

KNOWLEDGE OF CLINICAL ASSESSMENT OF FETAL ALCOHOL SYNDROME: HOW
MUCH IS TAUGHT IN A PA SCHOOL CURRICULUM?

A Research Project by
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We hereby recommend that the research project prepared under our supervision by Michelle Hinkle entitled Knowledge of Clinical Assessment of Fetal Alcohol Syndrome: How much is Taught in a PA School Curriculum? be accepted as partial fulfillment for the degree of Master of Physician Assistant.

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DEDICATION

To my best friend and soon to be husband, Jason: Thank you for all your love, support, and patience this last year. And to my mom, who never stopped pushing me to finish strong

Every child has the right to earn whatever degree of independence he or she is capable of without jeopardizing the loss of that independence. The child also has a right to safety and quality of life.

It is crucial to be able to recognize the limitations without losing hope of fulfilling the child's potential, in order to find the balance that offers the greatest chance for success.

Teresa Kellerman, author, *Broken Beaks and Wobbly Wings*

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ABSTRACT

The effects of maternal alcohol use on unborn children have been observed for millennia. These effects include abnormal facial variations, growth retardation, neurological or behavioral problems, decreased cognitive functioning, poor socialization skills, and attention and distractibility problems. Patients may have any degree of symptoms, from mild to severe, or any combination thereof, thus presenting health care providers with the dilemma of correct diagnosis. The purpose of this study is to evaluate the curricula of the Physician Assistant education programs regarding clinical assessment, diagnosis and treatment of fetal alcohol syndrome.

Design – Cross sectional, evaluative survey. **Participants** – all US PA programs. Measurement - A responder from each PA program [either Director or faculty member] was asked a series of 5 questions concerning knowledge of the disorder, diagnosis and treatment, and adequacy of the training provided. **Data Analysis** - Data was collected and analyzed using standard statistical estimates. **Results** -69 programs responded to the survey, for a response rate of 51.1%. Most PA programs (94%) believe there is a need for FAS education in PA schools. Although the majority of the programs that responded did so in the affirmative to our questions, the average total time spent talking about FAS in the classroom was only 0.873 hours. This is likely not enough time to adequately explain all of the subtopics and special issues concerning FAS that were addressed in the survey instrument, and may also indicate that PA students are not getting the quality of education needed to diagnose FAS. Limitations of this study may include inadequate number of responses, unknowledgeable responder, intentional false answering, and/or design error.

PREFACE

“The patients who need the most help are the ones who are the most helpless.” With my heart I believe in this quote. In an effort to help these patients, I focused on a certain group, unborn babies, the most helpless of all, and how the effects of maternal alcohol intake can affect them. Only when all providers are made aware of how serious the problem is, can it be addressed and hopefully prevented. This knowledge should be given at the beginning, when the providers are still in school in order for it to be the most beneficial. This is why I chose to see how much is really being taught to PA students, in hopes that, after seeing my data, future researchers may be able to improve upon the curricula that are currently being taught.

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INTRODUCTION

The science and practice of medicine is constantly changing as our understanding and knowledge of diseases and conditions expands. One example is the effects of maternal alcohol use on embryonic and fetal development, or, Fetal Alcohol Syndrome (FAS). While not actually described as a syndrome until 1973,¹ the effects of maternal alcohol use on unborn children have been observed for millennia, even by patriarchs in medicine such as Aristotle and Plutarch.² Today, health care providers consider several characteristics of each patient before making a diagnosis of FAS. These include abnormal facial variations, growth retardation, neurologic and behavioral problems, decreased cognitive functioning, poor socialization skills, attention and distractibility problems, and psychiatric problems.^{3,4} The variation of facial features that may be seen include: a short palpebral fissure, an indistinct philtrum, a flat upper lip with a thin vermilion border, flat midface, and a short nose.⁵ (See Figure 1) FAS children often have abnormally low birthweights, failure to gain and/or maintain appropriate weights, and disproportional weight to height ratios. The spectrum of neurologic or behavioral problems noted in patients with FAS will affect both patient and family, as well as future teachers, friends, co-workers, and spouses. In fact, it is reported that teachers have a more difficult time teaching FAS babies, and that they have a harder time paying attention, participating in class, and learning the coursework than do other children.⁶ A study by Sood in 2001 suggests that children with any (meaning less than 0.5 oz per day based upon a maternal blood alcohol screening test) prenatal alcohol exposure were 3.2 times as likely to have delinquent behavior⁷ compared to children with absolutely no prenatal alcohol exposure.⁸

