Genetics in Occupational Therapy Education: A Survey of Professional Entry-Level Programs

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PURPOSE. Advances in genetics indicate a need for occupational therapists to develop literacy and skills in genetics as it relates to lifestyle and occupation. The purpose of this study is to identify genetics content areas taught, instructional methods used, and the importance of teaching genetics at the entry-level in occupational therapy curricula.

METHOD. A questionnaire was sent to all entry-level occupational therapy educational programs (N = 157). Structured mailing and follow-up were used.

RESULTS. The response rate was 63.9%. Most respondents (47%) rate teaching genetics as “moderately important.” Genetics content is predominately taught at the introductory or knowledge level rather than at the integration and application level. Respondents indicate a lack of time and space for genetics content and of faculty interest and expertise.

DISCUSSION. As occupational therapy practice evolves to include new genetics, curriculum change will need to be implemented. Development of teaching materials and methods addressing genetics is recommended.

Severeral times each week news headlines draw our attention to discoveries linking human health and behavior to genetics. Developments in the understanding of genetics, and new technologies that help probe for some of the smallest parts of our physical self, bring new excitement and enthusiasm about understanding nature as well as new implications for lifestyles.

Unraveling genome information across the population and among individuals is responsible for generating vast amounts of new knowledge about the ability to inherit traits and conditions or vulnerability to physical and behavioral conditions that affect people’s abilities to function. New genetics refers to vast amounts of new knowledge, new technologies, and new dilemmas that come with genetic discoveries and widespread applications within places such as medicine and public health. New genetics address interactions between lifestyle choices and genetic make-up, making us more aware of personal health risks in one’s lifetime and lifestyle. Thus with new genetics, occupational therapy practitioners face challenges and opportunities in contributing to care of individuals, families, and communities (Dudgeon & Low, 2003). However, in a recent study many occupational therapists reported a low level of confidence in their ability to provide genetic-based evaluations and interventions (Kyler & Thomas, 2000).

In recent years, the American Occupational Therapy Association (AOTA) has committed to assisting practitioners learn about and apply genetic information to practice and to promote genetics literacy as a valuable means to ensure competent service (American Occupational Therapy Association [AOTA], 2002). AOTA has had representation in the National Coalition for Health Professional Education in Genetics (NCHPEG) since 1996. It is the goal of NCHPEG to promote health
professional education and access to information about advances in human genetics (National Coalition for Health Professional Education in Genetics [NCHPEG], 2002). In this survey research study, we sought to determine how genetic education is currently being addressed within occupational therapy program curricula, as well as gauge the level of interest for this topic among occupational therapy educators.

**Human Genome Project and New Genetics**

Although Mendel described principles of inheritance in 1865 (Monaghan & Corcos, 1985), it wasn’t until James Watson and Francis Crick (1953) discovered the structure of DNA in 1953 that the process of gene transmission was understood. As part of an international effort starting in 1988, the National Institutes of Health and the Department of Energy provided federal funding to the Human Genome Project. A goal of this endeavor was to create a map of the genes that make up the human genome and that of other species (Jenkins, 2000). Completion of this project is resulting in the dawning of a new understanding about genetics and vastly new insights about human diseases and disorders. Ongoing discoveries are bringing change to medical procedures regarding diagnosis, prevention, and care. With every piece of emerging genetics knowledge comes concerns about responsible and ethical applications of new information. Physical, psychological, and social harms are of concern and create ethical imperatives for everyone (Kegley, 2003).

Genetics continues to be about heredity, environments, and chance. Diagnostic techniques and understandings about underlying genetic pathology are becoming evident, but it is also acknowledged that the majority of genetic disorders are multifactorial, meaning that they result from some combination of genetic and environmental contributions (Kyler, 2002). With the human genome mapped, it is now hoped that more will be understood about the contributions of multifactorial issues such as the interplay of genes, the environment or lifestyle, and the effects that they have on the presentation of disorders of the human organism. Volumes of information and insights are being developed about the contributions of specific genes, gene combinations, and possible environmental and behavioral triggers to various health conditions such as cancer, diabetes, and mental illness.

