>
<td>27 focus group discussions</td>
</tr>
<tr>
<td>Girls partially or not vaccinated</td>
<td>2 focus group discussions</td>
<td>15 focus group discussions</td>
<td>17 focus group discussions</td>
</tr>
<tr>
<td>Total number of girls participated</td>
<td></td>
<td></td>
<td>442</td>
</tr>
</tbody>
</table>
The disease is very painful and it kills, that is why I decided to get all three doses. I was told that if you got only one or two it was useless.

If you get the cancer you stay with it and keep crying till you die and I do not want that…my auntie suffered for a long time.

In nearly all focus groups, the fully vaccinated girls admitted that they were initially reluctant to be vaccinated fearing that the three injections would be painful. When they discussed why they changed their minds, they explained that they realized that the pain arising from the vaccination was likely to be short lived compared to the pain that they could potentially suffer if they got cancer:

I normally fear injections but when I thought about the pain that I could suffer if I got cancer I decided to be vaccinated no matter what.

I have had injections before and I know the pain lasts a short time but I feared that the pain from cancer can last forever…

Fully vaccinated girls reported that their experience with the initial dose of HPV vaccine helped them to overcome some of their fears and anxieties and motivated them to get the other doses. The majority also reported that they had initially feared possible side effects; but when they did not experience any after the first dose, they willingly went ahead to get the rest of the doses:

The first time I had feared but the injection was not painful… so I was ready for the second…

I didn’t have any pain when I was given any of the injections; but I was better prepared for the second injection than I was for the first.

The majority of the fully vaccinated girls understood vaccinations as protection for their uterus. The distinction between the cervix and the uterus was not fully understood by the majority of girls. This was partly because the local term used for the cervix is the opening of the uterus. During the focus group discussions, fully vaccinated girls explained that the vaccine was a means of protecting their uteruses against cancer and highlighted this as one of the important reasons for their willingness to be vaccinated:

I know that if a woman gets that cancer she cannot bear children and that is very sad.

I was fully vaccinated because I want to have children without any problems.

The cancer destroys your uterus and you can never have children. I do not want to die childless so I had to make sure that I got all three doses.

I wanted to protect my uterus; that is why I was vaccinated.

I know that if I get cancer I will not give birth and I do not want to be like that; that is why I decided to be vaccinated.

Most of the vaccinations in the two districts took place at school and absenteeism was relatively high in both districts. In cases where girls were absent from school on the day of vaccination, they were often advised to go to the nearest health unit for the missed dose. Fully vaccinated girls reported how they made sure that they attended school on the days of vaccination to ensure that they did not miss any of the doses. Even in cases where their parents or guardians tried to prevent them from attending school for different reasons, they insisted on going. Discussions with fully vaccinated girls revealed that they as individuals were convinced of the importance of being vaccinated and they made sure that they were vaccinated and that they completed all three doses.

Reasons for partial or non-vaccination

Discussions with partially and non-vaccinated girls revealed that their reluctance to be vaccinated was due to lack of understanding of what the vaccinations were for or the disease the vaccinations were protecting against, not knowing the importance of completing all three doses, fear of possible side effects, not understanding the benefit of the vaccine (to protect their uteruses), and lack of understanding of the eligibility criteria.

The majority of the partially and non-vaccinated girls, unlike those fully vaccinated, reported that they had not understood the disease that the vaccine protected against let alone the importance of being vaccinated and completing all the three doses, as illustrated by the following extracts:
I was not told what diseases I was being vaccinated against… the teacher just told us to go under the mango tree so the next time when they came I hid in the toilet…

I thought that I was only supposed to receive one injection so when I was told to go for a second one I refused …

It was evident from the discussions with the partially and non-vaccinated girls that they had genuinely not understood what the vaccinations were about. A few reported that they were absent from school when the health worker explained to the others about the vaccinations. Others reported that they were taken by surprise when they were told to go and line up for vaccinations without any explanation:

The teacher just told us to go quickly and line up outside and be vaccinated but she did not explain against what we were being vaccinated.

I missed school when the health worker came to explain. When I asked the other girls they did not explain properly; they just told me the teacher said we should line up.

I was injected the first time at school but when they came the next time I hid because I did not know what the vaccine was for so I did not want to be injected again…

This situation was not helped by the girls lack of understanding of the eligibility criteria, especially in the district where girls were vaccinated based on their age rather than their grade/class in school. It was not clear to the girls why only 10-year-old girls were being vaccinated. Partially and non-vaccinated girls explained that they were suspicious as to why only some girls were being vaccinated and not others:

I did not understand why we were being told to have three injections when others in the class were not being injected so the next time when the teacher told us not to miss school because the health workers were coming again I missed school on that day and told the teacher that I was sick …. The teacher came the first time and told all of us who were 10 years to put up our hands and I did, so they injected me but when they came the second time I hid behind the toilet. I wanted to know why only those who are 10 years were being vaccinated and what the vaccine was for.

The fear of possible side effects was another reason given by the girls for their partial vaccination status. Nearly half of the partially vaccinated girls reported that they received their first dose when the others were receiving their second doses.

When asked why, they explained that they had waited to see if anything happened to those that were vaccinated first before deciding to be vaccinated as well. When they realized that those who received the first dose had not experienced excessive pain or any side effects, they decided that the vaccine was safe for them.

A few partially or non-vaccinated girls reported that they feared that the vaccinations would reduce their chances of giving birth to children later on in life:

I heard women in the village saying that girls that were vaccinated may not have babies in the future. At the time I had already received the first dose so I decided not to receive the other two.

I did not understand why they were vaccinating only girls, the boys were laughing at us saying the injection would burn our eggs and we would not be able to give birth in the future so I decided not to go for the vaccinations, I told the teacher that I was nine years.

At first I agreed to be vaccinated but when I heard that the vaccinations could prevent me from having children I decided not to receive the other doses.

The majority of the partially vaccinated girls reported that they had not understood the dose schedule and when they were told to go to the nearest health unit for their missed doses some decided not to go there:

I was told by my teacher to go to the health unit and get the missed dose but I decided not to go because I thought one dose was enough.

When the teacher announced in class that those who missed their doses at school should go to the health unit, I thought they meant those who had not been vaccinated at all.

It was evident from the discussions with the partially and non-vaccinated girls that their reasons were directly related to inadequate preparation for the vaccinations.
Agency

Fully, partially, and non-vaccinated girls explained the different strategies that they devised to ensure that they were fully vaccinated or not vaccinated depending on what they had decided to do. Fully vaccinated girls explained how they made extra efforts to make sure that they attended school on the days of vaccination to ensure that they did not miss any of the doses. Even in cases where their parents or guardians tried to prevent them from attending school for different reasons they insisted on going:

My mother almost made me miss one of the doses by asking me to accompany her to the hospital on the day of vaccination. I explained to her that I could not miss school on that day because I would miss being vaccinated…

My grandmother tried to stop me from going to school, I refused. I told her that those who miss school and the vaccinations will have to go to the health centre which was far away from home, and she agreed.

Those who were absent from school reported that they had followed up with the health workers to ensure that they completed all three doses:

There was a day when I fell sick and missed being vaccinated at school. When I got better I went to the health centre and was injected…

The teacher told me I missed vaccinations yesterday so you have to go to the health centre, so I went there after school and the health worker injected me…

Others reported that they had made more than one visit to the health unit just to ensure that they were fully vaccinated:

I went to the health centre the first time and the health worker was not there, so I went again the following day and she was there and she injected me. I had to make sure that I did not miss any of the doses.

When I missed the vaccination at school the first time I was told to go to the health centre. I went the first time, the health worker was busy and she sent me away; the next time I went back she was not there, then I went the third time and found her and she injected me…

These text extracts from the focus group discussions illustrate girls’ conviction and determination as individuals to ensure that they were fully vaccinated.

