Journal of Adolescence 69 (2018) 33–43

Contents lists available at ScienceDirect

Journal of Adolescence

journal homepage: www.elsevier.com/locate/adolescence

Medication administration by caregiving youth: An inside look at how adolescents manage medications for family members

Margaret Nickels[a,1], Connie Siskowski[b], Cynthia N. Lebron[c], Julia Belkowitz[a,*]

[a] University of Miami Miller School of Medicine, Regional Medical Campus, 2500 N. Military Trail, Suite 260, Boca Raton, FL 33431, USA
[b] American Association of Caregiving Youth®, 1515 N. Federal Hwy, Suite 218, Boca Raton, FL 33432, USA
[c] University of Miami Miller School of Medicine, Department of Public Health Sciences, 1120 NW 14 Street (CRB), Suite 1087, Miami, FL 33136, USA

ARTICLE INFO

Keywords:
Caregiver burden
Caregivers
Medication management
Young carer
Youth caregiver
Family caregivers

ABSTRACT

Introduction: Children take on the role of family caregiver throughout the world. No prior published research exists surrounding the particular circumstances of the task of medication administration and management by these youth, which was explored in this study.
Methods: A series of focus groups were conducted using semi-structured interviews of 28 previously identified caregiving youth ages 12–19 years old who live in the United States. Data analysis followed guidelines of conventional content analysis.
Results: The following categories emerged about youth caregivers handling medications: 1) tasks involve organizational and administrative responsibilities; 2) youth have varying degrees of knowledge pertaining to these medications; 3) most share responsibility with other family members; 4) they lack formal education about their responsibilities; 5) multiple challenges exist relating to this task; 6) managing medications is associated with emotional responses; and 7) possible safety issues exist.
Conclusions: These responsibilities represent a unique hardship and merit support and research from the medical, healthcare, legislative, and public health communities, among others.

1. Introduction

Caregiving youth, also known as youth caregivers or young carers as they are variably termed in different countries, are a worldwide reality. These youth provide care to family or household members for a variety of reasons: chronic physical or mental illness, disability, substance misuse, and/or other health condition(s) (Aldridge, 2018; Bleakney, 2014; Cass et al., 2011; Fives, Kennan, Canavan, Brady, & Cairns, 2010; Kavanaugh, Stamatopoulos, Cohen, & Zhang, 2016). Their responsibilities range from assisting in both personal and medical care to managing the majority of household duties.

The global prevalence of this phenomenon is difficult to pinpoint for two major reasons: 1) lack of standardization across countries, in terms of both definition (i.e. what determines caregiving) and age (e.g. in the U.S. ages 8–18 versus in Australia under 25 years) (Becker, 2007) and 2) the 'hidden' nature of young caregiving because of the stigma associated with illness or because the family is concerned that authorities will get involved and separation will ensue (Aldridge, 2018; Pakenham, Bursnall, Chiu, Cannon,

* Corresponding author.
E-mail addresses: mcnickels12@gmail.com (M. Nickels), connie@aacy.org (C. Siskowski), CLebron@med.miami.edu (C.N. Lebron), Jbelkowitz2@med.miami.edu (J. Belkowitz).
[1] Present address: Pediatrics Residency Program, Ann & Robert H. Lurie Children's Hospital of Chicago, 612 N. Oakley Blvd #107, Chicago IL, 60612, USA.

https://doi.org/10.1016/j.adolescence.2018.09.001
Received 7 March 2018; Received in revised form 30 August 2018; Accepted 3 September 2018

& Okochi, 2006). While there may be some potential benefits to children from taking on caregiving responsibilities such as increased maturity, better preparation for adulthood and feelings of pride about their role (Rose & Cohen, 2010), the literature also shows that the requirements of this role can have a negative impact on caregiving youth academically, psychosocially, developmentally, and physically (Aldridge & Becker, 1993; Aldridge, Cheesbrough, Harding, Webster, & Taylor, 2016; Cass et al., 2011; Cohen, Greene, Toyinbo, & Siskowski, 2012; Fives et al., 2010; Kavanaugh et al., 2016).