With development of diagnostic technology, it is important to remember that treatments for genetic conditions are far behind the detection of these same disorders. How does this lag impact someone who tests positive for a disease-contributing gene that has no known treatment options? There are many additional ELSIs (ethical, legal, and social implications) that are emerging with new genetics. We live amidst fears of the potential for human cloning and genetic discrimination by insurance companies and employers, as well as media coverage and possible misinformation about every new discovery. As a society, we will all have to decide how to decipher and apply this new genetic information. The potential of these discoveries will bring forth the need for professionals, including occupational therapists, to develop “genetics literacy” (Dudgeon & Low, 2003). The NCHPEG, with AOTA membership, calls for health disciplines to develop practitioner skills in dealing with genetics and the medical, psychological, and social consequences of new discoveries and subsequent clinical options (NCHPEG, 2002).

**Genetics and Health Professionals**

Consumer needs will change as the substance of health care evolves. The shift to a more genomic-based medicine is bringing about change in the role of all health care providers (Guttmacher & Collins, 2002). Still today, most allied health professionals are not ready to implement genetics in a clinical context (Collins, 1997). In order to provide the best service possible in this new era, health care professionals must have a working knowledge of genetics, as the scope of their professions require (Lou, 2002). Surveys have been conducted to assess the need for and scope of genetics education in different professional programs (Jordan, 2000; Lapham, Kozma, Weiss, Benkendorf, & Wilson, 2000). Results indicate that work with genetics issues is frequently being conducted by allied health and counseling professionals, yet few have high confidence in this work due to little or no education in genetics. Many have expressed needs for continuing education in genetics content and application to practice.

The task of determining and establishing what needs to be taught within different professions is not an easy one. Each discipline requires varied and ongoing education that will allow professionals to learn the necessary material without being overly intensive (Guttmacher, Jenkins, & Uhlmann, 2001). Through a collaborative effort by a number of professional organizations, essential core competencies have been established (NCHPEG, 2002) to insure that allied health professionals have basic standards, thereby giving them a place to start when designing and creating curricular content for genetics education. Already in place are some genetics-based programs for specific professions such as physicians and nurses (Guttmacher et al., 2001; Lea, Feetham, & Monson, 2002). Each discipline continues to acknowledge training deficiencies and needs for curriculum development. Lea et al. draw attention to a bi-directional approach within nursing where national policy leadership is...
combining with educators and clinician initiatives at local and regional levels to influence genetics practice and scholarship. When developed and put into place, genetics education, even over a short period of time, has improved knowledge and attitudes about genetics and related services (Kolb, Aguilar, Dinenberg, & Kaye, 1999; Smith & Scott, 1988).

For health professionals, disciplines must tailor a genetics education program to fit the need of their profession so that consumers can benefit from work with professionals who are educated to handle issues that arise with genetics or genomics (Lou, 2002). Education will also enable professionals to both recognize and more effectively handle ethical, legal, and social implications of genetics in clinical practice (Homenko, 1997).

**Genetics and Occupational Therapy**

Many questions arise for individuals regarding genetic testing and diagnosis. For example, what if it is determined through the taking of a family history that one might carry the gene for a mid-life onset disorder such as Huntington's chorea? When does one seek diagnostic testing? Does disability happen even though the symptoms may not manifest for years or decades? At what point with this disorder should one begin to make lifestyle changes? How might treatment be regarded and what about other interventions to address health and function? These are some of the very questions that occupational therapists could assist with in clinical practice.

Occupational therapists address the impact of both physical ailments and the psychosocial aspects of health and wellness when working with clients and families. Because genetic conditions often change over time, what is evident today may bring more intensive or even new challenges tomorrow. This means that occupational therapists must be armed with a variety of skills necessary to help clients, families, and communities acknowledge and accommodate genetic disorders (Kyler, 2002). AOTA promotes the concept of genetics literacy among occupational therapy practitioners to help ensure competent occupational therapy services as part of interventions (AOTA, 2002). The goal of competency in genetics is to guarantee that recipients of occupational therapy services are not denied full access to the benefits of society by the discovery of genetic issues in his or her medical information (AOTA). Occupational therapists use genetic information to assist clients to anticipate changes in ability and to adapt personal skills or environments to support optimal function (Georgetown University Medical Center, 2001). Occupational therapists have the capacity to assume diversified roles depending on the nature of the genetic condition, going beyond current roles in practice. They are already evaluating and treating individuals with activity limitations related to genetic disorders. Occupational therapy evaluation data may provide information about development or behavioral symptoms that leads to a confirmation of a genetic disorder. Since individuals may have disorders that are asymptomatic for a long period of time or are rapidly progressive, addressing lifestyle changes and planning for functional decline that will occur over time necessitates a client-centered approach. Occupational therapists can help by recommending plans for individuals to maintain roles and valued tasks, and recommending activities to reduce limitations.