Partially and non-vaccinated girls also explained the strategies they devised to ensure that they were not vaccinated or that they did not complete all three doses. A few, for example, admitted that they had deliberately lied about their age to avoid being vaccinated:

When I knew that those who were 10 were the ones to be vaccinated I told the teacher that my mother said that I was 11…

I told the teacher that I was 9 years so that I could miss the vaccinations and she believed me because I am small…

Others reported that they had hidden or absented themselves from school on vaccination day, so as to not be vaccinated:

I could not lie about my age to the teacher because she already knew that I was 10, so when they sent us out to be vaccinated I quickly went towards the toilets and hid. I thought that perhaps they wanted to kill us or prevent us from having children.

When the teacher announced that we should not miss school tomorrow because of the vaccinations, I deliberately stayed at home and pretended to be sick.

The day when I knew that the vaccinations were going to take place at school I left home and then hid on the way until I was sure the health workers had left, then I went to school.

There is a growing body of literature that argues that young people are social actors with agency, meaning they are able or capable of making decisions on their own, in their own interest, without reference to their parents. A number of fully vaccinated girls reported that their parents or guardians and peers had tried to discourage them from being vaccinated. They reported that they reflected on the advice given in light of the information that they had received and then made their own personal decisions and acted on them. The majority of fully vaccinated girls perceived their decisions to be vaccinated and to complete all three doses among other things as a way of protecting themselves from cancer and as a means of securing their future as mothers. Statements such as ‘I decided,’ were repeated in many of the comments made by the girls, both fully vaccinated and those partially or not vaccinated. Partially and non-
vaccinated girls also perceived the decisions that they made as protecting themselves from future infertility and pain. These data suggest an agency of these young adolescents which cannot be ignored. School-based programs sometimes assume that young people will more or less fall into line based on what they are told by their teachers or parents, but this obviously is not always the case.

**Discussion**

Published studies of HPV vaccine acceptability have been primarily cross sectional surveys with adults conducted before the prophylactic vaccines were more widely introduced or available in the public health system (6–9,16,17). Furthermore, most measured knowledge, general attitudes about HPV vaccination, and willingness to vaccinate one’s daughter (16,18). Earlier reviews showed that research on adolescent attitudes regarding vaccination, separately from parental attitudes, were very limited in scope, reflecting the dominant role of parents in the vaccination decision. A study from Manchester, UK and another from Australia—two developed countries that have national HPV vaccination programs—have made some contributions in our understanding by exploring with adolescents themselves their experience with HPV vaccination (11,19).

In our study, the majority of the fully vaccinated girls reported that they chose to be vaccinated because they perceived the vaccine as preventing cancer, protecting them from a potentially painful death, and a means of protecting their uteruses. These perceptions of the disease and of the vaccine as protection were key influencers of their willingness to be vaccinated. The reasons girls mentioned for getting vaccinated were strikingly similar to reasons that parents from these same communities mentioned in a survey assessing vaccine coverage – protection against cancer and protection against disease (12). HPV vaccine as prevention was also a concept echoed in the findings from Australia and the UK as a motivator for acceptance by adolescents (14, 19).

Over 90% of girls in Manchester, UK said they were vaccinated for protection against cervical cancer.

Concerns regarding the safety of the vaccine mentioned by girls in our study concur with the findings from research conducted elsewhere (18), but surprisingly few parents of girls in Uganda mentioned safety as a concern in a survey of vaccine coverage (12). All girls, regardless of their vaccination status, were concerned about their future as mothers and needed assurances of the safety of the vaccine. Fully vaccinated girls reflected not only on the benefits of being vaccinated but also on the possible consequences of not being vaccinated for their future as mothers. Furthermore, the fully vaccinated girls in our study noted their positive experience with the first dose where they experienced minimal pain and no serious side effects which influenced them to complete all three doses and served as affirmation for them that the vaccine was safe, and they could go ahead to receive the second and third dose. Those not vaccinated or partially vaccinated reflected on possible negative consequences of being vaccinated such as infertility. It was evident from the discussions that the girls did reflect on the vaccinations and made choices based on the information that they had or did not have and on their understanding of the benefits and likely consequences of their choices. Safety has also been a common concern mentioned by adolescents vaccinated in other countries (19), suggesting this concept resonates universally.

For girls that decided not to complete all three doses or those that did not get vaccinated at all, the lack of understanding of the benefits of the vaccine and of the criteria for vaccinating a particular age group and not others resulted in reluctance or unwillingness on the part of some girls to be vaccinated in our study. Consequently, some girls deliberately missed school on the days of vaccination, hid when the vaccinators came to their school, or lied about their ages so as to avoid being vaccinated. Because the majority of vaccinations took place at school, the influence of parents’ acceptance of the vaccine on the girls’ acceptance was reduced. Discussions with the girls revealed that being vaccinated at school accorded them more space within which they themselves could decide whether to be vaccinated or not. Teachers were responsible for mobilizing the girls at school for vaccination, but this did not seem to have prevented girls from devising ways to avoid vaccinations.
Agency was also a key theme in our findings. Our results show that adolescent girls were actively involved in decision-making and taking action regarding whether to be vaccinated against HPV or not and whether to complete all three doses. They were not passive receivers. About a third of the fully vaccinated girls reported that their parents, and in some cases guardians, tried to discourage and/or prevent them from being vaccinated. Because they were convinced that the vaccine was good for them, they went ahead and got vaccinated. Their independence in making this decision, even when parents were discouraging, suggests a degree of independence girls of this age feel regarding their own health. Brabin et al. also suggested a degree of independence in the vaccine decision from their study of adolescents vaccinated in Manchester, UK. They found that the majority of girls (77%) reported that they had shared in the vaccine decision. A total of 42% of girls whose parents refused vaccination stated that they wanted the vaccine and 70% of those vaccinated thought that girls of their age should be able to agree to have the vaccine without parental consent (11). Independent agency was also noted in the study by Cooper Robbins et al, where there was discordance between the wishes of the girl to receive the vaccine and the parental decision to not provide written consent for their daughter (19). Adolescents often contribute to the familial decision-making and their attitudes were found to be similar to those of their parents regarding vaccine efficacy, the influence of recommendations by health care professionals, and consideration of vaccine cost (20,21). Taken together, these results provide strong evidence for policymakers and program planners to understand the dynamics of decision-making for HPV vaccination and the participation of girls of this age in choices that affect their personal health.

The new sociology of childhood emphasizes the competence of children as ‘social actors’ and as informants about their lives. With an emphasis on agency and a move away from the assumption of children as passive recipients of action, has come a parallel and consistent move away from relying on statements by adults about children’s worlds and experiences and instead toward considering as equally reliable, statements by children themselves. There is emphasis on the need for children’s voices in understanding children’s experiences (13). Listening to what children had to say about their experiences with the vaccinations enables us to act on their understanding in relation to vaccinations. Policymakers can and should appreciate that children, while ‘governed’ as objects, are also active subjects who can speak to their lives, their experiences, and their futures as knowing and informed agents (22). What children need is knowledge and information that enables them to make the decision.

Conclusion

Providing full and accurate information to young adolescents enables them to make choices to accept (or not accept) HPV vaccination and to act on the choices they make regarding their lives. The converse is also true, indicating that the girls who did not get full information on why they were being vaccinated or the reasons for a particular age group did choose to avoid the vaccination. This particular age group is not routinely targeted by health programs, and policy and program design needs to take into account the fact that they can receive information independently, make choices, and act on the choices they make.