While some of these characteristics are easy to see, patients may have any degree of symptoms, from mild to severe, or any combination thereof. This presents health care providers

with the challenge of making a correct diagnosis. In a 2002 survey of physicians regarding their knowledge of FAS, only 8% were able to identify the three most important features associated with FAS, even when provided with a list of all associated features.⁹ When the physicians were asked about their own perceived competency at diagnosing FAS, 81% felt that their training was inadequate.⁹ Other studies by Abel,¹⁰ Morse,¹¹ and Brewster¹² have supported this finding, showing consistency in the general idea that physicians are not properly trained to diagnose this easily preventable disease.

A number of factors have been suggested regarding the reluctance of primary care providers to screen for FAS. These may include, but are not limited to, inadequate training to make the diagnosis, time involved in the comprehensive maternal screening, possible litigation for incorrect diagnosis as well as lack of treatment options or support services in that geographical area once a diagnosis is established.^{9, 13, 14}

To make up for these identified training deficits, there have been policy initiatives and new curricula have been created and implemented by various medical schools, but there is still a lack of diagnoses by practicing physicians.⁹ Also, various educational courses have been developed by the Center for Disease Control (CDC) for health care providers that address one or more aspects of FAS diagnosis, treatment, and prevention.¹⁴ However, these are new, and not yet in many areas of the country, and to date, no cumulative global curriculum has ever been created. In 2002, the CDC implemented FAS regional training centers (RTCs) with the goal of identifying a comprehensive set of core competencies that would be the foundation for a variety of educational and training programs.¹⁴ These RTCs are currently provide educational programs that will facilitate training of healthcare providers in the diagnosis, treatment, and prevention plan of FAS.

Despite these efforts, the incidence of FAS in the US is estimated to be 9.1 per 1000,¹⁵ while annual costs of FAS patient care is estimated to range from \$74.6 million to \$9 billion.¹⁶⁻¹⁸ Another study suggests that the total lifetime cost for a child with FAS born in 1980 ranges from \$596,000¹⁸ to as high as \$1.4 million.^{17,19} Although this cost is likely to be covered by a private insurance plan, it is well known that a lower socioeconomic status correlates with increased incidence of FAS,¹⁶ meaning that Medicaid or some other government insurance plan is picking up the tab, putting more strain on the United States (US) budget. The results of a study by Klug and Burd demonstrated that the prevention of one case of FAS through prevention programs would result in a yearly savings of \$2,342.²⁰ Extrapolating their findings, they stated that by preventing one case of FAS per year in North Dakota (the state in which they were conducting their research), there would be a savings of \$128,810 in 10 years.²⁰ Based on this information, it is clear that prevention and early diagnosis can reduce the cost of FAS for the patient as well as for taxpayers.

REVIEW OF LITERATURE

Review of literature was undertaken using Medline, FirstSearch, and ERIC databases from 1973, when FAS was first recognized, to the present. The search was conducted using the keywords fetal alcohol, education, knowledge, physician, physician assistant, and curriculum. A majority of the studies that have already been done concerning healthcare providers addressed multiple specialties within healthcare, including family physicians, pediatricians, obstetricians, and nurse practitioners, but in regard to physician assistants (PAs), no studies have been completed. Rather than assuming that the data concerning physicians' awareness of FAS holds true regarding physician assistants' awareness of FAS, the lack of data gives cause to further

investigation. As an initial step in addressing PA awareness and knowledge regarding FAS, a survey was conducted of PA educational programs to identify what is being taught in PA education programs regarding clinical assessment, diagnosis and treatment of fetal alcohol syndrome.

