

Standards of professional practice for genetic metabolic dietitians

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New discoveries in the field of genetics and recent developments in newborn screening have created opportunities and challenges for genetic metabolic dietitians, placing increasing demands on dietitians to plan appropriate nutritional interventions for patients with metabolic disorders. An appropriate assessment tool must be developed to identify gaps in training and knowledge to assure that dietitians are prepared for advances in this emerging field. Using a multistage process, the Genetic Metabolic Dietitians International founders group developed a set of professional standards modeled after the American Dietetics Association's Standards of Professional Practice and the National Coalition for Health Professions Education in Genetics's core competencies. The Standards of Professional Practice for Genetic Metabolic Dietitians were validated by means of an electronic questionnaire distributed nationally to dietitians through the PRO-METLAB listserv. Statistical measures were used to determine whether perceived importance was significantly associated with compliance for each of the indicators included in the Standards of Professional Practice. The Standards of Professional Practice for Genetic Metabolic Dietitians will be used to structure continuing education opportunities, guide research and evaluation, and will serve as a basis for certification and professional accreditation. **Genet Med 2008;10(4):290–293.**

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Completion of the Human Genome Project and technological advances in the field of genetics have led to vast improvements in gene mapping and sequencing. As a result, genetic tools are being used with growing frequency across the health care field.^{1,2} Historically, metabolic dietetics was limited to the treatment of a few single-gene defects, such as phenylketonuria and maple syrup urine disease,^{3,4} but the number of new metabolic conditions being identified and diagnosed is rising rapidly. As disorders are added to the newborn screening panel, demands for nutritional interventions and treatments tailored to the individual and the disorder will only grow. What remains unclear is whether the field of metabolic dietetics is prepared for the opportunities and challenges that genetic advances bring.

To date, evaluating the practice of genetic metabolic dietetics has proved impracticable because of a lack of appropriate instruments, such as assessment tools and professional guidelines. To assess existing gaps in the knowledge and training of metabolic dietitians, a set of standards or competencies would need to be developed. Competencies help to define emerging fields and reduce variations in quality of care.⁵ The American Dietetics Association (ADA) published the Standards of Professional Practice

for dietitians and dietetic technicians in 2005 as a means of describing “a competent level of dietetics practice and professional performance.”^{6,7} In addition, several specialized areas within the dietetics profession have adapted these standards to fit their specific needs.^{8–11} Nevertheless, the field of genetic metabolic dietetics remains without such a set of competencies. These competencies would serve as a means of evaluating the responsibilities, priorities, and educational needs of practicing genetic metabolic dietitians and establish a foundation for the field. It was to these ends that Genetic Metabolic Dietitians International (GMDI) undertook the current project.

METHODS

The urgent need for continuing education for metabolic dietitians first became apparent at the fall 2004 national meeting of the GMDI founders. The GMDI founders group consisted of 15 practicing genetic metabolic dietitians from across the United States who had demonstrated leadership in the field of metabolic dietetics based on their involvement in regional and national conferences, active participation in the PNO-METLAB listserv (a listserv specific for the field of genetic metabolic dietetics developed and maintained by the author) and by maintaining visibility in the field. The members of the founders group completed a multistage process to define the unique areas of competency and the levels of competency that are essential to the emerging field of genetic metabolic dietetics. This process involved meetings, conference calls, and communication via e-mail. The founders group met to begin the development of the Standards of Professional Practice for Genetic Metabolic Dietitians on April 9, 2005, after the Ross National

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Metabolic Conference. The meeting began with a brief introduction to competency structure and development and a review of published competencies and articles regarding the appropriate tools for competency development.^{12–14} The group established the target audience, scope, and domains, the latter of which were modeled after those in the ADA's Standards for Professional Practice.⁷ Each member of the founders group submitted a log of their daily activities to delineate the duties of genetic metabolic dietitians. Competencies pertaining to the specific responsibilities of genetic metabolic dietitians, modeled after the National Coalition for Health Professions Education in Genetics's core competencies¹² and the ADA's Standards for Professional Practice,⁷ were later added under each domain. Special consideration was given to the effect these competencies would have on academia and the education of genetic metabolic dietitians, as well as how to use the competencies to create training guidelines for existing professionals, with an eye toward basing certification and credentialing efforts on the document.

