Health risk behavior among chronically ill adolescents: a systematic review of assessment tools

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Abstract

Background: Adolescents living with chronic illnesses engage in health risk behaviors (HRB) which pose challenges for optimizing care and management of their ill health. Frequent monitoring of HRB is recommended, however little is known about which are the most useful tools to detect HRB among chronically ill adolescents.

Aims: This systematic review was conducted to address important knowledge gaps on the assessment of HRB among chronically ill adolescents. Its specific aims were to: identify HRB assessment tools, the geographical location of the studies, their means of administration, the psychometric properties of the tools and the commonest forms of HRB assessed among adolescents living with chronic illnesses globally.

Methods: We searched in four bibliographic databases of PubMed, Embase, PsycINFO and Applied Social Sciences Index and Abstracts for empirical studies published until April 2017 on HRB among chronically ill adolescents aged 10–17 years.

Results: This review indicates a major dearth of research on HRB among chronically ill adolescents especially in low income settings. The Youth Risk Behavior Surveillance System and Health Behavior in School-aged Children were the commonest HRB assessment tools. Only 21% of the eligible studies reported psychometric properties of the HRB tools or items. Internal consistency was good and varied from 0.73 to 0.98 whereas test–retest reliability varied from unacceptable (0.58) to good (0.85). Numerous methods of tool administration were also identified. Alcohol, tobacco and other drug use and physical inactivity are the commonest forms of HRB assessed.

Conclusion: Evidence on the suitability of the majority of the HRB assessment tools has so far been documented in high income settings where most of them have been developed. The utility of such tools in low resource settings is often hampered by the cultural and contextual variations across regions. The psychometric qualities were good but only reported in a minority of studies from high income settings. This result points to the need for more resources and capacity building for tool adaptation and validation, so as to enhance research on HRB among chronically ill adolescents in low resource settings.

Keywords: Health risk behavior, Adolescents, Chronic illness, Assessment tools, Lifestyle, Tool adaptation

Background

Research focusing on health risk behaviors (HRB) among adolescents living with chronic illness has increased over the past few decades. HRB are defined as specific forms of behavior associated with increased susceptibility to a specific disease or ill health on the basis of epidemiological or social data [1]. Examples of HRB include: alcohol, tobacco and drug use, unhealthy dietary habits, sexual behaviors contributing to unintended pregnancy and sexually transmitted diseases, behavior that contributes to unintentional injury or violence, and inadequate...
physical activity [2, 3]. In the past, it was presumed that chronically ill adolescents are restricted by their ill health from engaging in HRB [4, 5]. However, a growing body of evidence shows that chronically ill adolescents engage in such behavior at rates equivalent to [6–8] or at times higher [9–12] than their healthy peers. Some studies for example report higher frequency of cigarette smoking among adolescents with asthma [13, 14] and more substance or drug use among adolescents with mental illnesses [9, 15] compared to their healthy peers. In addition, chronically ill adolescents are often victims of behaviors resulting in unintentional injury and violence, such as bullying and sexual assault [16, 17]. Other problematic forms of HRB among chronically ill adolescents include; inadequate physical activity [18–20], risky sexual behavior [10, 11], and poor dietary habits [21].

Engagement in HRB is problematic for chronically ill adolescents because it hinders optimal care and management of ill health [22]. For example, studies among young people living with HIV report that anti-retroviral therapy adherence rates are poorer among the patients with riskier health lifestyle as compared to their HIV infected peers who have healthier lifestyles [23, 24]. Similarly, engagement in HRB such as tobacco use, recreational drugs use, and risky sexual behavior has been shown to hamper proper management of type 1 diabetes [25], asthma [26], and mental illness [27] among adolescents. Poor disease management compounded by direct adverse effects resulting from engagement in HRB, most likely translates into poorer health outcomes among chronically ill adolescents [5, 28]. Thus, promotion and maintenance of healthier behavioral practices early in adolescence has great potential to enhance positive long-term health outcomes for these patients [23].

Regarding the public health burden posed by HRB, frequent monitoring of such behaviors is recommended for supporting clinical and preventive efforts directed at improving lives of young people with chronic illnesses and their families [5, 29]. Although there are numerous measures of HRB, evidence is still meagre on the most frequently utilized HRB measures as well as the psychometric properties of HRB tools among chronically ill adolescents in various geographical contexts. Moreover, without proper adaptation, measurement bias and compromise to various psychometric properties like validity and reliability may arise [30, 31]. Bias also arises from unfamiliar content of the tests, translation challenges and unfamiliar means of tool administration [30]. Studies have similarly shown that variations in how questions are administered and how respondents are contacted affects the accuracy and quality of data collected [32]. There is still a lack of knowledge concerning the major forms of HRB, their commonly utilized assessment tools, their psychometric properties and their methods of administration in studies among chronically ill adolescents.

We therefore carried out this review to determine the current gaps in knowledge about tools to measure HRB. The review synthesizes findings from empirical studies conducted globally among adolescents living with chronic illnesses so as to: (i) identify the commonly utilized HRB assessment tools or sources of items used; (ii) describe the geographical utility of HRB assessments tools; (iii) identify the common means of HRB tool administration; (iv) document the reported adaptation and psychometric properties of HRB assessment tools or items; and (v) summarize the commonly assessed forms of HRB. We expect the results of this systematic review to aid HRB tool adaptation and validation procedures as well as enhance planning of research and interventions targeting adolescents living with chronic illnesses especially in low and middle income settings.

