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SP.COL. T2011 S4625

Communication barriers between providers and parents of ADHD adolescent patients who use Complementary and Alternative Medicine

Ву

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A project submitted in partial fulfillment of
Requirement for the Master of Science Degree
College of Nursing
University of North Dakota
Spring 2011

PERMISSION

Title: Communication barriers between providers and parents of ADHD adolescent patients who use Complementary and Alternative Medicine

Department: Nursing

Degree: Master of Science

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Abstract

There is increased use of complementary and alternative medicine (CAM) to treat attention deficit hyperactivity disorder (ADHD) symptoms in children and adolescents. Some of the most common types of CAM used in ADHD include: modified diet, vitamins/and or minerals, dietary supplements, aromatherapy and chiropractic care. Many parents/patients do not share their use of CAM with their provider. This inadequate communication between parents and health care providers can be dangerous. This paper addresses the prevalence of ADHD, the types of CAM being used and discusses evidence in support of these therapies. Communication between patients and providers regarding the use of CAM and traditional medications is investigated. Finally, informational materials to help facilitate this communication will be developed for use in health care settings.

Communication barriers between providers and parents of ADHD adolescent patients who use Complementary and Alternative Medicine

Introduction

4.4 million (7.8 percent) of children aged four to seventeen, are estimated to have a diagnosis of attention deficit hyperactivity disorder (ADHD). It is one of the most common childhood mental health disorders in the United States (Fulton et al., 2009). "Children with this disorder often face long-standing problems with academic achievement, social relationships, life skills, risk of injury and functional independence" (Fulton et al., 2009, p. 1075). More than two decades of research have been done regarding the short term efficacy of stimulant medications in the treatment of ADHD. Despite years of research, the use of stimulant medications is still controversial for many parents (Fulton et al., 2009). Many parents of adolescents with ADHD have concerns regarding traditional stimulant medication side effects. The most common side effects of stimulant medications are associated with appetite suppression and sleep pattern disturbances. These are usually mild and manageable. However, there is a potential for more serious side effects including: cardiovascular problems, inhibited physical growth and inappropriate use by non-diagnosed individuals for cognitive enhancement or recreational purposes (Fulton et al., 2009).

Many parents of ADHD adolescents choose to use complementary and alternative medicine (CAM) either in addition to traditional stimulant medications or as mono therapy (Bussing, Zima, Gary & Wilson-Garvan, 2002). "Common nontraditional treatments for children include elimination diets, dietary supplements, herbal regimens, homeopathy, massage, acupuncture, biofeedback and religious approaches such as faith healing" (Bussing et al., 2002,

p. 1096). It is estimated that nine-46 percent of ADHD adolescents are using CAM. (Bussing et al., 2002).

Purpose

There are communication barriers between providers and parents of adolescent patients with ADHD regarding the safety, efficacy and use of CAM. The purpose of this project is to identify the barriers to and facilitate communication between patients and providers regarding the use of CAM for ADHD. This paper will discuss the prevalence of ADHD, describe the types of CAM being used for its treatment and provide evidence in support of some these therapies. Communication between parents, patients and providers regarding the use of CAM and traditional medications is also investigated. Finally, informational materials to help facilitate this communication will be developed for use in health care settings.

Significance

As the body of research about CAM grows, parents are using it more. This is in large part due to the unwanted side effects of stimulant medications used to treat ADHD. Parents' use of internet sources for medical information is greater than ever; this is thought to be related to the increasing CAM use for ADHD symptoms (Bussing, et al., 2002). Many parents/patients do not share that they are using CAM with their provider; this is due to the lack of scientific evidence and the dismissal from the medical community of CAM usage (Bussing et al., 2002). Many traditional medications can be affected by various CAM therapies including megavitamin supplements, elimination diets and herbal regimens (Bussing et al., 2002).

The communication between parent/patients of ADHD and their health care provider is inadequate (Sibinga, Ottolini, Duggan & Wilson, 2004). Health care providers often lack adequate knowledge regarding CAM for ADHD (Winslow & Shapiro, 2002). Parents and

patients often believe that CAM use is not accepted practice by medical professionals. This makes communication difficult (Bussing, et al., 2002). It is a priority to open communication regarding the use of CAM between patient and provider (Bussing, et al., 2002).