The draft of the Standards of Professional Practice for Genetic Metabolic Dietitians was validated by means of an electronic survey distributed to the PNO-METLAB listserv in November 2006. Of the 227 listserv members who had access to the electronic questionnaire, 65 surveys were submitted with a response rate of 28.6%. Respondents practicing outside of the United States and Canada and respondents who completed only the demographic section of the questionnaire were excluded, leaving 50 completed surveys for analysis. For each indicator, survey respondents were asked (1) whether they perceived the indicator as essential to the practice of genetic metabolic dietetics and (2) whether they regularly applied the indicator to the practice of genetic metabolic dietetics. Descriptive statistics were used when responses to Question 1 were 100%; otherwise, Fisher's exact test was used to determine whether compliance was significantly associated with perceived importance. A response frequency of <80% for Question 2 was considered to represent low compliance for that indicator. SAS version 9.0 (SAS Institute, Cary, NC) was used for all analysis. The final version of the Standards of Professional Practice for Genetic Metabolic Dietitians is presented in Figure 1, A and B.⁷ This study was approved by the ethics committee at Emory University.

RESULTS/DISCUSSION

Of those responding to the survey, 100% of respondents were registered dietitians and 84% of respondents worked with a mixed pediatric/adult patient population. The number of metabolic patients seen by responding dietitians ranged from <10 (4%) to >200 (26%). Survey participants found most standards and their indicators important; at least 75% of respondents reported each indicator as essential to the practice of genetic metabolic dietetics. Dietitians applied most indicators to their practice of genetic metabolic dietetics on a regular basis; reported compliance for 42 of the 53 indicators was 80% or greater. Low compliance was concentrated in four areas: policy, research, budget, and participation in continuing education. Low compliance is indicative of gaps in knowledge and training.

Policy

Policy and advocacy comprise important components of genetic metabolic dietetics that many dietitians may not pursue or engage in as part of their work. Reported compliance for indicators 1.7 and 5.10, both relating to issues concerning policy and advocacy for client-focused issues, were low: 63% ($P = 0.0013$) and 58% ($P < 0.0001$), respectively. Dietitians believed that participating in policy and advocacy were "beneficial," but not essential and admitted that this area often was "placed on the back burner." Dietitians may not perceive policy issues as important because of a lack of knowledge or exposure in this area. Through seminars, continuing education, and involvement with advocacy groups, dietitians can become aware of current policies and develop an understanding of why involvement in policy and advocacy is an important element of the profession.

Research

Research leads to a more complete understanding of metabolic disorders and drives the field of genetic metabolic dietetics forward, opening up new avenues for treatment and management of metabolic disorders. Reported compliance for 4 of the 10 indicators for Standard 2, the Application of Research (33–51%), and for indicator 6.5, "participates in quality assurance and research endeavors" (64%), were low. Compliance was significantly associated with perceived importance for only one indicator, indicator 2.5: "collects measurable data outcomes" ($P = 0.0226$). This implies that dietitians understand the importance of the role of research to the profession, but may not have the opportunity to participate in research studies. Dietitians expressed a desire to conduct research, but noted barriers such as part-time employment status, lack of appropriate patient populations, small practice size, and limited funding. These barriers can be minimized by creating opportunities for research through collaborations between dietitians, health researchers, dietetic practices, and other metabolic centers. Collaborations can be formed by attendance at professional conferences, participation on the PNO-METLAB listserv, and through the formation of a subgroup of the PNO-METLAB listserv specifically designated for genetic metabolic research endeavors. Conducting research is necessary to expand the knowledge of dietitians, dietetic practices, and the field of genetic metabolic dietetics.