Caregiving tasks are often divided into two categories. The first is Activities of Daily Living (ADLs), such as bathing, dressing, toileting, feeding, diapering, and assisting with mobility. The second is Instrumental Activities of Daily Living (IADLs), which includes handling finances and appointments, housework, transportation, translating, keeping company, meal preparation, using medical equipment, and managing medications. Medically related tasks are unique from other caregiving tasks because, if done incorrectly, can be life threatening. Medication management includes using judgement, such as when a dose is missed, along with a range of responsibilities such as organizing multiple medication schedules, measuring doses of medications, and physically administering medications through varied routes such as eye drops, nebulized solutions, physical placement of pills into care receiver's mouth, and injection of medications, each of which requires complex organizational and sometimes technical skills. Adult caregivers have reported that among the complexities the most stress provoking involved keeping multiple prescriptions filled, managing variable doses of medications, and remaining constantly vigilant for problems (Travis, Bethea, & Winn, 2000).

Clearly these varied responsibilities require different levels of knowledge and understanding. This distinction has been made by organizations that regulate home healthcare delivery. For example, the Florida Agency for Healthcare Administration (AHCA), which regulates tasks in home health, has determined that oral medications can be managed by an unlicensed home health worker, but recognizing the advanced skills needed for injection of medication, requires that this be done by a trained professional (Agency for Healthcare Administration [AHCA], 2016). Yet families, without the benefit of qualified trained health workers in their homes, take on these complex skills on a daily basis. As another example, local authorities in the United Kingdom, the most outspoken region in the world about young carers with research and campaign originating there (Aldridge & Becker, 1993, 1996; Keith & Morris, 1995), carry out young carers' assessments evaluating the appropriateness of caretaking for the person in question (Children and Families Act 2014). Inappropriate or excess care is defined as anything that will have a detrimental impact on the young carer, and administration of medication is definitively listed as an inappropriate responsibility (“Care & Support Statutory Guidance”, 2016).

Studies reporting various types of care work have shown that approximately one third of youth caregivers in the US and half of young carers in the UK assist their family member(s) in general and nursing care which includes medication administration (Assaf, Siskowski, Ludwig, Mathew, & Belkowitz, 2016; Dearden & Becker, 2004; Hunt, Levine, & Naiditch, 2005; Kavanaugh et al., 2016). Qualitative studies show that young carers in Ireland reported administering medication as young as 10 years of age (Fives et al., 2010), and young carers in the US reported drawing up insulin as young as 5 years of age (Jacobson & Wood, 2004). However, this research team has not identified any previous studies that explore the issue of medication management by children. Thus, this qualitative study was undertaken to gain insight into the children's reported experiences and perceptions surrounding their responsibility related to medication management.

2. Methods

2.1. Study design

A qualitative research methodology, conventional content analysis, was used to collect data from focus groups. Focus groups are often used for examining perspectives of individuals who have a shared experience, but who might find it easier to articulate that experience if expressed collectively or in response to others (Kitzinger, 1995). Using groups with children and youth as the research method can empower participants to have confidence that their perspective is valuable (Carey & Asbury, 2012).

2.2. Participants

Participants of this study were school children ages 12–19 years enrolled in the Caregiving Youth Project of the American Association of Caregiving Youth®. Enrollment eligibility for the Caregiving Youth Project is based on high levels of caregiving responsibilities and weekly time spent in caregiving. The American Association of Caregiving Youth is a nonprofit organization headquartered in Boca Raton, Florida, with a mission of identifying and addressing the multitude of unrecognized issues of youth caregivers. The organization's model direct services program, the Caregiving Youth Project, works in partnership with The School District of Palm Beach County, and annually serves more than 600 youth caregivers and their families through a Skills Building curriculum, counseling, support services, respite, academic support, family strengthening, and a variety of fun activities. Partnering with the American Association of Caregiving Youth for this research allowed direct access to this specific population of youth caregivers, who are often otherwise unidentified. The caregiving youth participants of this study were identified by American Association of Caregiving Youth records or staff as involved in their care recipient's medication management.

Initially, seven caregiving youth were recruited by Caregiving Youth Project staff members and one of the researchers via face-to-face interactions at an American Association for Caregiving Youth holiday party in which both children and families were present and could provide consent. However, because of logistical issues (ex., transportation), only two of these students participated in the study. The rest of the participants were recruited by Caregiving Youth Project staff members working directly with children at individual schools, and parents were contacted after initial identification to provide consent. For the focus group that was held onsite at a school after hours, participants were recruited directly by Caregiving Youth Project staff members at that site in order to minimize logistical