METHODOLOGY

Design

This cross-sectional, evaluative study was administered through the Department of Physician Assistant at Wichita State University between November and December 2006. The survey utilized was a condensed version of one previously used and approved by the Center for Disease Control (CDC), and consequently already peer reviewed and approved as valid.^{6,21} See Appendix for a full version of the survey instrument used. The Physician Assistant Education Association (PAEA) provided assistance with identification of the United States PA educational programs to be surveyed. This project was also approved by the Internal Review Board (IRB) at Wichita State University and the IRB of the PAEA.

Methods

This survey was originally conducted via the internet. An e-mail was sent to each of the PA school's program directors. It asked that either the program director, or one faculty member, presumably the one most knowledgeable concerning the FAS curriculum, click on the link listed to answer the survey questions. After 2 weeks, only 2 responses had been completed and electronically returned. A reminder e-mail was then sent. After another 2 weeks, only 3 more surveys had been completed. At this time, a new method was formulated. The survey was subsequently conducted via telephone. It was presented to the Program Director, who either

chose to answer or deferred to a faculty member in charge of that part of the curriculum. This was determined by each program director, so that the responder was someone most familiar with the program's curricula and how much is being taught to current students. The responder from each PA program was asked a series of 5 questions concerning knowledge of the disorder, diagnosis and treatment, and adequacy of the training provided.

All PA program directors in the US were contacted by telephone. If the program director was not available, a message was left to return the call to the research team. After two weeks, if no response was received, a second call was placed to the program director. If the director was unavailable, a second message was left. If no response was returned following another two week waiting period, the attempt was considered unsuccessful. After the second unsuccessful attempt, no further attempts were made to contact that program, and that program was considered to be a non-responder.

RESULTS

Sixty-nine programs responded to the survey, for a response rate of 51.1%. In response to the first question, regarding the need for FAS education in PA program curriculum; 65 (94.2%) programs stated "yes"; 4 (5.8%) programs stated "no". In response to question two, regarding formal training in the following FAS competencies; 38 (55%) programs answered "yes" to all subtopics. The subtopics that were most frequently included in all the program's curricula that responded included: the ability to educate pregnant women about the effects of alcohol on their babies" (95.7%), the ability to plan and perform clinically relevant treatment and management plans to assist and aid both the patient with FAS and their families (88.4%) and the ability to recognize the constellation of features associated with FAS and other alcohol-related effects" (85.5%). The subtopics that were most frequently not taught in schools included the

ability to assist clients in accessing local FAS-related resources, including family support (31.9%); demonstration of the ability to provide ethical protections to the patient with FAS regarding confidentiality and autonomy (26.1%), and the ability to conduct alcohol cessation brief interventions (17.4%). (See Figure 2 for a complete listing of responses.)

Question 3 addresses specific issues associated with fetal alcohol syndrome, and which, of these listed, were taught by each program. Of the issues associated with FAS, the most commonly taught were birth defects and malformations (95.7%), delayed development (92.8%) and low birth weight (92.8%). The most common issues not included in the curricula about FAS were found to be: legal problems (29%), addictions (14.5%), and attention deficit hyperactivity disorder (14.5%) with behavioral problems (13%) not too far behind. See Figure 3 for a complete listing of responses.