**Methods**

This systematic review was conducted following recommended guidelines for conducting systematic reviews [33]. We searched for relevant literature in four bibliographic databases: PubMed, Embase, PsycINFO and Applied Social Sciences Index and Abstracts. The search was initially conducted between November and December 31, 2015 and later updated in May 2017. The search strategy was formulated by two reviewers (DS and AA) and comprised of the following non-MeSH terms combined with Boolean operators: risk behavior OR risk taking OR health behavior OR healthy lifestyle AND adolescents OR Youth OR Teens AND Chronic condition OR Chronic disease OR Chronic illness. Additionally, other relevant studies were identified by searching the reference lists of the retrieved articles.

In this review, our study inclusion criteria were: (i) empirical studies published in a peer reviewed journal from January 1, 1980 to April 30, 2017; (ii) studies with participants aged 10–17 years or with mean age within this age bracket; and (iii) studies assessing for both HRB and chronic illness among the same study participants. The chronic conditions considered are those documented by the United States Department of Health and Human Services for the standard classification scheme [34]. Only studies published in English were included in this review. Studies were excluded if: (i) they were non-empirical (such as reviews, commentaries, letters to editor, conference abstracts), (ii) their participants had an age range or mean age below or above the 10–17 years’ category and (iii) they assessed only HRB without consideration of chronic illness or vice-versa.

Data extraction was done by two independent reviewers (DS, MKN). The data was extracted to Microsoft
Results

The literature search yielded a total of 1623 articles and following a systematic appraisal of this literature (refer to Fig. 1), a total of 79 full articles were eligible for inclusion in this review.

Majority of the eligible studies were conducted in North America (60%) and Europe (24%). The rest of them were from Asia (8%), South America (2%), Oceania (2%) and a few were multi-site studies conducted in both Europe and North America (2%). The study site of one eligible study was not reported in the article [35].

Results of the most frequently utilized HRB tools/items are shown in Table 1. Briefly, from a total of 37 full version HRB tools, 7 tools namely: Health Behavior in School-aged Children (HBSC), Youth Risk Behavior Surveillance System (YRBSS), Korea Youth Risk Behavior Web-based Survey (KYRBS), Swiss Multi-centric Adolescent Survey on Health (SMASH), car, relax, alone, forget, friends, trouble (CRAFT) substance Abuse Screening Test, Alcohol Use Disorder Identification Test (AUDIT) and Life and Health in Youth questionnaire were the most commonly utilized. The items on HRB in 12 of the studies from this review were either newly developed or their sources were not specified [23, 36–46].

The HBSC tool is a self-completion questionnaire administered in class room settings to adolescents aged 11–15 years and the HBSC study is conducted every 4 years across 44 countries in Europe and North America since its inception in 1982 [3]. The key health behaviors captured by this tool include; bullying and fighting, oral hygiene, physical activity and sedentary behavior, sexual behavior, substance use (e.g. alcohol, tobacco and cannabis), weight reduction behavior, behaviors resulting in injury, and dietary habits [3]. The YRBSS tool (Standard and National High School questionnaires) is developed by the US Centers for Disease Control and Prevention (CDC) to monitor HRB that are considered leading causes of disability, death and social problems among youths in 9th to 12th grade (approximately 14–18 years) in the US Students complete the self-administered questionnaire during one class period and record their responses directly in an answer sheet. This tool assesses 6 forms of HRB: sexual risk behaviors, tobacco use, alcohol and other drug use, inadequate physical activity and unhealthy dietary behaviors [2].

Results on the most frequently assessed forms of HRB are summarized in Table 2. Overall, alcohol, tobacco and other drug use and physical inactivity were the most frequently assessed forms of HRB.

The HRB tool/item administration (Table 3), adolescent self-completed paper and pencil format, face-to-face interview with the adolescent, and Audio Computer Assisted Self Interview (ACASI) were the most frequently utilized means.

Adaptation or psychometric properties of the HRB tools or items among the study population were only reported in 17 studies moreover. Most of these (82%) were conducted in the USA (see Table 4). Five of these studies reported aspects of adaptation such as forward-back translations, content validity, item completeness, and cultural appropriateness but without reporting any psychometric data [44, 47–50]. Among those that reported psychometric data, only 6 studies [9, 18, 51–54] reported this data for an entire HRB tool or entire tool from which HRB items were borrowed while the rest reported only data for select items from the HRB tool. Psychometric
data for the whole HRB tool was reported for the following instruments: Kriska's Modifiable Activity questionnaire; Modified Self Report of Delinquency; Risk Behavior and Risk Scale; Delinquency Scale; and the Denys Self-Care Practice instrument. Moreover, psychometric properties of Youth Self Report; Child Behavior Check List; and the Structured Clinical Interview for the DSM-IV in the context of HRB evaluation were also reported. The reported psychometric properties of these tools satisfied the recommended thresholds for psychometric rigor for example the internal consistency (coefficients ranged from 0.73 to 0.98) and test–retest reliability (coefficients ranged from 0.58 to 0.85). The psychometric data reported on selected HRB items were mainly for items assessing physical activity or sedentary behavior [38, 55] and these also had good test–retest reliability ranging from 0.8 to 0.81 and good internal consistency of 0.73.

The HRB tools were largely used among adolescents with the chronic conditions of mental illness, especially depression (21.4%), respiratory conditions such as asthma and cystic fibrosis (13.8%), metabolic conditions such as diabetes (9.4%) and neurological conditions such as autism spectrum disorders, epilepsy and cerebral palsy (6.9%). To a lesser extent, the HRB tools were also utilized among adolescent patients with musculoskeletal conditions such as arthritis, cardiovascular conditions (e.g. congenital heart disease and hypertension), HIV, cancer, digestive tract conditions (e.g. inflammatory bowel disease and gastritis), disabling conditions (e.g. visual, speech and hearing problems) and dermatological conditions such as atopic dermatitis and eczema. The detailed summary of eligible studies is presented in Table 4.