Acknowledgments

We wish to acknowledge the team of competent researchers who conducted the focus group discussions in the two districts. Special thanks go to Phoebe Kajubi and Eunice Kyomugisha who led the teams in the two districts. Special thanks also go to the District Health Officers, Dr. Julius Bamwine (Ibanda) and Dr. Gerald Ssekitto (Nakasongola), together with the entire District Health Team for their support.

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Acceptability of HPV vaccine


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Menarcheal age of Nigerian urban secondary school girls in Benin City

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Abstract

Age at menarche varies with time and the influence of social factors depends on the population under consideration. Objective: To determine the mean age at menarche among secondary school girls in Benin City and examine some social factors that might influence it. Methods: In this cross-sectional study in Benin City, Nigeria information on age at menarche was obtained from 1,640 menstruating secondary school girls (aged between 10 and 20 years) using the status quo method. Information sought in the structured questionnaire used included date of birth, date of menarche, educational attainment of parents, occupation of parents, birth position, family size and state of origin. Data was analyzed using SPSS (Statistical Package for Social Sciences), version 15.0. Results: The mean age at menarche was 13.44±1.32 years (95% Confidence Interval, CI= 13.36-13.50). Of the 1,640 girls who have attained menarche, 31(1.9%) were below the age of 12 years (early menarche). Socioeconomic status, birth position and family size had significant bearing with mean menarcheal age at p< 0.001, p< 0.01 and p< 0.01 respectively. Conclusion: The current mean age at menarche among secondary school girls in Benin City is 13.44 years and it is influenced by socioeconomic status, birth position and family size.

Keywords: Adolescence, menarche, health, Nigeria

Introduction

Menarche (the first menstrual bleeding of a female)(1) represents the endpoint of a complex sequence of events that characterize sexual maturation and puberty in girls (2). It is unique, and probably, the most accurately recallable indicator of puberty among girls and a widely used indicator of adolescence sexual maturation (3,4). Variations in age at menarche between individuals and populations have been documented (5-7). It is influenced by social, environmental and genetic factors (5-9).
The mean age at menarche varies from one population to another. For instance, the reported mean age at menarche were as follows: Iran 12.91+1.23 years (10), South Africa 12.75+1.32 years (8), India 13.18+1.08 years (9), Kenyan 12.5+2.8 years (11). Even within Nigeria, similar variations in age at menarche have been observed; 13.98+1.30 years in the West (12), 13.03+1.02 years in the East (13) and 13.50+1.33 years in the North (14). A study involving one secondary school in Benin City, Nigeria reported a mean age at menarche of 13.16+1.22 years (15). In both developing and developed countries, some studies have reported a decline in the average age at menarche (16-19). This trend towards a reduction in the average age of menarche has been attributed to improvement in living standard and nutrition (1). On the other hand, in some countries, this downward trend seems to have come to a halt (20). In view of the reported secular trend, there is a need to monitor the age at menarche. Data on age at menarche are useful in health planning, establishment of adolescent health centres and improvement in health promotion services for girls (21). In addition, contemporary issues such as introduction of sex education in Nigerian schools require knowledge of the age at menarche as well as the sequence of events of puberty; menarche being the last in this sequence.

An early age at menarche is associated with an increased risk of some clinical conditions, such as breast cancer (22), obesity (23), endometrial cancer (24) and uterine leiomyomata (25). Some studies have indicated that women who attained menarche at the age of 11 years and below have a higher risk of development of breast cancer than those who attained menarche at the age of 12 years and above (26,27). Late menarcheal age is thought to protect, at least to some extent, women in Sub-Saharan Africa from breast cancer (28). In this regard, the observed trend towards a reduction in the average age at menarche in West African countries (Nigeria inclusive) portends some danger as it relates to occurrence of breast cancer (13,14). In addition, there are indications in the literature that the age at menarche might be related to subsequent reproductive performance, such as the age at first intercourse, the age at first pregnancy and risk of subsequent miscarriage (29). From the foregoing, it is obvious that there is a need to monitor closely the average age at menarche in Nigeria. Majority of the Nigerian studies that focused on age at menarche were conducted some decades ago (12-14).

The purpose of the present study was to determine, in this new decade, the age at menarche among secondary school girls in Benin City, Nigeria and identify some social factors that might influence it.

**Methods**

This cross-sectional study was conducted in two public secondary schools for female students in Oredo Local Government Area (OLGA), Edo State, Nigeria. According to Edo State Ministry of Education Statistics, there are nine public secondary schools in the LGA comprising 4 females-only, 3 co-educational and 2 males-only (30). Consent for the study was obtained from the school authorities. Of the four girls’ secondary schools, two were randomly selected by ballot. The total population of students in the two schools selected were school A 1,394 and school B 772, giving a grand total of 2,166 which was the target study population. The survey was designed to include all the student in the two schools (schools A and B). The principal of each of the two schools introduced the authors during the morning assembly. Subsequently, we addressed the students on the relevance of the study and how to accurately fill the questionnaire. We also emphasized to the students that the questionnaires were anonymous and that their participation was voluntary. Data was collected between October and November, 2011, using a structured-anonymous questionnaire. Information sought in the questionnaire included: date of birth, date of onset of first menstrual bleeding, birth position among their siblings, family size (number of siblings), state of origin, level of education and occupation of both parents/guardian. The family size was categorized into small size (no sibling or one or 2 siblings); medium size (3 or 4 siblings); large size (5 or more siblings). The socio-economic status of the parents was determined using the classification suggested by Ogunlesi et al (31). This was analyzed via combining the highest educational attainment, occupation and income of the parents (based on the mean income of each educational qualification and occupation).
Menarcheal age in Nigeria

classes I and II represent high social class, class III represents middle social class while classes IV and V represent low social class. In this way, the girls were categorized into high, middle and low socio-economic groups. The data was analyzed using the SPSS (Statistical Package for Social Sciences), version 15.0.

Results

At the time of this survey, a total of 2,166 female students (1,394 in school A and 772 in school B) were attending the two public girls’ secondary schools in the LGA (randomly selected by ballot). Seven students (5 from school A and 2 from school B) declined to participate. The response rates were 99.4% in school A and 99.7% in school B. Overall response rate was 99.7%. The questionnaires of 9 students were excluded from the analysis because they were incompletely filled, thereby leaving a total of 2,150 questionnaires (respondents) for data analysis. Students in both schools had similar socio-demographic characteristics, thus further analysis of data was carried out for the combined group of students.

Of the 2,150 respondents, 1,640 (76.3%) have attained menarche while the remaining 510 (23.7%) have not. Analysis of the questionnaire of the 1,640 girls who have attained menarche showed that the mean age at menarche for both schools combined was 13.44±1.32 years (95% Confidence Interval, CI= 13.38-13.50) while it was 13.25±1.23 years (95% CI= 13.19-13.31) for school A and 13.50±1.36 years (95% CI= 13.40-13.60) for school B. Of the 1,640 girls who have attained menarche, 31(1.9%) were before the age of 12 years (early menarche); (Table 1). The mean age at menarche was significantly higher in low socioeconomic group compared to high socioeconomic group (Table 2). Girls belonging to high socioeconomic class attained menarche 8.0 and 9.0 months earlier than girls belonging to middle and low socioeconomic classes respectively (Table 2). As shown in Table 3, first-born children attained menarche earlier than latter-born children with first-born children attaining menarche 8.0 months earlier than eight-born children. Of the 1,640 girls who have attained menarche, 8(0.5%) were the only child in their family and the mean age at menarche was 12.80±1.11 years (95% CI= 12.03-13.57). Table 4 shows the mean age at menarche according to family size. As shown in Table 4, girls from small-size families attained menarche 4.0 and 7.0 months earlier than their counterparts from medium-size and large-size families respectively. Based on state of origin, the mean age at menarche did not differ.