Theoretical Framework

According to Knowle's adult learning theory, the role of the advanced practice nurse is to promote learning rather than to teach (Bastable, 2003). A non-didactic approach should be taken in the case of patient education. Nondirective learning should be patient centered; transferring responsibility from the advanced practice nurse to the patient. This is evident in the use of CAM. Bussing et al., (2002) showed the use of Internet sources for medical information has increased CAM usage. The advanced practice nurse's responsibility has progressed to involving patients in planning, linking learners to learning resources and encouraging learner initiative. When discussing CAM with patients the APN should be learning alongside the patient at times (Bastable, 2003). Health care professionals are in a state of continuous development of medicine - traditional and nontraditional. Providers need to keep an open mind, listen and guide the patient and family in terms of safety and efficacy of various CAM therapies and help to decipher information when managing ADHD. Encouraging patients to discuss CAM use as well as their personal experience with it is important in maintaining a trusting provider-client relationship as well as providing safe care.

The term andragogy refers to, "The art and science of helping adults learn" (Bastable, 2003, p. 140). The framework is horizontal in nature; patient/learner centered instead of one party instructing knowledge on another. The principles of this theory are related to the patient centered care approach with CAM, as well as provider continuing education regarding CAM. Winslow and Shapiro (2002) found that clinicians are learning alongside their patients when it

comes to the safety and efficacy of CAM therapies. They found 60% of clinicians expressed a desire to learn more about CAM.

The andragogical perspective of Knowles' learning framework transforms the learner from having a self concept of dependent behavior to an autonomous independent individual. A rich resource for learning is developed from past experiences. The learner's social role development supports an increasing orientation for readiness to learn. The learning process is changed from subject oriented to problem centered and a delayed application of knowledge is changed to immediate application. The perspective of time changes in these processes enabling the learner to apply their knowledge to the problem (Bastable, 2003).

Patient centered communication is intended to improve the patient-provider relationship.

When this is applied to communication regarding CAM usage it:

- 1. Results in a closer agreement between clinician and patient about treatment plans,
- 2. Reduces misunderstandings between patients and clinicians,
- 3. Uncovers potential herb-drug interactions,

- 4. Strengths the quality of the patient-clinician relationship, and
- 5. Provides an opportunity to discuss specific CAM modalities with high-quality evaluative evidence (Shelley, Sussman, Williams, Segal & Crabtree, 2009, p.140).

These theories provide a framework to guide interventions that improve communication between the patient and provider to offer the best healthcare outcomes. The theories encourage conventional health care professionals to obtain sufficient knowledge and understanding of CAM philosophies in order to provide high quality, evidence based advice to patients.

Process

In order to learn more about CAM therapies and communication with providers, a literature search was performed utilizing several databases and keywords. The words "attention deficit hyperactivity disorder" and "ADHD" were used as keywords in combination with "CAM", "complementary and alternative medicine", "dietary supplements", "nutrition", "fatty acids", "megavitamin supplements", "homeopathy", "communication", "food additives", "elimination diets", "stimulants", "medication side effects", "providers", "prevalence", "provider education". The search was conducted using the UND Harley French Library. Pubmed, Cinahl and the Cochrane Library data bases were used.

Review of Literature

ADHD and CAM Therapies

CAM use for ADHD treatment is becoming increasingly popular. In fact, due to increasing CAM use among adolescents, the National Institute of Health has funded many ongoing studies to determine the efficacy of different types of CAM (Tilburt, Curlin, Kaptchuk, Clarridge, Bolcic-Jankovic, Emanual & Miller, 2009).

Sinha & Efron (2005), sent families a 20 point questionnaire regarding the use of CAM. . The results of the study established the most common used CAM therapies as: modified diet, vitamins/and or minerals, dietary supplements, aromatherapy and chiropractics. The most frequent factors rated as important in choosing CAM therapy were minimizing symptoms, adding to the benefit of conventional treatment and avoiding side-effects. Sixty-four percent of families reported that they informed their pediatrician of their CAM use.

The assessment of the efficacy of zinc sulfate in the treatment of ADHD is established in a study by Bilici et al. (2003). Bilici's study suggests that zinc has a substantial role on ADHD.