Discussion
This review identified the commonly utilized HRB assessment tools or sources of items used; describing the geographical utility of HRB assessments tools, the common methods of HRB tool administration, the adaptation and
psychometric properties; and providing a summary of the forms of HRB commonly assessed. Our findings show that the YRBS and HBSC are the most frequently used tools to assess HRB or sources of items on HRB. This may partly be explained by their high level of comprehensiveness in assessing priority and multiple forms of HRB thereby being useful in many contexts. While both tools assess for HRB among adolescents, the YRBSS targets an older adolescent age group compared to the HBSC. The HBSC however focuses more on the social and environmental context for HRB such as influence of peers, school environment, and family characteristics. The YRBSS explores HRB in greater detail compared to the HBSC although the former lacks items on oral hygiene, health complaints and chronic illnesses. Besides the YRBSS and HBSC, a wide range of other HRB tools have been utilized, and some of them assess the same form of HRB but in a different format. One challenge that this may present is the lack of uniformity or standardized formats to compare similar HRB outcomes across different study populations.

Findings from this review also indicate that research on HRB among chronically ill adolescents living with chronic illnesses in low and middle income countries (LMIC) is still limited. This is unfortunate since the majority of the adolescent population lives in LMICs [56] where a disproportionately higher burden of HRB occurrence is also reported [57]. There are three potential reasons that may explain the limited research on HRB among chronically ill adolescents in LMIC. First there is limited research that explicitly focuses on the adolescent age-group [5]. Second, research on this topic is not adequately prioritized [4]. Nonetheless, research on HRB among chronically ill adolescents has significantly grown over the past two decades [4, 5] though with disproportionately lower prioritization especially in LMICs. The third reason is the scarcity of standardized measures on various health outcomes among chronically ill adolescents [5]. The need for more investment in research on health and behavioral outcomes among chronically ill adolescents especially in LMICs cannot be overemphasized given that the burden of chronic diseases is increasing in such settings [58].
| Author | Country     | Age/mean age (years) | Illness                                    | Form of HRB                                           | HRB tool or source of HRB items | Adaptation and psychometric properties |
|--------|-------------|----------------------|--------------------------------------------|------------------------------------------------------|---------------------------------|-----------------------------------------|
| Holmberg and Hjern [71] | Sweden      | 10                   | ADHD                                       | Behavior resulting into violence Sedentary lifestyle | Items adapted from HBSC         | NR                                      |
| Husarova et al. [72]     | Slovakia    | 13–15                | Asthma, learning disability or presence of a long term illness | | Health Behaviour in School-aged Children | NR                                      |
| Park et al. [21]         | USA         | 15–17                | Asthma                                     | Tobacco smoking, poor dietary habits                | 2009 YRBSS questionnaire       | Convergent validity: the item on soda-intake from the questionnaire correlated with soda intake from 24 h dietary recalls (r = 0.44) |
| Kim et al. [73]          | Korea       | 13–18                | Asthma                                     | Tobacco use, physical inactivity, sedentary lifestyle | 2007 Korea Youth Risk Behavior Web-Based Survey (KYRBWS) | NR                                      |
| Rhee et al. [13]         | USA         | 16                   | Asthma                                     | Tobacco use, illicit substance/drug use, alcohol drinking | Periodic Assessment of Drug Use (PADU) | NR                                      |
| Jones et al. [8]         | USA         | 14–18                | Asthma                                     | Physical inactivity, sedentary lifestyle             | 2003 YRBSS                     | NR                                      |
| Jones et al. [14]        | USA         | 14–18                | Asthma                                     | Tobacco smoking, drug/substance use                  | 2003 YRBSS                     | NR                                      |
| Tercyak [74]             | USA         | 16.1                 | Asthma                                     | Tobacco smoking behavior                             | Adapted from the YRBSS         | NR                                      |
| Swahn and Bossarte [16]  | USA         | 14–18                | Asthma                                     | Behavior resulting into violence                     | 2003 YRBSS                     | NR                                      |
| Lee and Shin [75]        | Korea       | 12–17                | Atopic dermatitis depression               | Self-harm, poor sleep behavior, behavior resulting to violence, alcohol drinking, tobacco smoking, physical inactivity | Korean Youth Risk Behavior Survey 2013 (KYRBS) | NR                                      |
| Oh et al. [76]           | Korea       | 14.8                 | Atopic disease (asthma, allergic rhinitis, atopic dermatitis) | Poor sleep behavior                                 | Korean Youth Risk Behavior Survey 2013 (KYRBS) | NR                                      |
| Lunt et al. [60]         | Australia   | 14.6                 | Cardiac disease                            | Physical inactivity                                  | Items adapted from New South Wales Schools Fitness and physical activity survey | NR                                      |
| Barbiero et al. [19]     | Brazil      | 2–18                 | Congenital heart disease                   | Tobacco smoking, physical inactivity                | International Physical Activity Questionnaire (IPAQ) | NR                                      |
| Uzark et al. [42]        | USA         | 16.1                 | Congenital heart disease                   | Sexual risk behavior, tobacco smoking, alcohol drinking, physical inactivity | Source of items not clear | NR                                      |
| Nixon et al. [18]        | USA         | 7–17                 | Cystic fibrosis                            | Physical inactivity                                  | Kriska's Modifiable Activity questionnaire | Convergent validity: physical activity measured by HRB tool correlated significantly with measurements by a Caltrac motion sensor (r = 0.4, p = 0.04) Test–retest reliability: a 3 months period test–retest reliability was ICC = 0.77, 0.70, 0.58 for 3 levels of physical activity |
| Author                | Country | Age/mean age (years) | Illness               | Form of HRB                                                                 | HRB tool or source of HRB items                                      | Adaptation and psychometric properties |
|-----------------------|---------|----------------------|-----------------------|----------------------------------------------------------------------------|---------------------------------------------------------------------|----------------------------------------|
| Adrian et al. [77]    | USA     | 15–19               | Depression            | Tobacco smoking, drug/substance use, alcohol drinking, poor dietary, physical inactivity, poor sleep behavior | Washington State Healthy Youth Survey                               | NR                                     |
| Lampard et al. [78]   | USA     | 144                 | Depression            | Poor dietary habits, tobacco smoking                                        | EAT 2010 Survey Tool                                                | EAT 2010 Survey Tool was first pilot tested with 129 students Test–retest reliability of the item used to capture any of these behaviors was ICC = 0.85 |
| Adrian et al. [77]    | USA     | 15–19               | Depression            | Tobacco smoking, drug/substance use, alcohol drinking, poor dietary, physical inactivity, poor sleep behavior | Washington State Healthy Youth Survey                               | NR                                     |
| Lampard et al. [78]   | USA     | 144                 | Depression            | Poor dietary habits, tobacco smoking                                        | EAT 2010 Survey Tool                                                | EAT 2010 Survey Tool was first pilot tested with 129 students Test–retest reliability of the item used to capture any of these behaviors was ICC = 0.85 |
| Frazer et al. [54]    | USA     | 16.1                | Depression            | Anti-social acts (delinquent behavior), drug/substance use, alcohol use     | Delinquency scale                                                   | Internal consistency (Cronbach’s alpha = 0.84) |
| Allison et al. [79]   | Canada  | 12–17               | Depression            | Physical inactivity                                                        | Items extracted from the YRBSS                                      | NR                                     |
| Tortolero et al. [37] | USA     | 11.2                | Depression            | Behavior resulting into violence                                            | Source of items is not clear                                        | NR                                     |
| Dube et al. [80]      | USA     | 12–17               | Depression            | Tobacco smoking                                                             | National Health and Nutrition Examination Survey                    | NR                                     |
| Richardson et al. [81]| USA     | 13–17               | Depression            | Drug/substance use, alcohol drinking                                        | CRAFT substance Abuse Screening Test                               | NR                                     |
| Katon et al. [15]     | USA     | 13–17               | Depression            | Tobacco smoking, drug/substance use, alcohol drinking, poor dietary habits, physical inactivity, sedentary lifestyle | CRAFT substance Abuse Screening Test                               | NR                                     |
| Simpson et al. [12]   | Canada  | 14–18               | Depression            | Sexual risk behavior, tobacco smoking, drug/substance use, alcohol drinking, poor dietary habits, physical inactivity, sedentary lifestyle | 2001/2 HBSC                                                         | Construct validity: a one-factor solution with loadings 0.63–0.80 indicated the following items: lifetime cannabis use, unprotected sexual intercourse; lifetime use of other illicit drugs; lifetime drunkenness; and present smoking status Internal consistency: an excellent Cronbach’s alpha = 0.81 was obtained for the entire HRB tool |
| Tercyak et al. [82]   | USA     | 14.1                | Depression            | Tobacco smoking, physical inactivity, sun protective behavior              | Items derived from Youth Risk Behavior Survey (YRBOSS)              | NR                                     |
| Elder et al. [55]     | USA     | 15.5                | Depression            | Tobacco use, alcohol drinking, poor dietary habits, physical inactivity, sedentary lifestyle | Items adapted from: 1997 YRBOSS, 24 h food intake record (FIR), 7 day physical activity recall | Inter-observer reliability for FIR was r = 0.72 for 12 key nutrients Test–retest reliability of the items on TV watching in terms of total hours per week was 0.80 at pilot testing |
| Pronk et al. [83]     | USA     | 13–17               | Depression            | Tobacco smoking, alcohol drinking, poor dietary habits, physical inactivity, | Items adapted from: Behavior Risk Factor Surveillance System and from Recommended Food Score | NR                                     |
| Author                      | Country          | Age/mean age (years) | Illness                                      | Form of HRB                                                                 | HRB tool or source of HRB items                                      | Adaptation and psychometric properties                                                                 |
|-----------------------------|------------------|----------------------|----------------------------------------------|---------------------------------------------------------------------------|----------------------------------------------------------------------|----------------------------------------------------------------------------------------------------------------|
| Brooks et al. [47]          | USA              | 14–18                | Depression                                   | Sexual risk behavior, tobacco smoking, alcohol drinking, substance/drug use, poor dietary, physical inactivity, behavior resulting into violence | Massachusetts Adolescent Health Survey                                | The tool was reviewed by academic experts, adolescent health practitioners and survey researchers for content validity and cultural appropriateness. HRB items were pilot-tested among 4 adolescent focus groups and were pre-tested for clarity, length and completeness of closed ended questions. |
| Schmitz et al. [38]         | USA              | 11–15                | Depression                                   | Physical inactivity, sedentary lifestyle                                   | Source of items not clear                                            | The test–retest reliability for the item on physical activity was 0.65. The test–retest reliability for sedentary lifestyle was 0.81 and a Cronbach’s alpha of 0.73. |
| Shrier et al. [39]          | USA              | 17.1                 | Depression                                   | Sexual risk behavior, drug/substance use, alcohol drinking                | Source of items not clear                                            |                                                                                                               |
| Moradi-Lakeh et al. [84]    | Saudi Arabia     | 15–19 (majority)     | Diabetes mellitus, congestive heart failure, renal failure, cancer | Physical inactivity, sedentary lifestyle, poor dietary habits, tobacco smoking, unintentional injuries | Saudi Health Information Survey (SHIS)                                 |                                                                                                               |
| Ohmann et al. [85]          | Austria          | 9–19                 | Diabetes                                     | Anti-social acts                                                          | Child Behavior Checklist, Youth Self Report                           |                                                                                                               |
| Scaramuzza et al. [6]       | Italy            | 14                   | Diabetes                                     | Sexual risk behavior, self-harm, tobacco smoking, alcohol drinking, substance/drug use | Items adapted from YRBSS                                              |                                                                                                               |
| Kyngas [36]                 | Finland          | 13–17                | Diabetes                                     | Tobacco smoking, alcohol drinking, physical inactivity                    | A newly developed questionnaire                                       |                                                                                                               |
| Soutor et al. [86]          | USA              | 9–17                 | Diabetes                                     | Poor dietary habits, physical inactivity                                  | 24 h recall interviews                                              |                                                                                                               |
| Gold and Gladstein [35]     | Not stated       | 15                   | Diabetes                                     | Tobacco smoking, substance/drug use, alcohol drinking                     | Modified Michigan Alcohol Screening Test                               |                                                                                                               |
| Timko et al. [87]           | USA              | 10–11                | Juvenile rheumatic disease                   | Tobacco smoking, drug/substance use, alcohol drinking                     | Health and daily living form                                        |                                                                                                               |
| MacDonell et al. [88]       | USA              | 15.8                 | HIV                                          | Substance use                                                             | The car, relax, alone, forget, friends, trouble (CRAFT)               |                                                                                                               |
| Elkington et al. [89]       | USA              | 9–16                 | HIV                                          | Sexual risk behavior, tobacco smoking, alcohol drinking, substance/drug use | Adolescent Sexual Behavior Assessment (ASBA), Diagnostic Interview Schedule for Children-IV |                                                                                                               |
| Lagrange et al. [23]        | USA              | 17.2                 | HIV                                          | Poor dietary habits, physical inactivity, poor sleep behavior             | Six questions with unclear sources                                   |                                                                                                               |
Table 4 continued