For Question 4, the opinion of the responder was sought, regarding the overall adequacy of the training of FAS in his/her PA program curricula. Responses to this question varied, with the highest response being “Good” (72.5%) followed by “Fair” (15.9%), and only 5.8% of surveys responded “Excellent”. (See Figure 4)

The survey concluded with the following question: “How many in-class hours does your program dedicate specifically to FAS?” Responses to this question were also highly variable, ranging from 0 hours (10.1%) to 2 hours (5.8%), with the most frequent response being 1 hour (29.0%), and the mean time spent being 0.873 hours. (See Figure 5)

DISCUSSION

From the survey results it is easy to see that most PA programs (94%) believe there is a need for FAS education in PA schools. This is a good start. However, with the number of

undiagnosed cases in the US, there could be some correlation between this inadequacy of PA training and further studies should be conducted. Although the majority of the programs responding to the survey did so in the affirmative to our questions, the average time spent talking about FAS in the classroom was only 0.873 hours. In order to address all of the 23 special issues associated with FAS recorded in our survey instrument, each subtopic would only be given 0.038 hours, or 2.28 minutes. This is unlikely to be enough time to adequately explain all of the subtopics and special issues concerning FAS that were addressed in the survey instrument.

Programs like the FAS Regional Training Center's implemented by the CDC have been created out of necessity to make up for this lack in education. The findings of this study are important and may have an impact on the future curricula of PA schools. From a larger perspective, this training deficit may be corrected, and may spread to the curricula of nurse practitioners and physicians, and could globally change the FAS protocols followed today.

Our study has several limitations. Although the 51.1% response rate is consistent with normative values for physician survey research and respondents represented members of the PAEA, our findings may not represent all PA programs. It is possible that responders with greater interest in FAS were more likely to complete the survey. Also, this survey was limited to one responder from each program, rather than all faculty members, so some information could have been lost. The question regarding whether FAS should be included in the overall curricula is an opinion of the responder and may not reflect the opinion of the overall program. Also, this survey does not address knowledge of practicing PA's, so the number of missed diagnoses may not be a fault of any PA, but other health care providers.

CONCLUSIONS

Applications to Physician Assistant Practice

The first step in treatment and management of FAS patients involves recognition of the disorder.²²

Fetal alcohol syndrome is the most prevalent birth defect, yet still, many cases are going unnoticed.

A PA who has undergone proper education in recognizing, diagnosing, and treating FAS may improve the quality of life for that patient for many years.

Recommendations

We recommend that all PA programs include in their curricula the basic principles of FAS diagnosis and management, including the abnormal facial characteristics, growth delay, and basic behavioral problems that patients might have.

Furthermore, PA's going into a primary care or pediatrics care clinic should strongly consider attendance at one of the CDC's training courses in order to better understand and more easily recognize and treat the syndrome so prevalent among America's children. This is especially recommended to those who do not feel they have received adequate training from their PA program and/or can not answer the basic questions related to FAS found in the survey instrument.

We recommend that PA's consider FAS when evaluating microcephaly, intrauterine growth retardation, developmental problems, hyperactivity, behavioral problems, and school failure, as FAS will provide a unifying diagnosis in a small percentage of these more common conditions.²³