The study results reflect that zinc sulfate was statistically superior to placebo in reducing hyperactive, impulsive, and impaired socialization symptoms but not in reducing attention deficiency symptoms.

Multiple studies have found that children with ADHD have lower levels of essential fatty acids (Belanger, 2009; Curtis & Patel, 2008; Ng, Meyer, Reece & Sinn, 2009; Raz & Gabis, 2009). Though some do not note a decrease in symptoms with an increased intake (Ng, Meyer, Reece & Sinn, 2009), other studies noted a reduction in ADHD symptoms with supplementation and special diets (Harding et al, 2003; Raz & Gabis, 2009; Belanger, 2009; Curtis & Patel, 2008).

In a review by Curtis and Patel (2008) regarding nutritional and environmental approaches to preventing and treating ADHD, they found that many, but not all, studies link exposure to toxins such as mercury, lead, pesticides, and in-utero smoking exposure to higher levels of ADHD. Some studies reviewed by Curtis and Patel reported many nutritional deficiencies in ADHD patients. Numerous studies also reported that supplemental nutrients such as omega 3 fatty acids, vitamins, zinc, magnesium and phytochemicals may provide moderate benefits to ADHD. Avoidance of food allergens, food chemicals and chelation therapy may also provide some relief to ADHD patients. ADHD is a complicated condition in which nutritional and environmental factors play major role. Curtis and Patel encourage larger studies to determine optimum treatment plans involving nutrition, environmental control, medication and behavior/education/speech/physical therapies.

In a study evaluating the comparison of Ritalin versus food-supplement treated children with ADHD, there was a sample size of 20 children with ADHD, 10 children were treated with Ritalin, and the other 10 were treated with dietary supplements (Harding et al., 2003). The study

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supports the effectiveness of food supplement treatment in improving attention and self-control in children with ADHD and suggests that food supplementation in ADHD may be of equal efficacy to Ritalin treatment. "The neurobiological etiology of ADHD has been postulated to be associated with deficiencies in catecholamines, such as norepinephrine and dopamine, with little discussion concerning the physiological origins of the multifaceted mechanisms required to generate such neurotransmitters, Likewise, the therapeutic effect of Ritalin is thought to be linked to its effects on norepinephrine and dopamine. In contrast to this view of neurotransmitters as isolated variables that exist independent of the whole organism, this study protocol attempted to restore and regulate neurotransmitters in test subjects by supplementing the diet with amino acid precursors likely to be deficient in the subject as determined by symptoms" (Harding et al., 2003, p. 320).

Bussing et al. (2002) sought to determine the lifetime use of CAM and the parent's perspective of the effectiveness of CAM for ADHD. Bussing et al. (2002) describes the use of CAM in ADHD adolescents and explores the possible predictors of choosing CAM to treat ADHD in adolescents. The study examines the likeliness of parents to inform their health care provider of CAM usage due to the dismissal of the medical community from lack of scientific evidence. According to Bussing et al. (2002), as potential complementary and alternative medicines are being researched and slowly being understood, health care providers should have a common practice of asking patients about CAM. The use of complementary and alternative medicine was significantly higher among children who had received a diagnosis of ADHD.

Nontraditional treatments were more likely to have been used among children with a diagnosis or a suspected diagnosis of ADHD and those whose parents used the Internet as a source of information than among other children (Bussing et al., 2002). "Because nontraditional treatments

are not addressed in professional ADHD practice guidelines or parameters, these sources provide no guidance on the clinician's role in eliciting information on use of CAM or in counseling parents on the efficacy or potential harm of such interventions" (Bussing et al., 2002, p. 1097).

Provider to Patient Communication

In a retrospective study done by Flannery, Love, Pearce, Luan and Elder in 2006, Kentucky ambulatory primary care clinicians were given a survey regarding their perspective of communication about CAM. It was a retrospective study of self-administered surveys. The study investigated how primary care clinicians communicate with patients about CAM and determined interest in additional education about CAM. The study found that clinicians are aware of their patients' CAM use, although they also report few clinicians consistently asked their patients about CAM. It was shown that clinicians who describe themselves as comfortable in advising patients about CAM are more likely to inquire explicitly about CAM use. The survey found a positive attitude towards CAM from clinicians. Seventy percent of the clinicians expressed interest in continuing education about CAM (Flannery, Love, Pearce, Luan & Elder, 2006).