Occupational therapists must be prepared to discuss and address psychosocial issues associated with genetics (Kyler, 2000). The ethical, legal, and social issues include a wide range of concerns including confidentiality, insurance, workplace discrimination, and community stigmatization. The occupational therapist’s background in both social and physical sciences, with the focus on occupation, puts occupational therapists in the unique position of being able to discuss limitations of activity participation within treatment teams and with clients. In all settings, occupational therapists are likely to deal with dynamic decisions regarding genetics that will create ethical dilemmas. Families of patients with Alzheimer disease, Parkinson disease, and multiple sclerosis will all want to know more about their genetic past and future. Attention to cultural and personal issues involved in testing, treatment, and care of genetic disorders may affect entire communities. Consumers will face the ethical, legal, and social issues of genetic testing. They will look to their health professionals, including occupational therapists, to answer their questions (Broginsky, 1999). Genetics and ethics will remain entwined issues for many years to come.

With expected changes in practice, occupational therapists must be current in best practices and respond to needs of clients and their families. Thus, it will be important to educate future therapists regarding genetics. The reason for addressing this issue at the academic level is to ascertain the level at which genetics education is occurring and to determine what base of knowledge is expected of future practitioners in our field. Entry-level programs in occupational therapy will influence the prevailing attitude about the role of the occupational therapist in addressing genetic issues with their clients, as well as the need for and importance of continuing education in genetics.

**Purpose of Study**

The purpose of this study is to identify what is currently being taught in professional entry-level occupational therapy programs relevant to genetics and current opinions of occupational therapy educators about teaching genetics.
Study aims included review of genetics topics, instructional methods being used, perceived importance of genetics in occupational therapy curricula, and challenges to teaching genetics content.

Method

Participants

Participants included all 157 directors of professional entry-level programs accredited by the Accreditation Council for Occupational Therapy Education (ACOTE) as of 2002. Each program director was asked to solicit information from their faculty to facilitate accurate responses on the survey. Participation was voluntary, and completion and return of the survey was considered consent to participate.

Instrumentation

A mail survey was designed specifically for this study based on a comprehensive review of the literature and NCHPEG guidelines. The survey was pretested by three occupational therapists with expertise in genetics and occupational therapy education, providing feedback to improve the content and clarity of the questionnaire. The survey consisted primarily of closed-ended questions that focused on courses in which genetics is taught, specific genetics content taught, instructional methods used, who teaches genetics, and how faculty view the importance of teaching genetics. Two open-ended questions queried for respondents’ opinions regarding scope and methods of teaching and the barriers and challenges relative to teaching genetics content that exist within programs.

Procedure

A modified version of Dillman’s (2000) Tailored Design Method was used to maximize response rate. This approach consisted of an initial mailing and two follow-up mailings, each including a cover letter, the survey, and self-addressed postage paid return envelopes. The surveys were coded for the purpose of follow-up mailings.

Participants were given the opportunity to decline participation and the receipt of future mailings by checking a box on the first page of the survey and returning it in the enclosed envelope. University of Washington Human Subjects, through an expedited review, approved the procedures.

Data Analysis

The closed-ended questions were analyzed using descriptive statistics calculated on an Excel spreadsheet. Open-ended questions were analyzed using textual analysis that includes indexing, comparing and contrasting written answers (Miles & Huberman, 1994). Data from this study is reported as aggregate numbers and percentages and does not identify any specific respondents.

Results

Of the 157 ACOTE accredited occupational therapy programs that were included in the study, 83 program directors completed and returned the survey. Sixteen respondents selected not to participate and 11 surveys were returned as undeliverable. The response rate of 63.9% was calculated after removing the non-eligible and nondeliverable surveys (Dillman, 2000).

