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Position paper

The Use of Medication by Adolescents and Young Adults

The Society for Adolescent Health and Medicine

A B S T R A C T

This paper articulates the Society for Adolescent Health and Medicine positions regarding access to, and use of, medications by adolescents and young adults (AYA). AYA encounter a significant number of medication-related challenges. System barriers such as supply disruption, cost, and complicated refill systems affect adherence and contribute to complications and long-term sequelae. AYA need to be able to access medications easily, confidentially, at minimal (or no) cost, and without stigma. Optimal use of medications should ideally result from a process negotiated through the triadic relationship between AYA, their parents/caregivers, and health professionals. This should be underpinned by access to developmentally appropriate information, support and education, including credible online sources developed to support AYA self-management. Self-management should be facilitated by meaningful AYA and parent/caregiver involvement in decision-making so that medication regimens are built around the life and developmental context of the AYA and form an integral part of their transition to adult health services. In addition, there should be facilitated involvement of AYA in the development of, licensing of, and access to new medications, including clinical trials. The positions presented in this paper are a comprehensive set of recommendations to improve AYA access to, and use of, medications for chronic illness, contraception, and self-limiting conditions.

This position paper explores a number of interconnected issues and challenges that affect the use of medication by adolescents and young adults (AYA). There are issues highlighted at a global systems level and at a local level within the therapeutic relationship. It is not a systematic review of all issues affecting access to, and supply of, essential medicines, nor is it a clinical guideline about medication adherence. This paper focuses on a number of policy issues about medication that are unique to adolescents and to young adults in the transition to adulthood. In addition to using acute medication for self-limiting illness and acute injury, many young people with chronic physical and emotional illness require regular medication. The preventive use of regular contraception, especially daily pills, entails the same cognitive, health literacy, and adherence demands for young women as for chronic conditions.

For AYA who regularly take prescribed medication, several tasks may be required including consulting with a health professional; obtaining a prescription; paying for the prescription to be filled or presenting an insurance card; and finally, taking the medication correctly. These tasks all require a significant level of health literacy. Parents or caregivers are variably involved, depending on the autonomy and capacity of the AYA and parent/caregiver, the severity of the illness and the consequences of not taking medication as prescribed. The triadic partnership between health professionals, the AYA and their parents can support young people to get the best outcome from their medication.

The positions presented here concern access to medication, supporting medication use, and a greater role for AYA and families in medication development, licensing, and access policies.

The Society for Adolescent Health and Medicine supports the following positions:

1. AYA must have access to quality medication of reliable provenance without disruption to the supply chain.
2. National essential medication lists must include products that are commonly prescribed for AYA, including contraception and immunization.
3. AYA must be able to access medication for contraception and chronic illness at no, or minimal, cost.
4. AYA must have confidential access to medication.
5. AYA must have access to medication with efficacy that is supported by an age-appropriate evidence base.
6. Health care providers must work concordantly with AYA and their caregivers to facilitate a shared understanding of issues affecting medication use.

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7. AYA must be actively involved in and consent to all decisions about their medication, according to their legal context.
8. Medication regimens must be built around the life context of the AYA—and not the other way round.
9. AYA should be supported to increasingly assume responsibility for medication management as they mature, especially as they transition to adult health care.
10. AYA must be more involved in pediatric medication development, licensing and access policies, including through participation in clinical trials.

Access to Medication

Safe supply

There are many situations in which access to medication can be compromised for the community, including AYA. In areas of the world where there is war or civil unrest, obvious disruptions to the supply chain can occur. In other regions, investments in strengthening health systems are required to promote continuous access to quality health services, including having continuous stock of medication held by community pharmacies or dispensaries. Supply shortages demand improved distribution systems and innovative financing mechanisms.

An increasing threat to the security of the medication supply chain worldwide is that of "spurious/falsely labeled/falsified/counterfeit" (SFFC) medication. SFFC risks to users vary from reduced or absent active ingredients through to adulteration with different active ingredients and toxins. The prevalence of SFFC varies from up to 1% of medication in countries with effective regulatory systems to estimates of over 30% in parts of Africa, Asia, and Latin America [1]. International advocacy is needed to address these endemic system challenges. AYA are particularly vulnerable in those parts of the world where medication dispensing can bypass the official (regulated) health care system [2]. In addition to the reduced opportunity to gain these skills and competencies, they face additional threats from inappropriate choice of medication and poor-quality medication, which will be compounded by unregulated marketing.