The purpose of the study by Winslow and Shapiro was to distinguish how clinicians discussed CAM with their patients and the factors that influence discussions and referrals. The study was done by issuing a survey to Denver, Colorado physicians regarding their retrospective experiences with their patient CAM usage and their educational experiences with CAM. The authors concluded physicians do not routinely inquire about their patients' usage of CAM therapies. Inquires that were made regarding CAM were related to a higher comfort level with the modalities of CAM. Physicians also

felt that they are aware of CAM usage among their patients due to patient self-disclosure (Winslow & Shapiro, 2002).

Education of Providers

Tilburt, Curlin, Kaptchuk, Clarridge, Bolcic-Jankovic, Emanual and Miller (2009), conducted a survey to determine whether clinicians were aware of current clinical trials regarding CAM therapy and whether the clinicians felt they were confident in interpreting research results. They found the ultimate clinical impact of clinical research in CAM depends on the training, attitudes, and experiences of the clinicians who could translate research results into clinical practice. Compared with conventional clinicians, CAM provider expressed much less research experience and less regard for trial results in their clinical decision making. Internists and rheumatologists reported the most comfort level in interpreting clinical research. Before health care professionals can be motivated to learn about and accept scientific research, they must believe it is useful (Tilburt et al., 2009).

In a review by Gaylord and Mann (2007), rationales for the implementation of educational programs about CAM for conventional health professional training programs were explored. They found a disconnection between patient-practitioner communication regarding their CAM usage. Patients give the following reasons for not discussing their CAM use with conventional practitioners: (1) the belief that it was not important for the doctor to know, (2) the doctor never asked, (3) it was not the doctor's business, (4) the doctor would not approve, (5) the doctor would disapprove, and (6) the doctor would discourage use (Gaylord & Mann, 2007). The review also discusses the short comings of the educational system for conventional practitioners. Practitioners have inadequate knowledge of CAM therapies leaving health care

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responsibilities in patients' hands. Patients are often forced to navigate the conflicting claims and recommendations of different providers, compensate for the poor communication among caregivers, and contend with limited information from the Internet and other media (Gaylord & Mann, 2007). When the patient is left to be the ringleader for their care often times conventional and CAM practitioners are not adequately informed about each other's therapeutic approach or about interactions of treatment. The break in communication potentially creates great inefficiencies, such as drug-herb interactions, duplication of therapies, lengthy searches for the correct treatment, and multiple diagnostic procedures (Gaylord & Mann, 2007).

Patient to Provider Communication

In the study done by Shelley, Sussman, Williams, Segal and Crabtree (2009), they sought to uncover the factors influencing communication between patients and their primary care clinician about CAM. This is a retrospective study including focus groups, in-depth interviews, and a video vignette conducted in Research Involved in Outpatient Settings Network. There were three themes that emerged from patient interviews on the degree to which they communicate with their clinician regarding CAM usage: (1) acceptance/judgment, (2) initiation of communication and (3) safety/efficacy. The patients' perceived clinician expertise in CAM was less important. Influencing factors regarding clinicians/ communication about CAM with their patients were related to their comfort with patients' self-care approaches and their level of concern about lack of scientific evidence of effectiveness and safety of CAM.

Parent-pediatrician communication regarding CAM use for children is investigated in a study done by Sibinga, Ottolini, Duggan and Wilson (2004). This was a retrospective study of anonymous self-report surveys of a convenience sample of

caregivers accompanying children to the pediatrician for acute or well visits at 4 pediatric practices in Washington, DC from July to November in 1998. The use of CAM in caregivers was 21% for their children. "Overall, 53% of parents expressed the desire to discuss CAM with their pediatrician, increasing to 75% among those who used CAM themselves and 81% among those who used CAM for their child. Among parents who used CAM for their child, 36% had discussed it with their pediatrician" (Sibinga, Ottolini, Duggan & Wilson, 2004, p. 367). CAM use in children younger than 6 years, bioenergetic CAM use and parent CAM non-use were all factors associated with increased disclosure to the pediatrician (Sibinga, Ottolini, Duggan & Wilson, 2004).