Seventeen (21%) of the respondent programs had baccalaureate programs only and 30 (37%) had entry-level master’s only. The remainder of respondents reported having 2–3 types of programs including baccalaureate, entry-level master’s, combined bachelor’s–master’s and entry-level doctoral programs. Five respondents (6%) reported having an entry-level doctoral program. The majority of respondents were from public institutions (56%), 38% were from private nonprofit, and 6% from private-profit programs.

Genetics topics addressed included three major areas: basic genetic concepts; ethical, legal, and social issues; and clinical applications. Tables 1, 2, and 3 show the highest level at which identified genetics topics are taught (i.e., introduced, knowledge and understanding, or integration and application). Introductory was defined in the survey as the topic being presented but not discussed in depth. Knowledge and understanding was defined as knowing terminology, facts, and principles. A smaller number of respondents answered that the genetics content was taught at the integrative and application level, which was defined as applying principles and solving problems.

The majority of participants (58%) reported that prerequisite courses provided genetics content. Within the entry-level occupational therapy programs, genetics content was reported as taught in several courses within the curriculum (39%) or as a lecture or series of lectures within one course (58%). When asked to identify all methods used to teach genetics content, respondents identified primarily lecture (85%), textbook readings (82%), case study discussions (38%), and videos (31%).

Respondents were also asked to identify all those professionals who taught genetics content. Of the 72 respondents who answered this question, 64 identified occupational therapy faculty as providing genetics lectures. Among these, 27 respondents said only occupational therapy faculty taught the content whereas the other 37 said that other professionals also taught genetics in the curriculum.
Table 1. Basic Genetics Concepts Taught in Occupational Therapy Curricula

<table>
<thead>
<tr>
<th>Genetics Topic</th>
<th>Introduced</th>
<th>Knowledge and Understanding</th>
<th>Integration and Application</th>
<th>Not Addressed</th>
</tr>
</thead>
<tbody>
<tr>
<td>Overview of human genetics (n = 74)</td>
<td>24 (32%)</td>
<td>30 (41%)</td>
<td>7 (10%)</td>
<td>11 (15%)</td>
</tr>
<tr>
<td>Genetics in common disorders (n = 80)</td>
<td>25 (31%)</td>
<td>32 (40%)</td>
<td>20 (25%)</td>
<td>3 (4%)</td>
</tr>
<tr>
<td>Genetic testing and screening (n = 76)</td>
<td>46 (61%)</td>
<td>13 (17%)</td>
<td>2 (3%)</td>
<td>15 (20%)</td>
</tr>
</tbody>
</table>

Note. Due to rounding, percentages do not always add to 100%.

Table 2. Ethical, Legal, and Social Implications Related to Genetics Taught in Occupational Therapy Curricula

<table>
<thead>
<tr>
<th>Genetics Topic</th>
<th>Introduced</th>
<th>Knowledge and Understanding</th>
<th>Integration and Application</th>
<th>Not Addressed</th>
</tr>
</thead>
<tbody>
<tr>
<td>Privacy and Confidentiality (n = 74)</td>
<td>22 (30%)</td>
<td>14 (19%)</td>
<td>17 (23%)</td>
<td>21 (28%)</td>
</tr>
<tr>
<td>Decision-making for genetic screening/testing (n = 74)</td>
<td>34 (46%)</td>
<td>11 (15%)</td>
<td>6 (8%)</td>
<td>23 (31%)</td>
</tr>
<tr>
<td>Informed consent to release genetic information (n = 71)</td>
<td>18 (25%)</td>
<td>13 (18%)</td>
<td>7 (9%)</td>
<td>33 (46%)</td>
</tr>
<tr>
<td>Discrimination due to genetic information (n = 77)</td>
<td>29 (38%)</td>
<td>16 (21%)</td>
<td>7 (9%)</td>
<td>25 (32%)</td>
</tr>
<tr>
<td>Racial/ethnic concerns (n = 70)</td>
<td>24 (34%)</td>
<td>12 (17%)</td>
<td>4 (6%)</td>
<td>30 (43%)</td>
</tr>
<tr>
<td>Resources, reimbursement, insurance (n = 73)</td>
<td>21 (28%)</td>
<td>9 (12%)</td>
<td>3 (4%)</td>
<td>40 (55%)</td>
</tr>
<tr>
<td>Public policy and legislation (n = 69)</td>
<td>23 (33%)</td>
<td>12 (17%)</td>
<td>4 (6%)</td>
<td>30 (43%)</td>
</tr>
</tbody>
</table>

Note. Due to rounding, percentages do not always add to 100%.