1. AYA must have access to quality medication of reliable provenance without disruption to the supply chain.

Recognizing the needs of adolescents and young adults

In countries with national essential medication lists that subsidize or prioritize medication access, medication used more commonly by AYA than other population groups may be omitted. For example, the 2010 WHO Model Formulary for Children [3] was introduced to highlight good practice for pediatric prescribing, but its information is indicated only for children up to 12 years of age, and it omits many medicines used for mental health conditions such as generalized anxiety disorder. Moreover, it notes that the section on contraceptive medicines was deleted from the second edition of the WHO Model List of Essential Medicines for Children. The challenge is that AYA are not seen as a group distinct from children and adults, with their own medication-related needs.

2. National essential medication lists must include products that are commonly prescribed for AYA, including contraception and immunization.

Cost of medication

AYA frequently have unmet needs with regard to financial coverage for medications [4]. AYA may be unaware of national schemes that reduce the cost of medication in different contexts, such as health insurance or prepayment certificates that cover all medication costs over a defined time period or for chronic diseases. Paying for medication may be difficult for AYA as many have low incomes, and others may have outgrown their parental coverage or the national children's insurance schemes. There must be an easily understood mechanism for minimizing the cost of medication for AYA that is facilitated in each country, with no assumptions made about the ongoing financial patronage or involvement of parents or caregivers. Situations where a manufacturer has a monopoly on a product, resulting in spiraling costs—as has been seen recently in the United States for the epinephrine autoinjector commonly used among AYA—must be prohibited.

3. AYA must be able to access medication for contraception and chronic illness at no, or minimal, cost.

Confidentiality

AYA may wish to keep their use of certain medications confidential from other members of their social circle, including their family, teachers, or employers. There may be cultural or societal norms and stigma that would make AYA feel uncomfortable or excluded if their medication use was discovered. Examples of such medications include contraceptives, medication for HIV/AIDS, and for mental health conditions. Integration of specialty services, such as HIV care and family planning, into routine care systems is important to avoid AYA use of specific medications being identified through using a particular clinic. When required, AYA must have confidential methods to access medication without unintended disclosure through billing practices or through access by parent portals to electronic prescribing records.

4. AYA must have confidential access to medication.

Appropriate evidence-based products

Many medications used to treat adolescents under 18 years old are provided "off-label," in that the medication has not been studied or authorized for such use [5]. Although different regions may use overly simplistic measures of age or weight upon which to base dosages—for example, in Europe AYA over 12 years old (or over 30 kg in weight) are usually considered "adults" for medication dosing—there are unique biological features of adolescence that need further consideration to ensure maximum effect and minimum risk [6]. Pubertal development may affect drug dosing schedules [6]. Examples include increased hydrocortisone requirements in adolescent females, and transient pubertal insulin resistance leading to increased insulin requirements in type 1 diabetes. Dimorphic gender developmental differences during adolescence are associated with body size, body composition, and pattern of sex hormone expression that have the potential to influence drug distribution and biotransformation [7]. The clearance of methotrexate, for example, changes over the course of adolescence, decreasing to adult rates by the end of young adulthood.

Gaining access to clinical trials for AYA is also challenging, a problem that has been particularly highlighted for young people with cancer [8]. The lack of clinical trial evidence for many medications used by AYA must be addressed [6]. Some countries use a system of incentives, rewards, and obligations for pharmaceutical companies to conduct robust pediatric clinical studies, including free scientific advice and protocol assistance. In the European Union [9], for example, since the Pediatric Regulation came into force in 2007, pediatric development is obligatory not only for new medicinal products but also for new indications, new routes of administration, and new pharmaceutical forms of existing products that are protected by a Supplementary Protection Certificate or a patent that qualifies for it. In the United States, two separate legislative acts address pediatric development of medications [10]. The Best Pharmaceuticals for Children Act provides incentives but is voluntary, while the Pediatric Research Equity Act establishes requirements to perform pediatric development under certain circumstances but does not offer incentives. These initiatives exemplify a systems approach to the development of medicinal products for use in the pediatric population from birth to less than 18 years.

5. AYA must have access to medication with efficacy that is supported by an age-appropriate evidence base.

Supporting Medication Use

Shared decision-making in medication use

Although the act of taking medication ultimately rests with the individual AYA, families and health providers can provide the support that makes the difference between a successful partnership and a frustrating impasse. A nonjudgmental and empowering approach may encourage AYA to adhere to a medication regimen since it has been negotiated with them, not simply because they are told to do so[4]. The term "concordance" has been used to reflect a shared decision-making process through which medication adherence might best occur, a way to help both sides recognize and acknowledge different, and often competing, priorities and goals [11]. The goal is that health professionals will work with AYA to achieve agreement about a developmentally appropriate negotiated plan. In doing so, the wider objective is that AYA are invited to take responsibility for their own self-care behaviors, rather than having someone else manage their health.