| Author                          | Country          | Age/mean age (years) | Illness                                                                 | Form of HRB                                                                 | HRB tool or source of HRB items                              | Adaptation and psychometric properties |
|--------------------------------|------------------|----------------------|--------------------------------------------------------------------------|-----------------------------------------------------------------------------|----------------------------------------------------------------|----------------------------------------|
| Asnani et al. [48]             | Jamaica          | 17                   | Sickle cell disease                                                     | Sexual risk behavior, tobacco smoking, drug/substance use, alcohol drinking | Jamaican Youth Risk and Resilience Behavior Survey             | Validity of instrument was assured through pretesting it among a youth group and a panel of adolescent health experts |
| AlBuhaian et al. [49]          | Saudi Arabia     | 15                   | Mental illness, asthma, hematological disorders, skin disorders, genito-urinal disorders | Tobacco smoking, drug/substance use, alcohol drinking, poor dietary habits, physical inactivity, sedentary lifestyle, unintentional injuries, behavior resulting into violence | Items adapted from YRBSS and Global School-based Student Health Survey | Items underwent cultural adaptation and culturally inappropriate items were excluded (e.g. on sexual behavior and sexually transmitted infections) |
| Kline-Simon et al. [46]        | USA              | 15                   | Mental illness conditions (depression, bipolar spectrum disorders, personality disorders, dementia, schizophrenia, other psychoses) Asthma, sinusitis, arthritis, rhinitis, diabetes mellitus, inflammatory bowel disease, migraine | Substance use                                                              | Source of items not clear | NR |
| Kunz et al. [43]               | USA              | 16.1                 | Cystic fibrosis, inflammatory bowel disease, arthritis, hematologic condition, cardiac condition | Tobacco smoking, alcohol drinking                                           | Source of items not clear | NR |
| Conner et al. [90]             | USA              | 15.9                 | HIV, Depression                                                         | Tobacco smoking, alcohol drinking, substance/drug use                       | Items adapted from Reaching for Excellence in Adolescent Care and Health (REACH) | NR |
| Olsson et al. [91]             | Sweden           | 15–16                | Rheumatism, autism, epilepsy, diabetes, ADHD, eczema, mental problem, asthma, visual/speech impairment, dyslexia | Poor dietary habits, physical inactivity, behavior resulting into violence | 2008 Ung l Värmland questionnaire                                  | NR |
| Singh et al. [92]              | USA              | 10–17                | Asthma, autism, depression, ADHD, learning disability, hearing problems | Tobacco smoking, physical inactivity, sedentary lifestyle, poor sleep behavior | National Survey of Children’s Health questionnaire                | NR |
| Woods et al. [51]              | USA              | 11–16                | Asthma, persistent bowel problems, diabetes, sickle cell anaemia, and others | Behavior resulting into violence                                             | Youth Self Report (YSR), Child Behavior Checklist (CBCL), Modified Self Report of Delinquency (MSRD) | Test–retest reliability of YSR was $r = 0.8$ and internal consistency, Cronbach’s alpha = 0.96 Internal consistency of MSRD was Cronbach’s alpha = 0.98 The internal consistency of CBCL was Cronbach’s alpha = 0.91 and 0.80 for externalizing and internalizing sub-scales respectively |
| Author | Country | Age/mean age (years) | Illness | Form of HRB | HRB tool or source of HRB items | Adaptation and psychometric properties |
|--------|---------|---------------------|---------|------------|-------------------------------|--------------------------------------|
| Wilens et al. [9] | USA | 6–17 | ADHD, depression | Tobacco smoking, alcohol drinking, drug/substance use | Structured Clinical Interview for the DSM-IV | Inter-rater reliability of the diagnosis procedures was assessed by comparing findings by assessment staff and those by certified child and adult psychologists who used the audio taped assessment interviews. Kappa coefficient for substance use disorder = 1.0 |
| Bush et al. [41] | USA | 11–17 | Asthma, depression | Tobacco smoking | Source not clear | NR |
| Silburn et al. [93] | Australia | 12–17 | Asthma, visual and hearing impairment, learning difficulties, speech problems | Sexual risk behavior, tobacco smoking, drug/substance use, alcohol drinking, physical inactivity, self-harm | Western Australia Aboriginal Child Health Survey | NR |
| Suris and Parera [11] | Spain | 16.1 | Diabetes, asthma, epilepsy, scoliosis, cancer, arthritis | Sexual risk behavior, tobacco smoking, drug/substance use, alcohol drinking | Catalonia Adolescent Health Survey 2001 | NR |
| Blum et al. [40] | USA | 16.2 | Physical disability, learning disability, emotional disability | Sexual risk behavior, tobacco smoking, alcohol drinking, self-harm, behavior resulting into violence | Source of items not clear | NR |
| Britto et al. [59] | USA | 15.6 | Cystic fibrosis, sickle cell disease | Sexual risk behavior, tobacco smoking, drug/substance use, alcohol drinking, unintentional injuries, behavior resulting into violence, self-harm | Modified version of YBS | NR |
| Choquet et al. [10] | France | 16.2 | Cancer, hemophilia, arthritis, nephropathy, diabetes, mental disease, metabolic disease, eczema, psoriasis, asthma, cardio-pathy | Sexual risk behavior | Items derived from HBSC and Choquet-Ledoux study | NR |
| Frey et al. [53] | USA | 14.2 | Diabetes, asthma | Sexual risk behavior, tobacco smoking, alcohol drinking, substance/drug use | Risky Behavior and Risk Scale | Internal consistency ranged from 0.85 to 0.95 for the three subscales of the HRB tool |
| Frey [52] | USA | 9–16 | Diabetes, asthma | Poor dietary habits, physical inactivity, poor sleep behavior | Denyes self care practice instrument | Internal consistency ranged from 0.73 to 0.79 |
| Suris et al. [7] | USA | 14–15 | Scoliosis, arthritis, muscular dystrophy, diabetes, seizures, asthma | Sexual risk behavior | Minnesota Adolescent Health Survey 1986–7 | NR |
| Nylander et al. [61] | Sweden | 15–18 | Presence of at least one chronic disease | Sexual risk behavior, tobacco smoking, drug/substance use, alcohol drinking, physical inactivity, behavior resulting into violence, self-harm | 2011 Life and Health in Youth questionnaire | NR |
| Author                  | Country                  | Age/mean age (years) | Illness                                             | Form of HRB                                                                 | HRB tool or source of HRB items                                                                 | Adaptation and psychometric properties                                                                 |
|-------------------------|--------------------------|----------------------|-----------------------------------------------------|------------------------------------------------------------------------------|-----------------------------------------------------------------------------------------------|---------------------------------------------------------------------------------------------------------|
| Warren et al. [44]      | USA                      | 16.6                 | Presence of comorbid chronic conditions             | Poor dietary habits, behavior resulting into violence, poor hygiene practices | Items borrowed from previous population level surveys                                       | Clarity and understandability of items assessed by expert panel review and cognitive interviews of adolescents |
| Ardic and Esin [94]     | Turkey                   | 160                  | Presence of any pre-existing or current chronic illness | Poor dietary habits, physical inactivity                                     | Adolescent Lifestyle Profile Scale                                                          |                                                                                                        |
| Nylander et al. [95]    | Sweden                   | 15–18                | Physical impairment or presence of a chronic disease (yes/no) | Sexual risk behavior, tobacco smoking, drug/substance use, alcohol drinking, behavior resulting into violence, self-harm, anti-social acts | 2008 Life and Health in Youth questionnaire                                                |                                                                                                        |
| Santos et al. [96]      | Portugal                 | 15                   | Presence of a chronic disease (yes/no)              | Alcohol use, behavior resulting into violence, self-harm                    | 2010 Health Behavior in School-aged Children (HBSC)                                       |                                                                                                        |
| Sentenac et al. [50]    | Multi-site (Europe and North America) | 11–16               | Presence of a chronic disease (yes/no)              | Behavior resulting into violence                                            | 2005/6 HBSC                                                                                     | Language equivalence was ensured by translation and back translation                                    |