Budget

The utilization and management of resources is an important component of the ADA's Standards of Professional Practice.⁷ The GMDI founders group agreed that this component was a basic element of the practice of genetic metabolic dietetics and that it was necessary for genetic metabolic dietitians to have some level of budget involvement. Compliance was low for three indicators related to budget: indicators 4.3 ($P = 0.0014$), 4.4 ($P < 0.0001$), and 5.9 ($P < 0.0001$). In addition to a significant association between perceived importance and compliance for these three indicators, there was also an increase in the number of missing values per indicator for Stan-

Standards of Professional Practice refer to the performance of individual genetic metabolic dietetics professionals regardless of the setting, project, case, or situation. They are defined statements of a dietetics professional's responsibility for providing services in all areas of practice. They describe the minimum level of performance expected of dietetic technicians and registered dietitians. The Standards for Professional Practice for Metabolic Dietitians are presented here as six domains or standards, followed by indicators and outcomes illustrating each domain.	
<p>STANDARD 1: PROVISION OF SERVICES. Dietetics professionals provide, facilitate, and promote quality services based on client needs and expectations, current knowledge, and professional experience.</p> <p>Indicators</p> <p>1.1 Collaborates with client to assess needs, background, and resources and to establish mutual goals in a culturally competent environment.</p> <p>1.2 Collaborates with federal and state agencies, community organizations, and private institutions as needed to advocate for the needs of patients with inborn errors of metabolism and related genetic disorders and their families.</p> <p>1.3 Applies knowledge and skills to determine the most appropriate action plan.</p> <p>1.4 Implements quality practice by following policies, procedures, legislation, licensure, practice guidelines, and the Standards of Professional Practice.</p> <p>1.5 Fosters excellence and exhibits professionalism in practice.</p> <p>1.6 Continuously evaluates and improves clinical processes and outcomes.</p> <p>1.7 Advocates for the provision of nutrition and genetic services specific to the unique requirements of patients with inborn errors of metabolism or related genetic disorders and their families through public policy.</p> <p>1.8 Incorporates knowledge of genetics and inborn errors of metabolism into nutrition care plans.</p> <p>Examples of Outcomes</p> <p>Clients actively participate in establishing goals and objectives</p> <p>Clients' needs are met.</p> <p>Clients are satisfied with service and products provided.</p> <p>Evaluation reflects expected outcomes.</p> <p>Public has access to food and nutrition services.</p>	<p>conclusions.</p> <p>2.9 Alters treatment protocols based on new, sound, and peer-reviewed data.</p> <p>2.10 Shares information on outcomes with others in the field of inborn errors of metabolism.</p> <p>Examples of Outcomes</p> <p>Client receives appropriate services based on the effective application of research.</p> <p>A foundation for performance measurement and improvement is provided.</p> <p>Outcome data supports reimbursement for the services of dietetics professionals.</p> <p>Research findings are used for the development and revision of policies, procedures, practice guidelines, protocols, and clinical pathways.</p> <p>Professionals use benchmarking and knowledge of "best practices" to improve performance</p> <p>STANDARD 3: COMMUNICATION AND APPLICATION OF KNOWLEDGE. Dietetics professionals effectively apply knowledge and communicate with metabolic patients and their families, other metabolic dietitians, other health care professionals, students, and the general</p> <p>3.1 Has knowledge of and understands general genetic principles.</p> <p>3.2 Is knowledgeable in the areas of biochemical basis, genetic causes, diagnostic criteria, nutritional intervention and monitoring of inborn errors of metabolism.</p> <p>3.3 Communicates only sound scientific principles, research, and theory.</p> <p>3.4 Integrates knowledge of food, food preparation and human nutrition to help design nutritional interventions appropriate for specific biochemical abnormalities in inborn errors of metabolism.</p> <p>3.5 Assesses the cultural background and educational level of the patients and their families, or members of the general public, when communicating complex information.</p> <p>3.6 Designs treatments that not only meet the nutrient requirements and biochemical limitations, but also are appropriate based on cultural and socioeconomic characteristics of the metabolic patient and family.</p> <p>3.7 Communicates short and long-term plans for treatment and monitoring with patients and caregivers.</p> <p>3.8 Involves patients and caregivers in the short and long term plans for treatment and monitoring.</p> <p>3.9 Communicates with the metabolic team frequently through team meetings and documentation of all activities and contacts with patients and caregivers.</p> <p>3.10 Keeps abreast of programs/funding/interventions/services at the local level which may benefit and extend the care of metabolic patients public.</p> <p>Examples of Outcomes</p> <p>Professional provides expertise in food, nutrition, and management information.</p> <p>Client understands the information received.</p> <p>Client receives current and appropriate information and knowledge.</p> <p>Client knows how to obtain additional guidance.</p>