Discussions and active engagement between AYA and health providers offer an opportunity for AYA to gain a set of generic skills and competencies around the development of medication-taking routines, how to order refills, and the importance of safe storage and disposal of medication. Treatment of self-limiting conditions, such as menstrual pain, with nonprescription medication is significant among AYA; evidence-based strategies for treatment should be discussed, especially when AYA have chronic illness and take prescription medication that might interact with remedies for common ailments. Health care providers must be tolerant and flexible, giving the AYA time to take on this responsibility without resorting to shame or guilt in an effort to accelerate the process. This process must be underpinned by a robust informed consent procedure, where the AYA is central to all decisions made and is provided with reliable and age-appropriate information, including credible online sources. AYA should be actively involved in all decisions about their medication; the extent to which they can consent will be based on their geographical location and legal jurisdiction.

6. Health care providers must work concordantly with AYA and their caregivers to facilitate a shared understanding of issues affecting medication use.
7. AYA must be actively involved in and consent to all decisions about their medication, according to their legal context.

Developmental and life context

The places where AYA live, learn, and work must facilitate access to personal medication use without delay or stigma. Medications need to be able to be taken where AYA go to school, college, or work in a manner that does not evoke shame, violate confidentiality or promote them being labeled by others as "different". Context often mitigates against effective medication taking [12]. For example, while education policies that require teacher supervision of all medication may be appropriate for primary school–aged children, greater flexibility in secondary education and workplace policy would support AYA with chronic illness to take medication at school or work without supervision when there are limited risks to themselves or others from such actions. Policies which impede timely access to potentially life-saving medication (such as reliever inhalers for asthma being taken from students and locked in a school medicine cabinet) are unacceptable and potentially dangerous.

8. Medication regimens must be built around the life context of the AYA—and not the other way round.

Transition to adult health care

Transition to adult services is a risky period for reduced engagement with health care, including threats to continued adherence [13]. AYA need to be prepared, both before and after transfer to adult services, to take responsibility for disease self-management. As AYA often lack knowledge of medication history and medication purposes, explicitly addressing all aspects of medication use, including the need for regular appointments, prescription refills, and medication costs are required as part of transition to adult health care. It is unrealistic to expect all AYA to master this before transfer to adult care; supporting efforts should continue in adult services. The milestone event of transfer to adult care is an important aspect of wider life transitions, which also require AYA to take on more adult roles and responsibilities.

9. AYA should be supported to increasingly assume responsibility for medication management as they mature, especially as they transition to adult health care.

Engaging AYA in pediatric medication development, licensing, and access policies

To improve their access to safe, efficacious medication, AYA must be engaged in the creation of policies regarding medication development, clinical trials, licensing, postlicensing monitoring, and access. The Lancet Youth Commission on Essential Medicine Policies (http://ycemp.com/), for example, is a way for young researchers, health providers, and advocates to influence access and promotion policies for essential medicines worldwide. The UK

Clinical Research Network for Children, as another example, actively uses consumer engagement strategies to ensure that AYA and families are involved in clinical research design, information design, and advice giving to research ethics authorities [14].

10. AYA must be more involved in pediatric medication development, licensing and access policies, including through participation in clinical trials.

The positions presented in this paper are a comprehensive set of recommendations to improve AYA access to, and use of, medications for chronic illness, contraception, and self-limiting conditions. The development of new medications, and the safe and effective use of currently available medications by AYA, would benefit from greater sharing of the expertise embodied within multidisciplinary adolescent health teams, incorporating pharmacy and clinical pharmacology, grounded in the understanding of the physiological and psychosocial factors that make this period of life so unique. We encourage Society for Adolescent Health and Medicine members to reflect on how they can influence national leaders to advocate for AYA access to essential medication and to promote adoption of shared decision-making locally to improve therapeutic outcomes for AYA.

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Prepared by:

Nicola J. Gray, Ph.D., M.R.Pharm.S.
Green Line Consulting Limited
Manchester, England, United Kingdom

Deborah Christie, Ph.D.
University College Hospital
London, England, United Kingdom

Imelda Coyne, Ph.D.
Trinity College Dublin
Dublin, Ireland

Helena Fonseca, M.D., Ph.D., M.P.H.
University of Lisbon
Adolescent Medicine Division
Hospital Santa Maria
Lisbon, Portugal

Calae D. Philippe, M.B.B.S., M.P.H.
Bahamas Ministry of Health
Nassau, The Bahamas

Susan M. Sawyer, M.B.B.S., M.D.
The University of Melbourne
Centre for Adolescent Health, Royal Children's Hospital
Melbourne, Australia

Lisa K. Tuchman, M.D., M.P.H.
Division of Adolescent and Young Adult Medicine
Children's National Health System
Washington, DC

Joan Versnel, Ph.D.
Dalhousie University
Halifax, Canada

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