Figure 1 - Abnormal Facial Features⁵

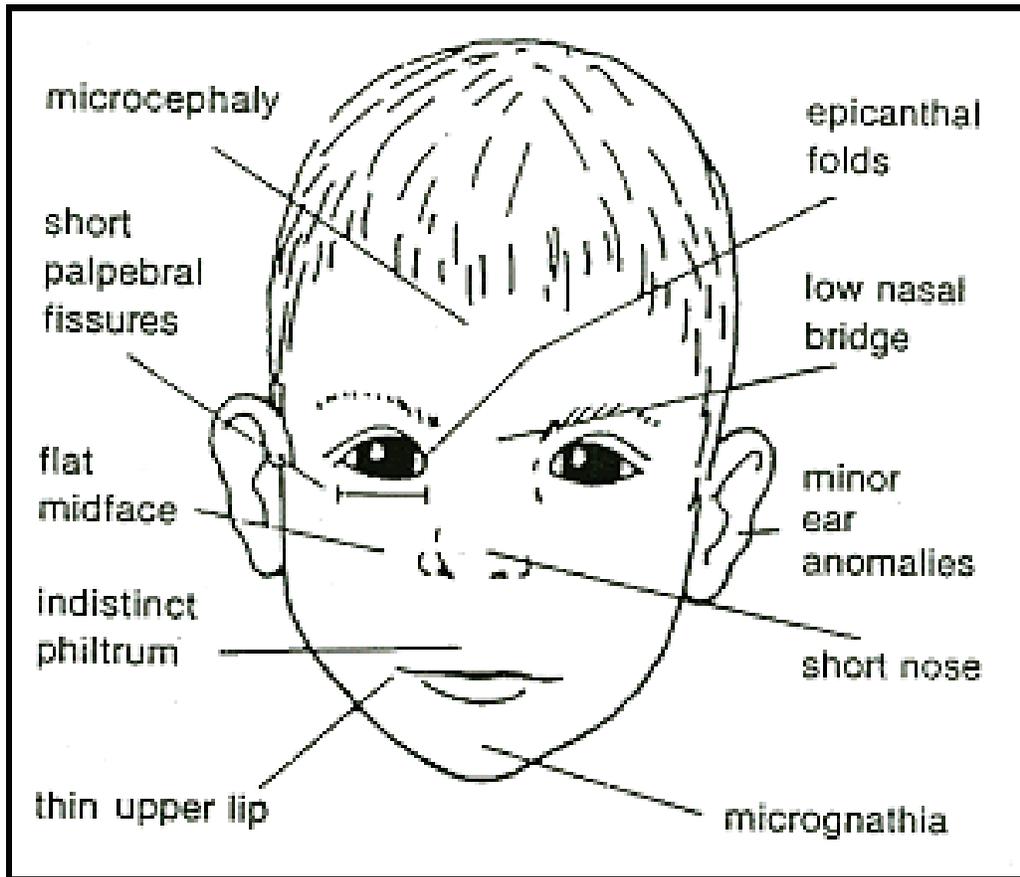