<table>
<thead>
<tr>
<th>Age in years</th>
<th>Total number of girls (respondents)</th>
<th>Number (%) who have attained menarche</th>
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<tbody>
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<td>10</td>
<td>2</td>
<td>0(0)</td>
</tr>
<tr>
<td>11</td>
<td>13</td>
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<td>12</td>
<td>109</td>
<td>16(15.1)</td>
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<tr>
<td>13</td>
<td>296</td>
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<td>356</td>
<td>218(61.2)</td>
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<tr>
<td>15</td>
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<td>490</td>
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<tr>
<td>17</td>
<td>315</td>
<td>313(99.4)</td>
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<tr>
<td>19</td>
<td>62</td>
<td>62(100.0)</td>
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<td>20</td>
<td>15</td>
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<tr>
<td>Total</td>
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<td>1640(100.0)</td>
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### Table 2. Socioeconomic status (SES) and mean age at menarche

<table>
<thead>
<tr>
<th>Age (years) at menarche</th>
<th>Total no of girls who have attained menarche</th>
<th>Socioeconomic status (SES)</th>
<th>Mean age at menarche</th>
<th>95% Confidence Interval, CI</th>
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<td></td>
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<td>High</td>
<td>Middle</td>
<td>Low</td>
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<tr>
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<td></td>
<td>No(%)</td>
<td>No(%)</td>
<td>No(%)</td>
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<td>95</td>
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<tr>
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<td>95(43.6)</td>
<td>17(7.8)</td>
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<tr>
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<td>337</td>
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<td>471</td>
<td>8(1.7)</td>
<td>143(30.4)</td>
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<td>16(5.1)</td>
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<td>57(91.9)</td>
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<td>12(80.0)</td>
<td>3(20.0)</td>
</tr>
<tr>
<td>Total</td>
<td>1640</td>
<td>205(12.5)</td>
<td>548(33.4)</td>
<td>887(54.1)</td>
</tr>
</tbody>
</table>

Mean age at menarche 13.44+1.32 12.78+1.21a 13.42+1.18b 13.56+1.29c


t-statistic a vs b=4.41 b vs c=2.08 a vs c=7.95

(p-value) (<0.01) (>0.05) (<0.001)

### Table 3. Birth position and mean age at menarche

<table>
<thead>
<tr>
<th>Birth position</th>
<th>Total no of girls who have attained menarche</th>
<th>Mean age at menarche</th>
<th>95% Confidence Interval, CI</th>
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</thead>
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<td>437</td>
<td>13.02+1.22</td>
<td>12.91-13.13</td>
</tr>
<tr>
<td>2nd</td>
<td>333</td>
<td>13.04+1.09</td>
<td>12.92-13.16</td>
</tr>
<tr>
<td>3rd</td>
<td>323</td>
<td>13.14+1.12</td>
<td>13.02-13.26</td>
</tr>
<tr>
<td>4th</td>
<td>164</td>
<td>13.30+1.23</td>
<td>13.11-13.49</td>
</tr>
<tr>
<td>5th</td>
<td>77</td>
<td>13.52+1.19</td>
<td>13.25-13.79</td>
</tr>
<tr>
<td>6th</td>
<td>33</td>
<td>13.53+1.38</td>
<td>13.06-14.00</td>
</tr>
<tr>
<td>7th</td>
<td>38</td>
<td>13.65+1.40</td>
<td>13.21-14.10</td>
</tr>
<tr>
<td>8th</td>
<td>27</td>
<td>13.68+1.43</td>
<td>13.14-14.23</td>
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<tr>
<td>Total</td>
<td>1640</td>
<td>13.44+1.32</td>
<td>13.38-13.50</td>
</tr>
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</table>

### Table 4. Family size and mean age at menarche

<table>
<thead>
<tr>
<th>Family size</th>
<th>Total no (% of girls who have attained menarche</th>
<th>Mean age at menarche</th>
<th>95% Confidence Interval, CI</th>
<th>t-statistic (p value)</th>
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</thead>
<tbody>
<tr>
<td>Small size</td>
<td>221(13.5)</td>
<td>13.09+1.31a</td>
<td>12.91-13.26</td>
<td>a vs c: t= 4.82 (&lt;0.01)</td>
</tr>
<tr>
<td>Medium size</td>
<td>1063(64.8)</td>
<td>13.41+1.28b</td>
<td>13.33-13.49</td>
<td>a vs b: t= 3.32 (&lt;0.05)</td>
</tr>
<tr>
<td>Large size</td>
<td>356(21.7)</td>
<td>13.64+1.37c</td>
<td>13.50-13.78</td>
<td>b vs c: t= 2.79 (&lt;0.05)</td>
</tr>
<tr>
<td>Total</td>
<td>1640(100.0)</td>
<td>13.44+1.32</td>
<td>13.38-13.50</td>
<td></td>
</tr>
</tbody>
</table>
Discussion

The mean age (13.44 years) at menarche observed in the present study in Edo State was comparable to 13.43 years reported from Port Harcourt among urban school girls (32), but lower than 14.22 years reported among rural school girls in Etche (both in Rivers State, Nigeria) (33). The lower mean menarcheal age observed in the present study might be explained by differences in socio-demographic factors. For instance, in the present study the subjects were urban school girls while in the study in Etche the subjects were rural school girls. The report of a study in Plateau State, Nigeria indicated that rural school girls tend to achieve menarche at an older age than urban school girls (14). In contrast, Goon et al (34) reported that the age at menarche was comparable between urban and rural girls. They attributed this parity to improved living conditions among their rural population. It must be noted that the methods of collecting and analyzing data vary from one study to another, indicating the need to exercise caution when comparing age at menarche in different studies.

Data from the present study showed that 1.9% of the girls attained menarche early (below the age of 12 years). A similar prevalence of early menarche was reported from Wannune, Benue State, Nigeria (34). A previous study in Benin City alluded to occurrence of early menarche in their series but failed to report the prevalence (15). The clinical implication is that this small group of girls with early menarche might be at increased risk of breast cancer, obesity, endometrial cancer and uterine leiomyomata (22-25) and require a close follow up. In addition, Schor (29) reported that the age at menarche might be related to the age at first sexual intercourse, which may result in an unwanted teenage pregnancy. Such a pregnancy may be catastrophic for the teenager. The practical implication is that sex education in Nigerian schools should be started early, well before the age of 12 years.

As in previous studies in Nigeria (12-15) socioeconomic status (SES) of the parents influenced their daughters’ age at menarche. In the present study it was observed that girls belonging to high socioeconomic class attained menarche 9 months earlier than their counterparts in the low socioeconomic class. This is comparable to the 8.5 months difference reported in a previous study in Nigeria (13). On the other hand, the observed difference in the present study is lower than the 11 and 12 months respectively reported in two previous studies in Nigeria (15,35). The reason for the smaller difference found in the present is not clear but it might mean that the effect of SES is becoming less prominent with time.

In the present study it was observed that first and early born girls tend to attain menarche at an earlier age than their counterparts who were born latter or were last born. A similar observation has been reported in a previous study (15). There is no readily available explanation for this observation. However, it has been speculated that there is usually more pressure and expectation on first-born children to achieve, forcing them to mature faster than latter-born children. It is, therefore, thought that this early attainment of maturity in first-born children, make them attain menarche at an earlier age compared to their latter-born siblings.

Data from the present study indicated that girls from small-size families tend to attain menarche at a younger age than girls from large-size families. A previous study has reported a similar finding (36). Family size may exert its effect on age at menarche through concealed poverty because the larger the family size the lower the income per capita. This effect is likely to be more pronounced in societies with low socioeconomic status.

In conclusion, the current mean age at menarche in Benin City is 13.44 years and it is influenced by social factors such as socioeconomic status, birth position and family size.