| Rintala et al. [97]     | Canada and Finland       | 13–15                | Physical disability or presence of a chronic disease (yes/no) | Physical inactivity                                                        | Items adapted from 2001/2 HBSC                                                                 | NR                                                                                                     |
| Wilcox et al. [45]      | USA                      | 104                  | Physical disability or presence of a chronic disease (yes/no) | Self-harm, anti-social acts, sexual risk behavior, alcohol/substance use behavior | Source of items not clear                                                                      | NR                                                                                                     |
| Alriksson-Schmidt et al. [17] | USA                | 15–18                | Presence of a chronic disease (yes/no)              | Tobacco smoking, drug/substance use, alcohol drinking, behavior resulting into violence                          | 2005 YRBSS                                                                                     | NR                                                                                                     |
| Han et al. [98]         | Korea                    | 12–19                | Presence of a chronic disease (yes/no)              | Tobacco smoking, alcohol drinking, self-harm                                 | 2006 Korea Youth Behavioral Risk Factor Surveillance                                         |                                                                                                        |
| Jones and Lollar [20]   | USA                      | 14–18                | Presence of a chronic disease (yes/no)              | Sexual risk behavior, tobacco smoking, drug/substance use, alcohol drinking, poor dietary habits, behavior resulting into violence, self-harm | 2005 YRBSS                                                                                     |                                                                                                        |
| Suris et al. [29]       | Switzerland              | 17.9                 | Presence of a chronic disease (yes/no)              | Sexual risk behavior, tobacco smoking, drug/substance use, alcohol drinking, poor dietary habits, behavior resulting into violence, self-harm | SMASH questionnaire                                                                      |                                                                                                        |
| Erickson et al. [67]    | USA                      | 14.9                 | Depression, presence of a chronic disease (yes/no)  | Tobacco smoking, drug/substance use, alcohol drinking, self-harm             | Items adapted from the Minnesota Student Survey                                           | The internal consistency of the items on substance use behavior was Cronbach's alpha = 0.79                  |
| Author                        | Country | Age/mean age (years) | Illness                                                                 | Form of HRB                                                                 | HRB tool or source of HRB items                                                                 | Adaptation and psychometric properties |
|-------------------------------|---------|----------------------|-------------------------------------------------------------------------|----------------------------------------------------------------------------|-----------------------------------------------------------------------------------------------|----------------------------------------|
| Heflinger and Saunders [99]  | USA     | 4–17                | Depression, presence of a chronic disease (yes/no)                      | Anti-social acts                                                           | Child Behavior Checklist, Columbia Impairment Scale                                             | NR                                     |
| Haarasila et al. [100]        | Finland | 15–19               | Presence of at least one chronic illness, depression                     | Tobacco smoking, alcohol drinking, physical inactivity                     | 1996 Finnish Health Care Survey questionnaire                                                  | NR                                     |
| Mattila et al. [101]          | Finland | 12–18               | Presence of a chronic disease (yes/no)                                 | Tobacco smoking, drug/substance use, alcohol drinking, poor dietary habits, physical inactivity, behavior resulting into violence, poor hygiene/sanitation | 1999 Adolescent Health and Lifestyle Survey questionnaire                                     | NR                                     |
| Huurre et al. [102]           | Finland | 16                  | Presence of at least one chronic illness, depression                    | Tobacco smoking, alcohol drinking, physical inactivity,                     | Alcohol Use Disorder Identification Test (AUDIT)                                               | NR                                     |
| Miauton et al. [103]          | Switzerland | 15–17 and 18–20    | Presence of a chronic disease (yes/no)                                 | Sexual risk behavior, tobacco smoking, drug/substance use, alcohol drinking, unintentional injuries, behavior resulting into violence | Swiss Multi-centre Adolescent Survey on Health (SMASH)                                         | NR                                     |
| Tremblay et al. [104]         | Canada  | 12–17               | Presence of at least one chronic illness, depression                    | Tobacco smoking, alcohol drinking, physical activity, poor dietary habits | Canadian Community Health Survey                                                               | NR                                     |
| Huurre and Aro [105]          | Finland | 16                  | Presence of at least one chronic illness, depression                    | Tobacco smoking, alcohol drinking, physical activity                      | AUDIT                                                                                         | NR                                     |
| Williams and Shams [106]      | England | 14–15               | Presence of at least one chronic disease                                | Tobacco smoking, drug/substance use, alcohol drinking, physical inactivity | Health and Lifestyle Survey, London                                                            | NR                                     |
The use of appropriate and psychometrically sound instruments is essential for having good insight in adolescents’ behavior so as to be able to address certain forms of behavior that could be dangerous either for the patients themselves or for others. However, our findings indicate that HRB tool adaptation and psychometric properties are rarely reported among studies on HRB of chronically ill adolescents. Partly, this could be due to the fact that the majority of the studies were conducted in the western context where the majority of these tools have been developed. To indicate the adaptation and psychometric properties, some of the authors simply cited studies where similar HRB tools or items have been previously utilized [59–61]. This may not guarantee validity and reliability for a number of reasons. First, some of the tools were previously adapted and validated for use among adolescents without chronic conditions and thus we cannot ascertain if they retain their good psychometric properties when used among chronically ill adolescents. Secondly, some of the original validation or adaptation may have taken place more than two decades back and considering the evolution of HRB, various behavioral constructs used in these tools may no longer be appropriate. Another observation is that many researchers borrow specific items from previously well validated or standardized HRB tools but without checking the item specific psychometric properties. Our findings also reveal that there is a tendency for researchers to perform the adaptation processes such as forward-back translation and content review for item completeness, clarity or cultural appropriateness; without performing psychometric evaluations. It should be emphasized that much as adaptation is an important process, psychometric evaluation is equally critical for ascertaining item reliability and validity. Without adequate adaptation and psychometric evaluation we cannot ascertain if the scales and items retain their good psychometric properties following the modifications made. Overcoming such challenges requires a mixed methods approach for tool adaptation and validation [31, 62, 63]. For instance, a four step approach has been suggested as adequate for adapting tools in low and middle income countries [64]. The four step approach suggested for LMICs entails: (i) construct definition which can be done through review of literature, and consultation with community or local professionals in order to achieve conceptual clarity and equivalence; (ii) item pool creation which involves preparation of a list of potentially acceptable items in a clear and unambiguous language using feedback from the first step; (iii) developing clear guidelines for administration of the items to ensure operational equivalence; (iv) test evaluation which involves psychometric evaluation to assess measurement and functional equivalence [64].