Discussion

Outcome/Dissemination

It is clear that there are multiple CAM therapies available for patients with ADHD. It is also apparent that communication with health care providers about these therapies is lacking. An informational brochure was created in order to present providers with information about CAM, available resources and to encourage open communication with patients regarding the use of CAM. The brochure was created to bring awareness to providers that their patients are using CAM for ADHD treatment and to encourage more communication - since patients may not voluntarily offer this information.

The brochure, titled "CAM Use in ADHD: A Resource for Providers" (Appendix) lists background information about ADHD and CAM, outlines the most common types of CAM used in ADHD treatment and discusses some of the reasons for communication barriers between patient and provider. It also lists website resource from the National Center for Complementary and Medicine (NCCAM) supported by the National Institute of Health. If more information is

available to encourage conventional health care professionals to obtain sufficient knowledge and understanding about CAM, this will promote high quality, evidence based care of patients with

The brochure was disseminated to four pediatric providers in a rural clinic in Bemidji, MN. The pediatricians as a whole did not feel their patients, particularly ADHD adolescents, use CAM therapies in their practice. Interestingly, in a discussion with one pediatrician, it was noted that although she does not routinely ask about CAM therapies during visits, she still believes parents usually ask about the safety and efficacy of CAM products before their use. This provider also felt that the treatment of ADHD of her patients is not being supplemented with CAM therapies (Dr. A. Masajo, personal communication, April 25, 2011). It is evident with this exchange that further education is needed in order to educate providers about the prevalence of CAM use and to increase communication between patients and providers regarding CAM therapies.

Implication for Nursing Practice

The need for increased communication, education and research in CAM therapies is evident. The lack of communication creates a barrier to continuity of care, increased risk of adverse effects and duplication of diagnostic testing. It has been noted there are multiple reasons patients do not reveal their use of CAM to providers. Patients feel the provider isn't educated regarding CAM, it is looked down upon the medical community and their provider doesn't believe in it. Communication of the provider to patient is also investigated with barriers related to lack of proven safety and efficacy, lack of adequate knowledge base to advise patients and drug-herbal interactions.

There is a need for education and research for providers and patients regarding CAM therapy. The usage of CAM is increasing in all aspects of health promotion and disease prevention. It is essential that providers are given the tools to research new and evolving CAM therapies. The ability to offer the most up to date recommendations regarding safety and efficacy of CAM therapies is very important. Providers can obtain more knowledge about CAM through a variety of sources including: the informational brochure offered here, web resources and journals. It would also be useful to promote the integration of CAM therapies into health professions curriculum.

Practice

Providers need to be aware of all medications that their patients are taking - including herbal supplements. The use of CAM - especially in younger patients should be discussed with health care providers. Providers should educate themselves on the efficacy and acceptance of various CAM therapies and try to create an environment where patients feel comfortable discussing these therapies. With more knowledge, providers may be able to offer recommendations when parents are reluctant to use stimulant medications or children have side effects with the medications.

Research

The use of CAM for the treatment ADHD is being widely used in place of traditional medications or in conjunction with traditional medications (Dayhew, Wilkinson & Simpson, 2009). There is a need for further research in this field. Clinical research in CAM is dependent on the training, attitudes, and experiences of the clinicians who translate research results into clinical practice. The belief that scientific research is of value must be established before conventional providers will be motivated to learn and accept its use.

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There are significant barriers to the awareness of clinical research in CAM. Intensive efforts will need to be approached to train clinicians in the use of evidence based resources and the dissemination of the research results. This is imperative for research to be applied to clinical practice.

Education

The addition of CAM education into the mainstream of health professionals training can lead to overall improvement in patient satisfaction. It will offer expanded treatment options for chronic diseases and health prevention and raise health care standards. The increased awareness and education will improve three way communication between conventional providers, CAM practitioners and patients. This advancement in awareness and education will expand treatment options, improve patient outcomes, reduce adverse reactions and enhance clinical and basic research in CAM therapies (Gaylord & Mann, 2007).