References


Nutritional status of Nigerian children with sickle cell anaemia in stable state


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Abstract

Sickle cell anaemia has multi-systemic manifestations and is associated with severe morbidity and high mortality. It commonly affects growth leading to wasting and stunting. The study aimed to determine the nutritional status using anthropometry, of children with homozygous sickle cell anaemia (SCA), aged one year to ten years in steady state at the Lagos University Teaching Hospital (LUTH). Methods: A cross-sectional study involving 100 children with sickle cell anaemia and 100 age, sex, and social class matched controls that fulfilled the inclusion criteria. Height and weight were measured while Weight-for-age, Height-for-age and Weight-for-height and their z scores were derived from NCHS standard while Body mass index was calculated using the formula Weight in kg/ Height in m² in Kg/m². Results: The study demonstrated a significantly lower mean weight and weight-for-height in the SCA patients than those of controls (p < 0.001) irrespective of gender, however, female SCA patients were shorter than their healthy controls. There was no significant difference with respect to BMI. The z score analysis revealed that SCA patients had significantly lower z scores for height-for-age, and weight-for-age compared with controls (p<0.02). Further analysis by sex revealed that the difference was more marked in males than in the females. Conclusion: The study revealed age related poor nutritional status in children with sickle cell anaemia compared with contemporary healthy controls and there was no association between anthropometry of subjects and haemoglobin concentration.

Keywords: Sickle cell anaemia, anthropometry, nutritional status

Introduction

Sickle cell anaemia (SCA) is a chronic haemolytic disorder caused by homozygous inheritance of abnormal haemoglobin called ‘haemoglobin S’ (HbS). It is an example of a single point mutation resulting in a qualitative defect in haemoglobin synthesis (1). It is
structurally different from the normal haemoglobin, due to replacement of the glutamic acid by valine in the sixth position of the β Globin. (2)

About 25% of Nigerians are heterozygous carriers of genes for sickle haemoglobin while the incidence of its homozygous state is about 2 - 3% (1).

Sickle cell anaemia is the commonest haemoglobinopathy affecting people of the Negroid race (3,4). It has multisystemic manifestations and commonly affects growth leading to wasting and stunting. (5) Assessment of the growth and nutritional status can be done using anthropometry. (6) The present study aimed to determine the nutritional status using anthropometry, of children with homozygous sickle cell anaemia (SCA), aged one year to ten years in steady state at the Lagos University Teaching Hospital.

Methods

This was a prospective, cross sectional and analytical study carried out at the Lagos University Teaching Hospital (LUTH) in Idi-Araba as part of a large study between October 2005 and January 2006. The subjects were 100 paediatric patients attending the Thursday LUTH sickle cell anaemia clinic who were consecutively recruited. They had haemoglobin genotype ’SS’ on haemoglobin electrophoresis and were aged one to ten years. They were in steady state at the time of recruitment.

Steady state was defined as absence of any crisis in the preceding four weeks, no recent drop in the haemoglobin level and absence of any symptoms or sign attributable an acute illness. (7) Patients with any form of acute illness, congenital heart disease or acquired heart disease, renal disease and hypertension were excluded from the study. Healthy controls were of genotype “AA,” from the Community Health Outpatient and Well baby clinics and healthy children attending other clinics at the POP department and were matched for age and sex, one for every sickle cell anaemia patient.

Height was measured to the nearest centimeter with the aid of a graduated wooden panel fixed to a vertical wall with the child barefooted, standing erect with the heels together against the wall, and looking straight ahead with the back against the wall. The head was held in such a way that the subject was looking forward with the lower border of the eye sockets in the same horizontal plane as the external auditory meatus. The wooden panel had a perpendicular (horizontal) projection built in to slide up and down which rested on the head of the subject (8). Subjects were weighed to the nearest 0.1kg using a Seca® scale or basinet scale as appropriate for the patient’s age with the subject standing or sitting respectively, barefoot wearing only their under-wear. The scales were checked for accuracy with standard weights after every 10th measurement, or whenever it was moved from place to place (8). Weight-for- age, Height- for- age and Weight-for-height were derived from NCHS standard while Body mass index was calculated using the formula $\text{Weight in kg/ Height in m}^2$ in Kg/m$^2$. Derived measurements were expressed as centiles using NCHS (9) standards and z scores were generated for each measurement (10).

Haemoglobin concentration was determined using the oxy-haemoglobin method. The data were recorded on standard questionnaires and later entered into a standard IBM compatible computer. The data were analyzed using Microsoft Excel Statistical Software supplemented by Mega Stat Statistical Package. The mean, median, standard deviation and other parameters of statistical location were generated as necessary for continuous data. Tests of statistical significance between subjects and controls included Student t-test for continuous data and chi-square analysis for discrete data. Regression and correlation models were set up and analyzed as necessary. Level of significance was set at $p < 0.05$. The Research and Ethical Committee of the Lagos University Teaching Hospital approved this study. Informed consent was sought from parents or caregivers of potential subjects and the controls before enrolment into the study.

Results

A total of 200 children were recruited into the study, this comprise of 100 test subjects in the 12 month to 10 year age bracket confirmed to have haemoglobin genotype SS who were all in steady state and receiving routine drugs consisting of folic acid, Proguanil and multivitamins. The control group consisted of 100 children within the same age bracket
who had haemoglobin genotype AA. The mean age was comparable between subjects and controls (75.1±30.3 Vs 74.8±29.4; t = 1.02, p =0.15). The male: female ratio in both subjects and controls was 1.9:1. The mean height and body mass index of the subjects were comparable with those of the controls. Controls however were significantly heavier and also had significantly higher mean weight-for-height. (p = 0.0001). Further analysis (Table I) showed that irrespective of gender, subjects were smaller than controls in terms of weight and weight-for-height. Female sickle cell anaemia patients were also significantly shorter than their healthy controls. There was no significant difference with respect to BMI. When the analysis was repeated for under-5 children (Table II), subjects showed a fairly consistent trend of being smaller but no significant difference was observed with respect to any of the selected anthropometric values. A similar trend was observed in children older than five years but this time, subjects were significantly smaller than controls in all parameters except BMI (Table III).

**Table 1. Gender-specific comparison of anthropometry between subjects and controls**

<table>
<thead>
<tr>
<th>Variables</th>
<th>Males</th>
<th></th>
<th>Females</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Subjects</td>
<td>Controls</td>
<td>Subjects</td>
<td>Controls</td>
</tr>
<tr>
<td></td>
<td>n =65</td>
<td>n =65</td>
<td>n =35</td>
<td>n =35</td>
</tr>
<tr>
<td>Mean±(SD)</td>
<td>Mean±(SD)</td>
<td>p</td>
<td>Mean±(SD)</td>
<td>Mean±(SD)</td>
</tr>
<tr>
<td>Height (m)</td>
<td>1.11±1.0</td>
<td>1.28±0.12</td>
<td>0.17</td>
<td>1.16±0.09</td>
</tr>
<tr>
<td>Weight (Kg)</td>
<td>18.3±4.5</td>
<td>20.9±0.6</td>
<td>0.001*</td>
<td>19.8±6.6</td>
</tr>
<tr>
<td>Wt for Ht in (kg/m)</td>
<td>15.4±3.3</td>
<td>16.2±0.4</td>
<td>0.049*</td>
<td>18.3±4.13</td>
</tr>
<tr>
<td>BMI (Kg/m²)</td>
<td>14.8±3.5</td>
<td>15.1±0.4</td>
<td>0.43</td>
<td>14.3±2.6</td>
</tr>
</tbody>
</table>

* Statistically significant.

m = meters.
Kg = Kilograms.
Wt for Ht = Weight- for -height in Kilograms per meter.
BMI = body mass index.
Kg/m² = Kilogram per meter squared.