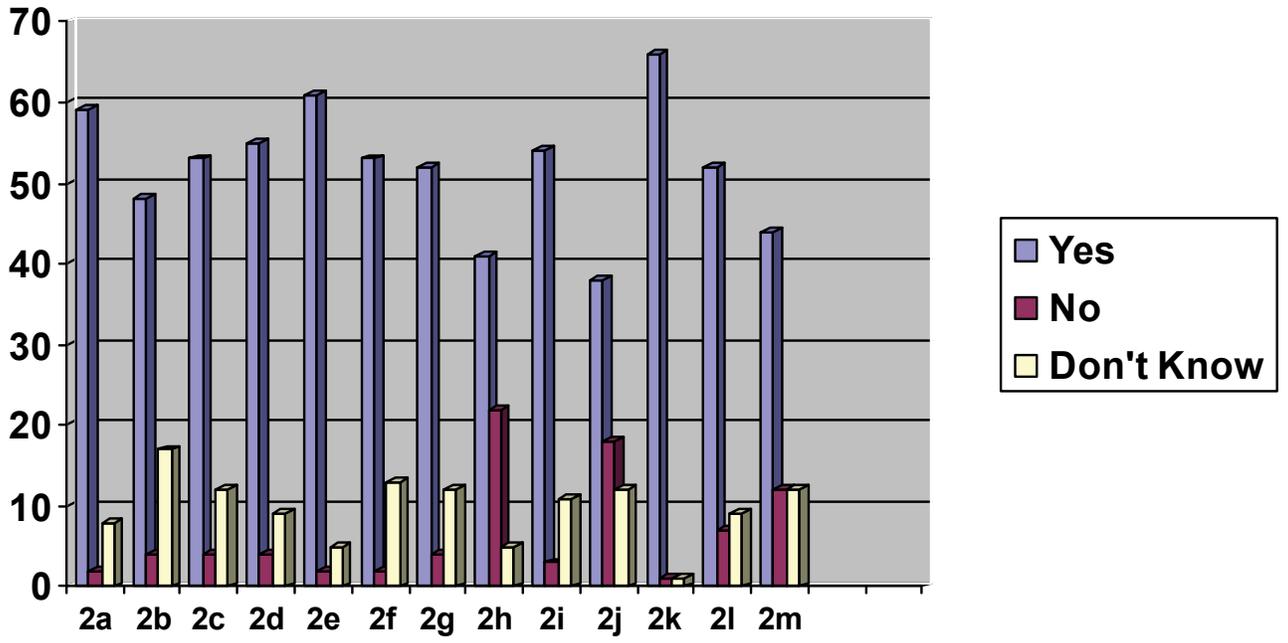
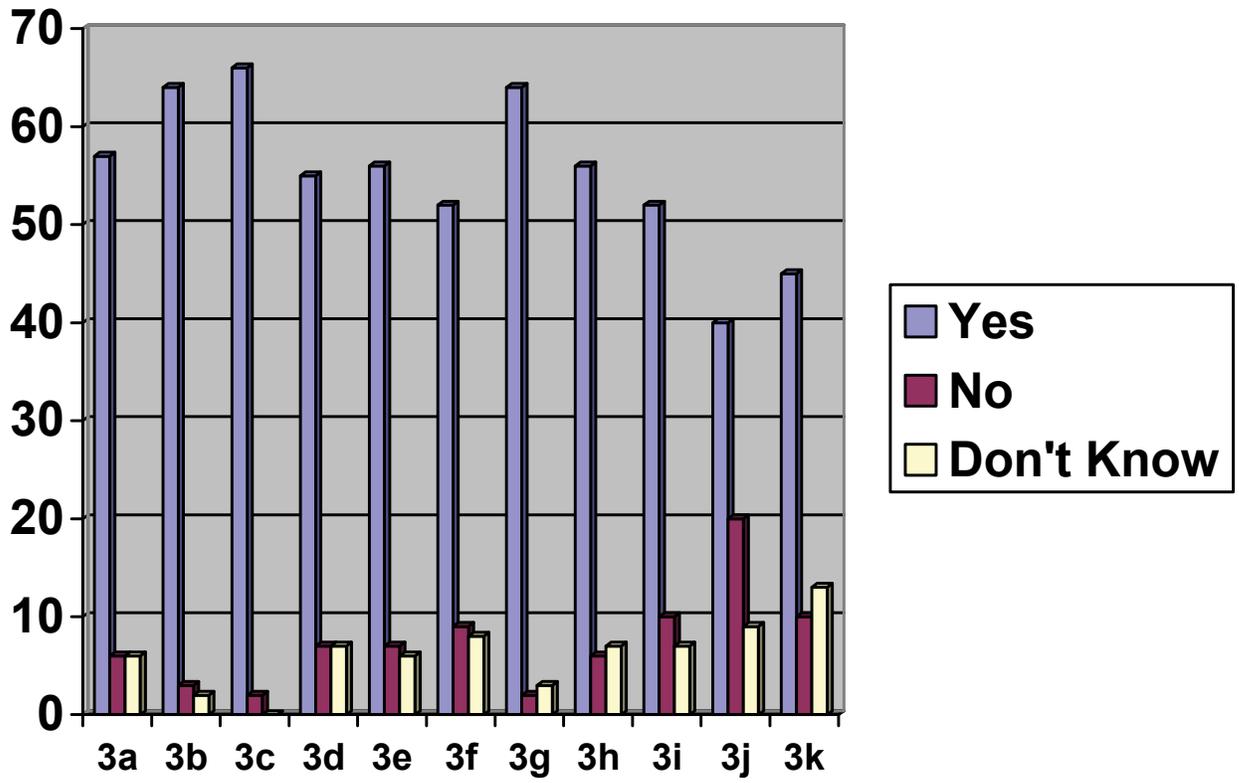