Gaylord and Mann (2007) suggest broadening core competencies in conventional health professions schools' curricula. CAM therapies fit into core competencies within the curricula such as: medical knowledge, professionalism, interpersonal and communication skills. The broadening of these areas will serve as an opportunity for conventional providers to increase their awareness and train in the safety, efficacy and communication with patients regarding CAM therapies.

Health Policy

Kreitzer, Kligler and Meeker (2009) made several suggestions regarding health policies at various levels. It is suggested that a group of representatives of the accreditation bodies for licensed health professionals supported by HRSA be charged with developing core competencies in integrative care for all health profession students. Reimbursement and incentive structures

should be created for conventional and licensed CAM health professions through legislation and regulation at the federal and state level. This will facilitate the advancement of reform and innovation in the healthcare system. At the state level, legislation and regulation should be enacted to facilitate advanced practice nurses and CAM providers to safely practice at the full potential of their license and scope of practice. A national strategic vision should be developed to implement new workforce planning based on new models of care encompassing conventional and licensed CAM providers.

Recommendations for Further Studies

The fact that many parents and patients with ADHD choosing to use CAM by itself or in conjunction with traditional medication do not inform their health care provider of their use is troubling. Many different CAM therapies can be used improperly and have interactions with traditional medications; patients must inform their health care provider to ensure they are receiving the best care possible with their treatments of choice. Guidelines in the use of CAM therapies must be established for providers. The production of guidelines to the use of safe and effective CAM therapies will bring acknowledgement and acceptance by the medical community. This will in turn take down the barriers of communication between providers and patients.

Conclusion

In conclusion, CAM use is increasing – especially for the treatment of ADHD symptoms. Many patients are seeking other options due to the side effects of conventional medication. Many CAM therapies are considered unsafe, making communication a necessity. It has never been more important to increase knowledge and awareness of available therapies and to address communication barriers between patient and providers. Encouraging providers to talk with their

patients about CAM, as well as providing them with information and resources is an important job. It is evident that provider education is lacking in regards to CAM therapies. Providers are in need of further education regarding the efficacy of CAM and a widened knowledge base of CAM practices as well as possible drug-herbal interactions. There are also patient barriers regarding communication of CAM with their providers. These include: past experiences, attitudes and misconceptions. Continued support and education in order to increase awareness of CAM use in patients with ADHD is necessary to provide safe evidence-based health care.

Appendix

Background

- √4-5% of adolescents suffer from ADHD in America, with variations across state and socioeconomic groups.
- ✓ Research and use of CAM is growing.
- Many parents are seeking other treatment options due to the side effects of the stimulant medications used to treat ADHD.
- ✓There is a need and a demand for more education, and clinical guidelines for CAM therapies.
- ✓ Many CAM therapies are considered unsafe, making communication a standard of care a necessity.

RESOURCES

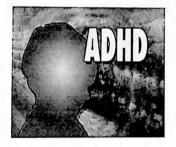
- The National Center for Complementary and Medicine (NCCAM) supported by the National Institute of Health:
- ✓ Provides evidence based research
- ✓ Practice guidelines
- Safety and efficacy in the use of CAM for various diseases and health prevention.
- ✓ Drug-herbal interactions.
- Offers grants to fund CAM research, career development opportunities and continuing education lectures/workshops that provide CME/CEU credits.

Website:

www.nccam.nih.gov

CAM Use in ADHD: A Resource for Providers

Angela Seitz, College of Nursing University of North Dakota, Grand Forks, ND



Common Types of CAM used in ADHD

- ✓elimination diets
- ✓ dietary supplements
- √herbal regimens
- ✓homeopathy
- √ massage

- √acupuncture
- √biofeedback
- ✓religious approaches such as faith healing

Communication Barriers

- Reasons providers not to inquire about CAM usage:
- ✓ lack of availability of information on proven efficacy
- ✓lack of an adequate knowledge base in CAM from which to advise patients
- ✓ concern about possible herb-drug interactions.

- Reasons patients not to communicate their CAM usage:
- ✓Past experiences
- **✓**Attitudes
- ✓ Misconceptions

Goals

Encourage conventional health care professionals to obtain sufficient knowledge and understanding of CAM philosophies and practice to provide high quality, evidence based advise to patients.

Improve communication between the patient and provider to offer the best healthcare outcomes.



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