**Table 2. Comparison of anthropometry between under-5 subjects and controls**

<table>
<thead>
<tr>
<th>Variables</th>
<th>Subjects</th>
<th></th>
<th>Males</th>
<th></th>
<th>Females</th>
<th></th>
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<td>n =27</td>
<td>n =27</td>
<td>n =27</td>
<td>n =8</td>
<td>n =8</td>
</tr>
<tr>
<td>Mean±(SD)</td>
<td>Mean±(SD)</td>
<td>p</td>
<td>Mean±(SD)</td>
<td>Mean±(SD)</td>
<td>p</td>
<td></td>
</tr>
<tr>
<td>Height (m)</td>
<td>0.94±1.6</td>
<td>1.26±0.3</td>
<td>0.3</td>
<td>0.98±0.1</td>
<td>0.98±0.0</td>
<td>0.87</td>
</tr>
<tr>
<td>Weight (Kg)</td>
<td>13.79±3.4</td>
<td>14.92±0.7</td>
<td>0.08</td>
<td>14.13±2.9</td>
<td>15.00±1.0</td>
<td>0.4</td>
</tr>
<tr>
<td>Wt for Ht</td>
<td>14.24±3.9</td>
<td>14.42±0.8</td>
<td>0.81</td>
<td>16.04±2.9</td>
<td>17.84±1.0</td>
<td>0.08</td>
</tr>
<tr>
<td>BMI</td>
<td>15.67±4.5</td>
<td>15.42±0.8</td>
<td>0.78</td>
<td>13.03±1.8</td>
<td>14.03±0.6</td>
<td>0.11</td>
</tr>
</tbody>
</table>

m = meters.
Kg = Kilograms.
Wt for Ht = Weight- for -height in Kilograms per meter.
BMI = body mass index.
Kg/m² = Kilogram per meter squared.
Table 3. Comparison of Anthropometry between subjects and controls older than five years

<table>
<thead>
<tr>
<th>Variables</th>
<th>Males Subjects</th>
<th>Controls Subjects</th>
<th>p</th>
<th>Females Subjects</th>
<th>Controls Subjects</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>n</td>
<td>38</td>
<td>38</td>
<td></td>
<td>27</td>
<td>27</td>
<td></td>
</tr>
<tr>
<td>Mean±SD</td>
<td>1.22±0.11</td>
<td>1.29±0.01</td>
<td>0.002*</td>
<td>1.22±0.1</td>
<td>1.26±0.01</td>
<td>0.003*</td>
</tr>
<tr>
<td>Weight (Kg)</td>
<td>21.5±5.7</td>
<td>25.2±0.9</td>
<td>0.001*</td>
<td>21.4±6.7</td>
<td>24.1±1.3</td>
<td>0.03*</td>
</tr>
<tr>
<td>Wt for Ht</td>
<td>16.23±2.8</td>
<td>17.5±0.5</td>
<td>0.007*</td>
<td>19.0±4.5</td>
<td>21.2±0.9</td>
<td>0.009*</td>
</tr>
<tr>
<td>BMI</td>
<td>14.2±2.6</td>
<td>14.9±0.4</td>
<td>0.08</td>
<td>14.8±2.8</td>
<td>15.5±0.6</td>
<td>0.17</td>
</tr>
</tbody>
</table>

* Statistically significant

m = meters.
Kg = Kilograms.
Wt for Ht = Weight- for -height in Kilograms per meter.
BMI = body mass index.
Kg/m² = Kilogram per meter squared.

Table 4. Comparison of weight-for-age z scores, height-for-age z scores and body mass indices-for-age z scores of subjects and controls

<table>
<thead>
<tr>
<th>Variables</th>
<th>Subjects Mean±SD</th>
<th>Controls Mean±SD</th>
<th>t</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>n=100</td>
<td>n=100</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Height-for-age z scores</td>
<td>-0.46±0.96</td>
<td>-0.11±0.1</td>
<td>-3.59</td>
<td>0.001*</td>
</tr>
<tr>
<td>Weight-for-age z scores</td>
<td>-0.56±0.63</td>
<td>-0.29±0.1</td>
<td>-4.35</td>
<td>0.001*</td>
</tr>
<tr>
<td>BMI z scores</td>
<td>-0.50±0.79</td>
<td>-0.33±0.1</td>
<td>-2.02</td>
<td>0.04 *</td>
</tr>
</tbody>
</table>

* Statistically significant.
BMI = Body mass index.

Table 5. Gender-specific comparison of weight-for-age z scores, height-for-age z scores and body mass indices-for-age z scores of subjects and controls

<table>
<thead>
<tr>
<th>Variables</th>
<th>Males Subjects</th>
<th>Controls Subjects</th>
<th>p</th>
<th>Females Subjects</th>
<th>Controls Subjects</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>n=65</td>
<td>n=65</td>
<td>p</td>
<td></td>
<td>n=27</td>
<td>n=27</td>
<td></td>
</tr>
<tr>
<td>Mean SD</td>
<td>-0.47±1.0</td>
<td>-0.11±0.1</td>
<td>0.005*</td>
<td>-0.44±0.8</td>
<td>-0.12±0.1</td>
<td>0.03*</td>
</tr>
<tr>
<td>Height-for-age z scores</td>
<td>-0.55±0.6</td>
<td>-0.25±0.1</td>
<td>0.001*</td>
<td>-0.58±0.6</td>
<td>-0.36±0.1</td>
<td>0.03*</td>
</tr>
<tr>
<td>Weight-for-age z scores</td>
<td>-0.52±0.9</td>
<td>-0.31±0.1</td>
<td>0.17</td>
<td>-0.44±0.5</td>
<td>-0.37±0.1</td>
<td>0.36</td>
</tr>
</tbody>
</table>

Figures shown are mean ± one standard deviation of the mean.
*Statistically significant.
BMI = Body mass index.
Tables IV and V show the comparison of weight-for-age z scores, height-for-age z scores and body mass index z scores of subjects and controls. They revealed that sickle cell anaemia patients had significantly lower z scores for height-for-age, and weight-for-age compared with controls (p< 0.02). Further analysis by sex revealed that the difference was more marked in males than in the females.

There was no statistically significant correlation between nutritional status and haemoglobin concentration in both subjects and controls.

**Discussion**

The present study was designed to determine the relationship between the steady state haemoglobin, nutritional status using anthropometry measurements of SCA aged one year to ten years at the LUTH. It was partly based on the premise that repeated and/or severe illness may manifest as sub-optimal growth detectable by anthropometry. Also, steady state haemoglobin level of any index patient may potentially impact on growth because of its direct relationship with oxygen delivery to tissues.

The study revealed poor nutritional status in children with sickle cell anaemia compared with contemporary healthy controls. Sickle cell anaemia patients had a significantly smaller mean weight compared with controls (p<0.001). A similar finding was recorded by earlier authors (11-14). This is because weight can be affected by acute and chronic stress like sickle cell anaemia which is a chronic disease. On the other hand, in the present study there was no statistically significant difference between the mean heights of sickle cell anaemia patients and controls. This agrees with the findings of Scott et al (16) in a study with a similar age cohort. Deficiency in height is a reflection of chronicity and severity of nutritional insult. It is plausible that the degree of nutritional insult in the sickle cell anaemia subjects was not severe enough to produce a significant difference. On the other hand, some workers demonstrated significant reduction in height among patient with sickle cell anaemia compared to healthy controls (12-14,16-17). The explanation for the discrepancy in findings is not immediately clear. Whitten (13) and Ebomoyi et al (14) studied children of comparable age (2 years to 13 years) so it is not easy to explain the difference in findings on the grounds of age alone. It may be speculated that other factors like severity of illness, which may not be readily comparable across studies might account for the disparity. However, some of the cited studies (12, 17-18) included much older subjects (16 to 20 years) than the current one. It is attractive to argue that the height of older patients would be more adversely affected because they have had the disease for a longer period. This may not be entirely applicable as some other report observed that sickle cell anaemia patients tend to catch up in height in late adolescence. Unfortunately, the studies referred to earlier (12, 17-18) did not stratify subjects by age to enable further comments. On the contrary, when height was related to age using z scores, subjects were found to be significantly further away from the mean than the controls.