Additionally, findings from this review indicate that there are numerous methods of HRB tool or item administration. Self-administered paper and pencil format was the most popular method and this could have been because of the participants’ good level of literacy given that majority of them were school attending adolescents. This method of administration is also preferred as it is associated with a high level of privacy and ease of administration [32]. On the contrary, its disadvantage arises from its requirement for some literacy levels among the respondents as well as the cognitive burden that respondents face in comprehending and recalling their experiences [32, 65]. Face-to-face interviews were also frequently utilized in assessing HRB. This method is linked to high response rates and the benefit of probing participants and clarifying unclear questions [65]. Nonetheless, face-to-face interviews are hampered by the lack of anonymity which may result to social desirability bias and impression management [32, 65]. Similar to findings from other studies [32, 66], our review shows that there is growing utilization of electronic methods of HRB tool and item administration. Electronic methods [such as the Audio Computer Assisted Self Interview (ACASI), telephone and internet based surveys] are valued for their high level of privacy or anonymity [32, 65] and some of them such as the ACASI have been further designed to benefit people with low literacy levels [65]. However, electronic methods require access to electronic devices and services (such as telephone, computer, and internet), may require greater auditory demands and some demand a high level of literacy [32, 66]. The presence of numerous HRB tool administration methods presents a wide set of options which can be tailored to suit contextual factors, research skills, resource availability and specific needs of study populations. However, researchers should carefully think through the dynamics surrounding tool administration and data collection procedures in order to identify the most appropriate methods to ensure that high quality data is collected.