<p>STANDARD 2: APPLICATION OF RESEARCH. Dietetics professionals effectively apply, support, and generate dietetics research in an effort to encourage continuous quality improvement and to provide documented support for the benefit of the client.</p> <p>Indicators</p> <p>2.1 Performs literature searches and reviews and evaluates information therein for application to practice.</p> <p>2.2 Makes direct contact with others who have similar patient populations or may be actively involved in research not yet published.</p> <p>2.3 Understands the concepts and implications of informed consent, confidentiality, and institutional review boards as they apply to research involving human subjects.</p> <p>2.4 Collaborates on research projects with others working with the same patient population.</p> <p>2.5 Collects measurable data outcomes.</p> <p>2.6 Applies or collaborates with others who can apply accepted techniques of statistical analysis for data collected.</p> <p>2.7 Presents data and conclusions in oral and written format for peer review.</p> <p>2.8 Incorporates changes in treatment and management of metabolic patients based on results of peer-reviewed research</p>	<p>STANDARD 4: UTILIZATION AND MANAGEMENT OF RESOURCES. Dietetics professionals use resources such as time, money, facilities and human resources effectively and efficiently in practice.</p> <p>Indicators</p> <p>4.1 Uses a systematic approach to maintain and manage professional resources successfully.</p> <p>4.2 Uses measurable resources such as personnel, monies, equipment, guidelines, protocols, reference materials, and time, in the provision of dietetics services.</p> <p>4.3 Analyzes safety, effectiveness, and cost in planning and delivering services and products.</p> <p>4.4 Justifies use of resources by documenting consistency with plan, continuous quality improvement, and desired outcomes.</p> <p>4.5 Educates and helps clients and others to identify and secure appropriate and available resources and services.</p> <p>4.6 Mentors other dietitians and health care providers who are either new to the field of inborn errors of metabolism or new to a particular inborn error of metabolism.</p> <p>Examples of Outcomes</p> <p>The dietetics professional documents use of resources according to plan and budget.</p> <p>Resources and services are measured and data are used to promote and validate the effectiveness of services.</p> <p>Desired outcomes are achieved and documented.</p> <p>Resources are managed and used cost-effectively.</p> <p>STANDARD 5: QUALITY IN PRACTICE. Dietetics professionals systematically evaluate the quality and effectiveness of the practice and revise the practice as needed to incorporate the results of evaluation.</p> <p>Indicators</p> <p>5.1 Participates as an integral member of the interdisciplinary genetics team managing inborn errors of metabolism.</p> <p>5.2 Assesses immediate nutritional needs and identifies resources for client and family.</p> <p>5.3 Provides current information about the potential risks, benefits, and limitations of treatment options.</p> <p>5.4 Implements medical nutrition therapy and monitors the efficacy, adjusting intervention as needed.</p> <p>5.5 Identifies relevant clinical data (i.e. lab tests, school reports, special tests, consultants' reports) and the impact on nutritional therapy.</p> <p>5.6 Provides family-centered care to all clients and assists with the integration of their care in all aspects of their lifestyle.</p> <p>5.7 Participates in professional and public educational programs about treatment of genetic inborn errors of metabolism.</p> <p>5.8 Seeks peer support resources for clients and families.</p> <p>5.9 Identifies the cost-effectiveness of medical nutritional therapy.</p> <p>5.10 Educates others about client-focused policy issues.</p> <p>5.11 Uses a comprehensive knowledge of nutrition, biochemistry, and physiology and relies on teaching and counseling skills.</p> <p>Examples of Outcomes</p> <p>Performance improvement criteria are measured.</p> <p>Actual performance is evaluated.</p> <p>Clients' outcomes meet established criteria (objectives/goals).</p> <p>Results of quality improvement activities direct refinement of practice.</p>
<p>STANDARD 6: CONTINUED COMPETENCE AND PROFESSIONAL ACCOUNTABILITY. Dietetics professionals engage in lifelong self-development to improve knowledge and enhance professional competence in order to maintain accountability to the public.</p> <p>Indicators</p> <p>6.1 Effectively uses new technologies to obtain current information about genetic metabolic disorders.</p> <p>6.2 Participates in professional and public educational programs about genetic metabolic disorders.</p> <p>6.3 Participates in and seeks opportunities for professional development and educational leadership.</p> <p>6.4 Obtains credible information about genetic metabolic disorders for the genetics team.</p> <p>6.5 Participates in quality assurance and research endeavors.</p> <p>6.6 Respects and understands the ethical issues of treatment.</p> <p>6.7 Understands the complications of untreated genetic metabolic disorders and the influences of genetics factors on the maintenance of health.</p> <p>Examples of Outcomes</p> <p>Dietetics professional uses self-reflection and feedback from a variety of sources to evaluate and implement professional change.</p> <p>Dietetics professional development needs are identified and directed learning takes place.</p> <p>Dietetics professional accepts accountability to the public.</p> <p>Dietetics professional obtains appropriate certifications.</p> <p>Dietetics professional supports legislation that promotes positive food and nutrition outcomes.</p> <p>Dietetics professional uses "best practices" to demonstrate competency.</p> <p>Dietetics professional meets Commission on Dietetic Registration recertification requirements.</p>	