The Z score is a more specific way of commenting on the anthropometry. Most other studies (12-14,17-18) did not reduce anthropometry to z scores and so it was not possible to make comparisons and draw conclusions. The significantly lower height-for-age z score obtained in the subjects can be explained by chronic ill-health, increased susceptibility to infections, high metabolic rate leading to energy wastage, chronic anaemia and relative tissue hypoxia that characterize sickle cell anaemia. The same explanation can be offered for the significantly lower z scores for weight-for-age found among sickle cell anaemia patients. The trend was worse among the males who also had significantly lower BMI z scores.

The weight-for-height of patients with sickle cell anaemia was significantly lower than the controls in this study (p<0.001). This is in agreement with the findings of Ebomoyi et al (14) in Ilorin. Weight-for-height is an index of wasting. Thus, the difference observed reflects some degree of wasting among patient with sickle cell anaemia. This may be due to the elevated resting energy expenditure and elevated protein turnover in these patients (20).

In the current study there were no statistically significant difference between the body mass indices of subjects and controls. This is contrary to the findings of Emodi and Kaine (8) in Enugu. The differences in the findings might be due to differences...
in the age groups studied. While the current study involved children aged one to ten years, the Enugu study (8) excluded under-fives and included adolescents up to 16 years old and found a statistically significant difference between the body mass indices of subjects and controls. Another plausible reason for similarity in BMI among subjects and controls in the present study may be that subjects and controls were matched for social class. The potential effects of social class may be indirect to the extent that people in the same social class are likely to have comparable health seeking behavior or access to quality health care.

The subjects had a mean steady state haemoglobin concentration of 76.9 ± 19.5 g/l, which was significantly lower than that (118.1 ± 2.0) obtained for the controls (t = 21.1, p = 0.000). This is in agreement with the findings in other report (5) and is probably as a result of premature haemolysis and reduced red blood cell lifespan in the subjects. Females subjects were observed to have higher haemoglobin level compared with controls, although this did not reach a level of statistical significance. The reasons advanced for this gender difference include hormonal problems secondary to severe hypogonadism in male sickle cell anaemia subjects, which leads to reduced androgen levels and hence poor growth. Females have also been found to have higher oxygen delivery to the tissues (21) and hence vaso-occlusive destruction of tissues is usually comparatively minimal compared with what happens in males. This has been attributed to the transcription factor for haemoglobin F which has been linked to X chromosome, therefore female sickle cell anaemia patient tend to have a higher mean haemoglobin F value and hence less vaso-occlusion, less destruction of RBC, higher haemoglobin and higher packed cell volume (21).

It was also observed that the mean steady state haemoglobin concentration obtained in the current study was somewhat lower than (78.7 g/l to 96 g/l) reported in some other studies (5, 22-23). There is no obvious reason for the observed difference.

The current study also attempted to establish an association between anthropometry of subjects and haemoglobin concentration, but no such association was found except with height for age. This observation suggests that haemoglobin concentration is not a reliable index of nutritional status, with specific reference to the sickle cell anaemia subject. This is because steady state haemoglobin does not depend on the nutritional status, but on the severity of the disease which depends on genetic factors.¹

In conclusion this study revealed age related poor nutritional status in children with sickle cell anaemia compared with contemporary healthy controls; the mean steady state haemoglobin concentration of subjects with sickle cell anaemia was 76.9 (SD 19.5) g/l which was significantly lower than 118.1 (SD 2.0) g/l obtained in the controls and there was no association between anthropometry of subjects and haemoglobin concentration.

There is a need for another to verify the claims in this study that prolong frequent crises has effect on the nutritional status of SCA patients and growth monitoring should extend beyond five years of age for SCA patients.

Acknowledgment

We specially acknowledge the subjects and controls who participated in this study, including their parents.

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[7] Anotia-Egebo O, Alikor EAO, Nkanginieme KEO. Malaria parasite density and splenic status by
Nutritional status of Nigerian children


Parental satisfaction and treatment outcome: A 3-year study in children’s mental health services

Stephanie Rosso, PhD*1 and Diomaris E Jurecska, PsyD1, 2
1Children’s Hospital and Research Center Oakland, California, USA
2Graduate Department of clinical psychology, George Fox University, Newberg, Oregon, USA

Abstract

Our objective was to explore the relationship between customer satisfaction and symptom reduction at a hospital-based behavioral pediatrics clinic for children from low socioeconomic and diverse backgrounds. Parental/customer satisfaction and levels of functioning were assessed by a modified version of the Family Satisfaction Questionnaire (FSQ). Methods: Over a 3-year period, data were collected regarding overall parental satisfaction, access to service, symptom reduction, and increase in functioning. Results: Clinician/staff ability and access to service were the stronger predictors of parental satisfaction. Cultural sensitivity and service ability were strongly associated with overall satisfaction. Conclusion: These results suggest that accessibility to services and cultural sensitivity are vital to the therapeutic relationship and treatment success when working with diverse populations.

Keywords: Cultural competency, parental satisfaction, children mental health services

Introduction

In the United States alone, one in every four to five youth meets criteria for a psychiatric diagnosis (1). An extensive body of literature supports the indication that most psychiatric disorders emerge during childhood or adolescence, making early intervention and prevention vital to future youth’s life outcomes (1–4). Recent trends show that externalizing disorders such as Attention Deficit and Hyperactivity Disorder (ADHD) have the highest national prevalence rates when compared to internalized childhood disorders (1). Current studies indicate that the presence of untreated psychiatric disorders leads to comorbidity and predicts severe impairment at the individual level (5). Barriers to mental health access for children are based on epidemiological, cultural, as well as economic factors (6–8).
In terms of demographics, both Hispanic and African American children are significantly less likely to access mental health services when compared to their Caucasian counterparts (1). Current statistics also show an unequal distribution between the genders regarding behavioral diagnoses with male rates being significantly higher than female (5). Fortunately, statistics indicate that some externalizing behaviors, such as ADHD, have the highest service rates 59.8% (1). Although externalizing childhood behaviors are present in a broad range of families; they are more prominent in families where risks outnumber protective factors (6). Barriers to mental health services, specifically for children, are strongly associated with poverty, culture, and being from minority groups (6-8).

Studies in adult services show that patient feedback is a key predictor of treatment efficacy. However; perception of quality of care in child and family services are not part of the current methods of treatment outcome evaluations (9). A lack of effective interventions has been associated with children’s mental health services. Therefore, providing evidence-based treatment (EBT) has been identified as one of the key components for moving forward in efficacy research with this population (10). Efforts to promulgate best practices or EBT without including patient’s perspective can be counterproductive to treatment. Specifically, when working with families, parental satisfaction needs to be identified as one of the key predictors of treatment success (11-16).

Despite this knowledge, customer satisfaction has often been neglected when evaluating outcomes of mental health services for children. A comprehensive review of the literature revealed less than a dozen studies asking how parents perceive the quality of psychiatric care for their children. Therefore, the aim of the study was to explore the relationship between overall satisfaction and treatment outcomes in children’s mental health services.