Figure 2



Question #2 Responses

Figure 3



Question #3 Responses

Figure 4

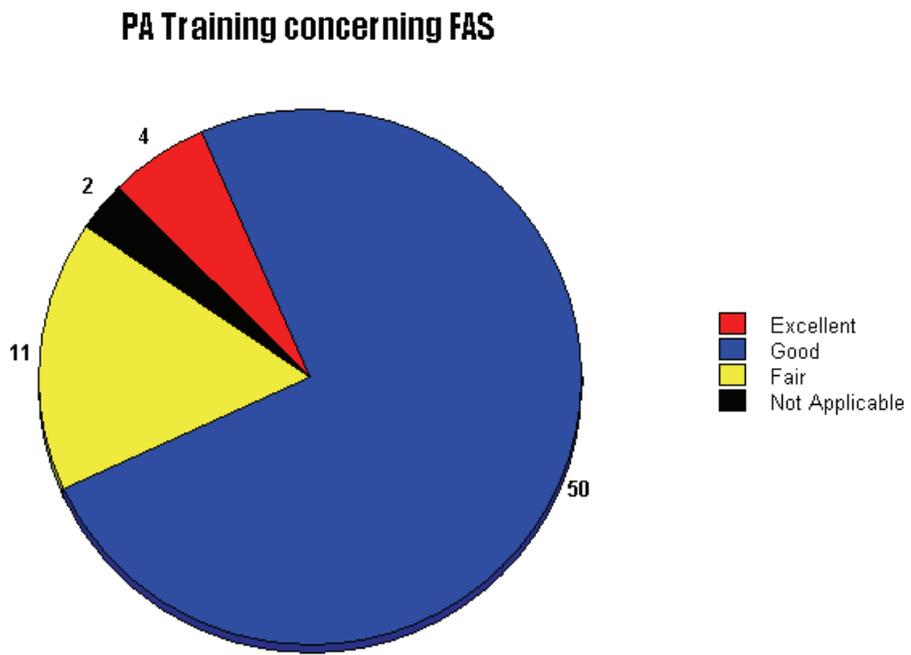
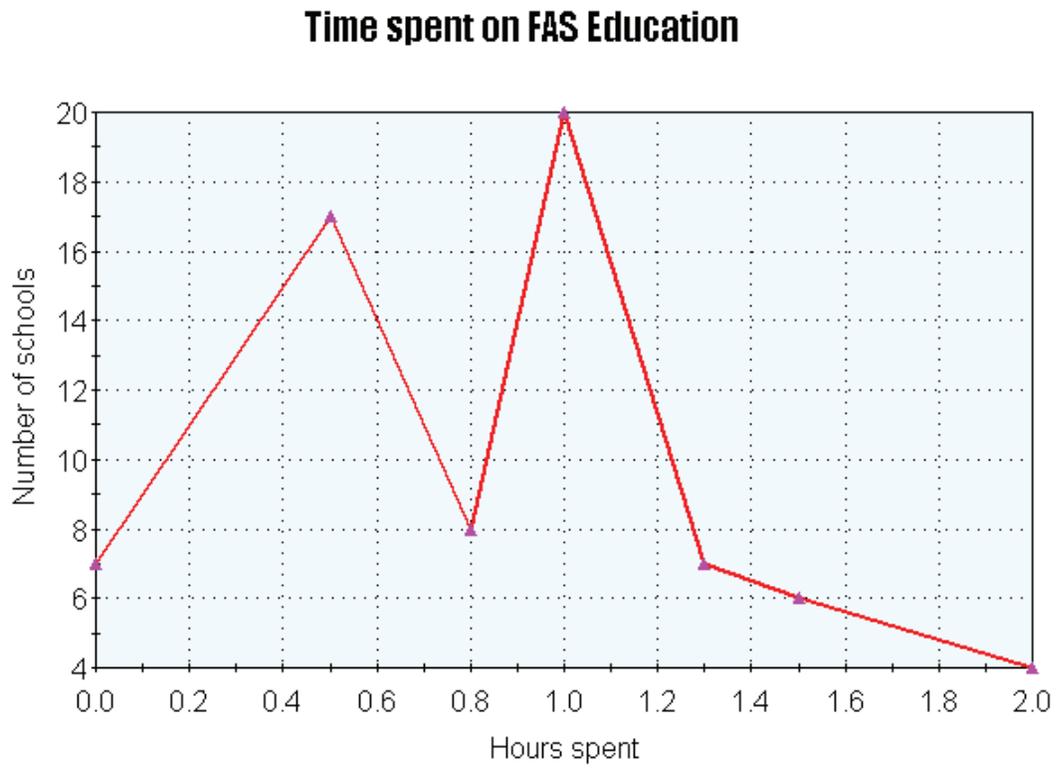