Furthermore, our findings show that alcohol, tobacco, drug use behavior and physical inactivity are the most frequently researched HRB among adolescents with chronic conditions. Substance use among chronically ill adolescents is of major concern and many studies report higher or equivalent rates of substance use (e.g. cannabis, tobacco, illicit drugs) among these adolescents in comparison to their healthy peers [12, 13, 67]. This may explain why most of HRB research among this group focuses on substance use behavior. Our findings also indicate that physical inactivity and sexual risk behavior are frequently assessed. Growing research interest on sexuality of chronically ill adolescents indicates that sexual risk behavior is a
concern [7, 10–12] and this dissents the earlier notion that they are less sexually active than their healthy peers [4]. Likewise, physical activity among adolescents with chronic conditions is gaining measureable research interest [28]. This may surround its vital role in appropriate management of chronic illness such as: cardio-respiratory fitness among asthmatic patients and optimization of quality of life among patients with cerebral palsy [28]. Our results also indicate that violence related behaviors are frequently investigated among chronically ill adolescents. Adolescents with chronic illnesses often fall victim of violence such as bullying, assault and forced sexual encounters [17, 50]; and thus raising the need for increased research on this matter. On the other hand, our findings show that poor hygiene, inadequate sleep and behavior resulting to unintentional injury were the least frequently assessed forms of HRB in this review. This may be due to the reality that most of these problematic behaviors are of greater research interest in LMICs (whose representation is still low) where their occurrence is documented to be greater, compared to high income settings [57, 68]. Our findings on the variation in the frequency of the forms of HRB assessed, may partly imply that there is some tendency to measure HRB in isolation. However, co-occurrence of different adolescent HRB is increasingly documented [69, 70], and therefore different forms of HRB should be assessed concurrently.