Methods

The Developmental and Behavioral Pediatrics Clinic (BPC) at Children’s Hospital and Research Center Oakland provides psychological evaluations and behavioral interventions to children ages 3 to 12 who are experiencing difficulties with behavioral regulation, attention, learning, and developmental issues. We value a multidisciplinary viewpoint and collaborate as a team with developmental behavioral pediatricians, and nurse practitioners who have had specialized training. We work from an integrative model of therapy, borrowing from psychodynamic, family systems, attachment theory, and cognitive behavioral therapy. As a teaching hospital, our services are provided by licensed clinical psychologists, pre-doctoral interns, and occupational therapists.

Participants

The total sample consisted of 72 survey parental responses, of which 70% were male and 30% were female. In terms of ethnic makeup, 38 were African American (52.8%), 17 were Hispanic American (23.6 %), 8 were European American (11.1%), 2 were Asian American (2.8%), and 1 was Native American (1.4%). The age reflects a range from 4 to 14 years with $M = 8.97$ ($SD = 2.5$). The entire sample had documented mental health diagnoses, while some of the most common diagnoses were: ADHD, Asperger Spectrum Syndrome (ASD), Mood disorder NOS, and Adjustment Disorder NOS. Inclusion criteria were having a child in treatment at BPC for at least three months.

Instruments

An adaptation of the Family Satisfaction Questionnaire used with the Center for Mental Health Services (CMHS) Comprehensive Community Mental Services for Children and their Families Program Consumer Survey was used to assess parental satisfaction (16). Our modified version contained 15 Likert-type scale questions, and with five-ordered response levels ranging from strongly disagree, to strongly agree. Items in the questionnaire were aimed at providing insight into the following areas:

1. Overall satisfaction with services received;
2. Changes in the patients levels of functioning at school and home (symptoms reduction);
3. Cultural sensitivity from both the staff and providers;
4. Effectiveness of treatment; and
5. Access to services.

**Procedure**

Questionnaires were given to parents while they were in the waiting room. They were invited to provide feedback to the clinic for the purpose of improving our services. Parents were asked to complete this questionnaire at their own convenience; the questionnaire included a verbal explanation that participation was voluntary, that participants could discontinue involvement at any time without penalty, and that only aggregate data would be reported. All surveys were collected during the month of May for a period of up to four weeks. Completed surveys were received (48% response rate) from 72 parents of a potential 150 children. This study followed the American Psychological Association’s ethical guidelines to protect the confidentiality of participants’ records, including de-identification of data. The Institutional Review Board of Children Hospital and Research Center Oakland authorized this project. The data were analyzed using SPSS for Macintosh to produce descriptive statistics (means and standard deviations) and to calculate Pearson product-moment correlation and multiple linear regressions.

**Results**

Our main goal was to assess the relationship between consumer satisfaction and the perception of improvement in the BPC (see descriptive of all the pertinent variables in table 1). To examine this association, we first conducted simple correlations among the primary variables (overall satisfaction, clinician and staff availability, access to services, communication with staff, spirituality and religion, effectiveness of interventions, respect from staff, cultural/ethnicity sensitivity, active participation in treatment, overall functioning, school functioning, and coping skills; see Table 2). Overall parental satisfaction with services was generally positive: the item mean ± SD was 4.67 ± .68 on a scale of 1 to 5, with higher scores indicating greater satisfaction. Overall satisfaction was significantly associated with clinician and staff availability, access to services, effectiveness of interventions, and respect from staff. Additionally, respect from staff was strongly associated with sensitivity to cultural and religious (spiritual) beliefs. Effectiveness of interventions was strongly correlated with respect from staff, and moderately associated with overall satisfaction, overall functioning, school functioning, and increase of coping skills. Lastly, we performed a multiple regression analysis for the overall satisfaction score. In this analysis, we treated the overall score as the dependent variable and entered the clinical availability, access to services, effectiveness of interventions, and respect from staff scores as independent variables.

<table>
<thead>
<tr>
<th>Table 1. Descriptive Statistics</th>
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<tbody>
<tr>
<td>Variables</td>
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<tr>
<td>Overall Satisfaction</td>
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<td>Clinician &amp; staff availability</td>
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<td>Access to services</td>
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<td>Communication with staff</td>
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<td>Spirituality/religion</td>
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<td>Effectiveness of interventions</td>
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<td>Overall functioning</td>
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<td>Coping skills</td>
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<tr>
<td>1. Overall</td>
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<td>3. Access to</td>
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<td>Services</td>
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<td>4. Communication</td>
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<td>w/ Staff</td>
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<td>5. Spirituality</td>
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<td>&amp; Religion</td>
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<tr>
<td>6. Effectiveness</td>
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<td>7. Respect from</td>
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<td>Staff</td>
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<td>8. Cultural</td>
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<td>Sensitivity</td>
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<td>9. Participation</td>
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<td>10. Overall</td>
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<td>Functioning</td>
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<td>11. School</td>
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<td>Functioning</td>
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<td>12. Coping</td>
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<td>Skills</td>
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Note. Intercorrelations for pertinent variables **Correlation is significant at the 0.01 level (2-tailed). *Correlation is significant at the 0.05 level (2-tailed).
The other variable that also explained a significant proportion of variance in overall satisfaction was access to services, $b = .328$, $t(65) = 3.785$, $p < .001$ in overall satisfaction $R^2 = .899$, $F(4,65) = 144.958$, $p < .001$. This procedure allowed us to determine the strength of the association among the variables. Results indicated that clinician and staff availability significantly predicted overall satisfaction, $b = .546$, $t(65) = 6.078$, $p < .001$.

**Discussion**

Findings from the current study corroborate those of previous investigations noting a significant association between patient’s relationships with providers and staff as an indicator of customer satisfaction (13,17). An unexpected finding in our study was that changes in levels of functioning were not strongly associated with overall customer satisfaction. These results are inconsistent with other outcome evaluation studies (18,19).

For example, Barber, Tischler, Healy (19) found that the highest predictor of consumer satisfaction of parents regarding their children’s mental health services was the reduction of symptoms. An explanation for this inconsistent finding may be the wide range of treatment length observed in the sample. Consistent with our philosophy, cultural sensitivity was strongly associated with parent’s satisfaction.

It appears that when delivering family services to diverse groups, cultural competence is vital for treatment success. Cultural context is an important consideration in studies of mental health services and customer satisfaction as some cultures might value their connection with the clinicians and the staff even higher than the goals of treatment (15,20). On a comprehensive literature review, Hernandez, et al. (21) provided an institutional model for cultural competence. Their model states that “cultural competence occurs when there is compatibility among four important factors: community context, cultural characteristics of local populations, organizational infrastructure, and direct service support” (12).

**Limitations and suggestions for future research**

In examining the effectiveness of children’s mental health services provided by the BPC, several limitations to this study emerged. First, although all the treatments provided at BPC have elements of EBT modalities, they were significant differences among provider’s approaches. It is also important to note that the diversity and needs of this population makes it difficult to have each child receive the same treatment. Our sample presents with significant differences in cognitive, and language abilities, which make treatment standarization a challenge. Although these results contribute to the literature on the effectiveness of mental health services provided to children, parents were the responders of the survey, and our findings do not provide information on the children’s satisfaction (22). Finally, the design and analyses make it impossible to infer causality.

The results of the current study point to a number of future directions. First, consistent with the US Public Health Service report (23) more research exploring predictors of success in mental health services delivered to children, adolescent, and families is needed (22). Perhaps, a start is establishing criteria of specific treatments modalities, and settings as best practices for specific disorders. Second, researches would also benefit from an understanding of the role that culture has on the development of the therapeutic relationship and treatment success with diverse patients. Finally, further research is needed to address the various forms of research methodology to access specialized populations. A combination of qualitative, quantitative, and longitudinal methods may be best suited for studying these populations.

**References**