Figure 5



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APPENDIX

Complete Survey Tool

This survey asks for information regarding your program curriculum in the areas of: knowledge, attitudes and beliefs about diagnosis, treatment and prevention of Fetal Alcohol Syndrome (FAS) and other prenatal alcohol-related disorders. Please answer the questions by checking the option(s) of the appropriate response(s), or by filling in the blanks.

1. Do you think there is a need for FAS education in PA program curriculum?
Yes No Prefer Not to Answer

2. Do you provide your PA students with any formal training in the following FAS competencies?
 - a) Ability to recognize the constellation of features associated with FAS and other alcohol-related effects
Yes No Don't Know
 - b) Understanding of the basic biomedical mechanisms that result in FAS
Yes No Don't Know
 - c) Ability to select valid and reliable assessment instruments to screen for/diagnose FAS and other alcohol-related disorders
Yes No Don't Know
 - d) Ability to identify risk factors and interventions for secondary FAS disabilities
Yes No Don't Know
 - e) Ability to plan and perform clinically relevant treatment and management plans to assist and aid both the patient with FAS and their families
Yes No Don't Know
 - f) When appropriate, be able to make a referral for further workup in a child with FAS
Yes No Don't Know
 - g) Appreciation and ability to use interdisciplinary team evaluations for individuals with FAS
Yes No Don't Know
 - h) Ability to assist clients in accessing local FAS-related resources, including family support
Yes No Don't Know
 - i) Utilization of techniques for effectively communicating information to individuals with FAS, their family members, and care providers
Yes No Don't Know
 - j) Demonstration of the ability to provide ethical protections to the patient with FAS regarding confidentiality and autonomy
Yes No Don't Know
 - k) Ability to educate pregnant women about the effects of alcohol on their babies
Yes No Don't Know
 - l) Ability to screen women for risky or hazardous drinking
Yes No Don't Know

m) Ability to conduct alcohol cessation brief interventions
Yes No Don't Know

3. Are any of the following issues associated with Fetal Alcohol Syndrome, included in your curriculum?

Yes No Don't Know

a) Infantile withdrawal symptoms
Yes No Don't Know

b) Delayed development
Yes No Don't Know

c) Birth defects/malformations
Yes No Don't Know

d) Psychiatric (DSM IV) disorders
Yes No Don't Know

e) Lowered IQ/retardation
Yes No Don't Know

f) Behavioral problems
Yes No Don't Know

g) Low birth weight
Yes No Don't Know

h) Long term emotional disorders
Yes No Don't Know

i) Addictions
Yes No Don't Know

j) Legal problems
Yes No Don't Know

k) Attention deficit hyperactivity disorder
Yes No Don't Know

4. Overall, would you say that the training from your PA program curricula is:
Poor Fair Good Excellent Not Applicable (no training provided)

5. How many in-class hours does your program dedicate specifically to FAS?

Vita

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