Table 3. Clinical Applications Related to Genetics Taught in Occupational Therapy Curricula

<table>
<thead>
<tr>
<th>Genetics Topic</th>
<th>Introduced</th>
<th>Knowledge and Understanding</th>
<th>Integration and Application</th>
<th>Not Addressed</th>
</tr>
</thead>
<tbody>
<tr>
<td>Discuss genetic conditions with clients (n = 76)</td>
<td>20 (26%)</td>
<td>24 (32%)</td>
<td>10 (13%)</td>
<td>22 (29%)</td>
</tr>
<tr>
<td>Discuss issues about genetic screening or testing with clients (n = 69)</td>
<td>24 (35%)</td>
<td>13 (19%)</td>
<td>2 (3%)</td>
<td>30 (43%)</td>
</tr>
<tr>
<td>Make referral for genetic counseling (n = 72)</td>
<td>29 (40%)</td>
<td>12 (17%)</td>
<td>2 (3%)</td>
<td>29 (40%)</td>
</tr>
<tr>
<td>Provide guidance to clients with genetics disorder about impact of condition (n = 71)</td>
<td>20 (28%)</td>
<td>17 (24%)</td>
<td>12 (17%)</td>
<td>22 (31%)</td>
</tr>
</tbody>
</table>

Note. Due to rounding, percentages do not add to 100%.

disciplines that were identified as teaching genetics content were physicians, ethicists, genetic counselors, or physical therapy faculty.

When asked to rate the importance of teaching genetics in occupational therapy curricula, 47% of participants answered “moderately important,” 28% “important,” and 21% “not important.” Only 4% of participants rated genetics education as “very important.” A preponderance of respondents, 69% (n = 75), indicated that a model curriculum including course outlines and lectures would be helpful in increasing the amount or quality of genetics education in their curriculum. In addition, 69% of respondents answered that model curricula and faculty development or continuing education workshops (59%) would be beneficial to them for the inclusion of genetics content in their curricula.

Emergent Themes

Two open-ended questions were included in the survey to provide participants with opportunity to express opinions about the scope and methods of genetics education in occupational therapy programs and to comment on the barriers or challenges encountered in teaching genetics content. Regarding scope and methods, less than 20% of respondents were satisfied with their current curriculum content, whereas greater than 35% acknowledged the importance and need to re-address genetics content. In terms of barriers or challenges, 25% saw no difficulties in addressing genetics, but over 40% acknowledged the importance of genetics and the difficulty they faced fitting genetics and implications for occupational performance into the curriculum.

Textual analysis of answers resulted in three themes. The first theme was that genetics content needs to be integrated throughout a curriculum and related to occupational performance. Respondents stated a preference for embedding genetics content within existing courses rather than creating stand-alone courses in genetics. Respondents stated the importance of learning basic genetics information, as well as the need for students to understand the clinical implications of genetic disorders, specifically relating to occupational performance and lifestyle change.
The second theme was lack of time and space in curricula for genetics content. Many respondents acknowledged the need to do more with genetics relative to today’s practice, with particular emphasis on ethical, legal, and social implications. However, difficulty in meeting all ACOTE standards and lack of a specific standard regarding genetics were also stated as a reason to not make changes.

The third theme identified a lack of faculty interest and knowledge. Expertise was identified as a barrier to making curriculum change. Some respondents explained that faculty did not perceive genetics as an important topic relative to occupational performance, or that they needed further understanding and development of their knowledge base. Some respondents felt that the area of genetics was extremely broad, thus, they foresaw difficulties deciding how to pare down the subject matter and select pertinent topics for an occupational therapy curriculum.

Discussion

Results of this survey help to address attitudes and perceptions regarding inclusion and teaching of genetics content, teaching methods and levels of learning, and implications and future needs regarding genetics content in occupational therapy curricula.