Fig. 1. Standards of professional practice for genetic metabolic dietitians. Based on reference 7.

Standard 4: Utilization and Management of Resources compared with the other standards. This suggests that dietitians may have not believed that budget-related items were important to the practice of genetic metabolic dietetics or that these indicators were not applicable to them. Dietitians may not always be involved in budget planning and management. The founders decided to retain the budget-related indicators despite lack of current participation, in anticipation that future credentialing will be based on the Standards of Professional Practice for Genetic Metabolic Dietitians, including the indicators related to budget and resource management. More thought and consideration may need to be given to this area in the future.

Participation in Professional Programs

Closing existing gaps in training and knowledge and ensuring dietitians have current information regarding genetic metabolic disorders and the treatment of these disorders is dependent on continuing education classes and professional programs. Compli-

ance to indicator 5.7, "participates in professional and public educational programs about treatment of genetic inborn errors of metabolism," was <80%, but was not significantly associated with perceived importance. This indicates that dietitians are aware of the importance of attending continuing education programs about genetic inborn errors of metabolism, but may not attend because of the scarcity of available programs and funding constraints. Currently only one course for genetic metabolic dietitians has been offered.¹⁵ There is both a demand for and a need to develop continuing education classes focused on genetic metabolic disorders. The organization and implementation of additional continuing education classes is essential for practicing dietitians to keep abreast with current knowledge.

Competencies in Practice

The Standards of Professional Practice were designed as a means to unify and standardize the profession of genetic met-

abolic dietetics. The Standards of Professional Practice will be used to structure continuing education opportunities, such as classes, seminars, Web-based applications, workshops, and conferences, as well as to guide research and evaluation. The competencies will also serve as a guide in certification, professional accreditation, and strengthening academic curriculum.

Although still a working draft, the formulation and organization of the Standards of Professional Practice for Genetic Metabolic Dietitians has already supported practical activities toward evaluating and improving upon professional goals and skills. In August 2005, a working draft served as a model in the development of an assessment instrument. The resulting questionnaire was distributed nationally via the PNO-METLAB listserv to identify the level of expertise among metabolic nutritionists in the region and to assist in setting education priorities and educational methodology preferences. Using the standards as a guideline, the questionnaire was able to capture core concepts related to the continuing education needs of metabolic dietitians.

CONCLUSION

In many areas of health care, including the field of genetic metabolic dietetics, advances in technology may be outpacing education.^{16,17} It became apparent through professional meetings and conferences that an evidence-based approach was needed to identify the gap between education and current practice and to assess the responsibilities of genetic metabolic dietitians. The Standards of Professional Practice for Genetic Metabolic Dietitians serves as a method of evaluation and helps to define the field of genetic metabolic dietetics, as well as what it means to be a genetic metabolic dietitian.

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