Our review draws its major strengths from the utilization of a rigorous methodological framework [33] and also its specific focus on the adolescent age-group in a global perspective. However, we did not appraise the quality of the studies included in our systematic review. Nonetheless, given that our study objectives aimed at describing extent of utilization of HRB tools and providing an over-view of various forms of HRB assessed, we do not expect any major issues arising from the quality of studies to influence our findings.

Conclusion

Overall, most research on health risk behavior among chronically ill adolescents emanates from high income settings such as Europe and North America where the majority of the HRB assessment tools have also been developed. Therefore more investment is needed in research on health and behavioral outcomes among chronically ill adolescents especially in LMICs. Although the YRBSS and HBSC are utilized most, a variety of other HRB tools are used as well, however without documentation of adaptation and psychometric qualities. This poses challenges for researchers and practitioners who are keen to evaluate HRB in LMICs. We recommend the use of the mixed methods approach for tool adaptation and validation, which involves both qualitative approaches (e.g. focus group discussions and in-depth interviews) and quantitative approaches (e.g. psychometric testing) to develop and standardize measures for use by health researchers especially from LMICs. In the industrialized setting, we recommend the use of YRBSS or HBSC owing to their comprehensive approach to assessing multiple forms of HRB. The results of more research on HRB among chronically ill adolescents could translate to significant clinical, public health and social economic benefits, especially for adolescents living with such illnesses and their families.

Abbreviations

ACASI: Audio Computer Assisted Self Interview; AUDIT: Alcohol Use Disorder Identification Test; CAPI: Computer Assisted Personal Interview; CRAFT: car, relax, alone, forget, friends, trouble; HBSC: Health Behavior in School-aged Children; HIV: human immunodeficiency virus; HRB: health risk behavior; LMIC: low and middle income countries; SMASH: Swiss Multi-centric Adolescent Survey on Health; YRBSS: Youth Risk Behavior Surveillance System.

Authors’ contributions

DS and AA conceived and designed the study. DS and MKN screened the studies, extracted and analyzed the data. DS wrote the manuscript while AB, CRN and AA participated in data interpretation and critically reviewed the manuscript. All authors read and approved the final manuscript.

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Competing interests

The authors declare that they have no competing interests.

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