Attitudes and Perceptions About Genetics Content

Most respondents did not view teaching genetics as a high priority in occupational therapy curricula. Few respondents rated genetics education as “very important” whereas many others answered that it was “not important.” This trend was also apparent in some of the answers to open-ended questions, in which respondents stated a lack of interest in the topic and a lack of understanding the relevance to occupational performance. One might surmise from the answers to this question, that respondents did not see the relevance of genetics to occupational therapy practice.

Respondents also mentioned the lack of ACOTE standards for genetics content and that it was difficult to allocate time for genetics content in already overloaded curricula. In addition, the lower than expected response rate (63.9%) to the survey may also indicate that program directors of entry-level occupational therapy programs were unsure how to respond or did not view new genetics as an important topic for educators. Given the growing impact that genetic knowledge has on people’s lives and on health care and lifestyle decisions, occupational therapy faculty may not be sufficiently responsive to these changes. Alternatively, occupational therapy educators may be waiting for more definitive changes to occur in practice before including this content in curricula.

Genetics Content Taught and Level and Type of Instruction

In all of the three major genetics content areas, the preponderance of teaching was reported to be at the “introductory” or “knowledge and understanding” levels (see Tables 1, 2, and 3). If occupational therapy educators are going to prepare new practitioners for the challenges of genetics, it is imperative that teaching moves toward the integrative and application levels. In doing so, students will learn how to apply principles to occupational therapy practice and to analyze and solve problems specific to genetics. To address this level of learning, case-based examples would be a recommended teaching method. Although controversy about outcomes persist with problem-based learning (Eshach & Bitterman, 2003; Norman & Schmidt, 2000), such examples might nicely reflect a holistic understanding of genetic content and the ethical, legal, and social dilemmas occurring in practice or as part of client and family decision making (Neistadt, Wight, & Mulligan, 1998). Clinical reasoning about assessment and strategies to address lifestyle decisions and accommodations can be sorted out through realistic presentation of challenges faced by clients and families.

Implications and Future Needs for Including Genetics Content

Barriers or challenges to teaching genetics that were identified by respondents indicate a need for guidance as to what to include (i.e., accreditation standards, model course outlines, or lectures). There was also expressed concern about the lack of expertise among occupational therapy faculty in this content area. Such barriers may be overcome through new collaborations. Ideally, genetics should be presented in an interdisciplinary manner and not be taught exclusively by occupational therapy educators. Interdisciplinary and transdisciplinary practices are likely with genetics, and representing that approach in education seems useful. Geneticists and many other more familiar colleagues could be recruited to develop and provide education within and across disciplines. Partnering between clinicians and classroom educators could also be strived for to make clients and families a focal point of teaching that builds toward identifying issues and recommending interventions. Likewise, the soliciting of individuals with genetic-based challenges to teach about his or her experiences is recommended. The Genetic Alliance and others have supported such inclusion in their recommendations (Genetic Alliance, 2003).

The strengths of this study lie in development and implementation of the survey. A modified version of the Dillman (2000) Tailored Design Method was followed to
design the survey instrument and provide follow-up mailing procedures, resulting in a high response rate of 63.9%. However, given the targeted professional audience, a higher response rate would have been more desirable. For example, if one surmises that the 36% who did not respond were just not interested in the topic of genetics education, important data are missing. All surveys have the inherent weakness of representing opinions at a particular point in time, and at this time genetics is still an emerging topic of conversation for occupational therapists.

Findings from this survey indicate a need for increased awareness of the implications and relevance of genetics to occupational therapy education and practice. If educators are to take a leadership role relative to genetics and practice, they will need to develop their own expertise and create teaching materials and methods that will promote genetic literacy and problem-solving. This will require an understanding of the relevance of genetics to the practice arena, thus involving both occupational therapy educators and practitioners.

Occupational therapy curriculum development needs are evident across the country and would best be dealt with through both bottom up and top down approaches. Local and regional collaborations can occur between college or university programs and clinical practice settings seeking to expand or formalize their services to include diagnostic conditions involving genetics. Much of the work calls for teaching about genetic disorders and issues, as well as inventive applications of occupational therapy principles and practices with underserved clinical populations. This would include anticipatory approaches to genetic diagnoses through lifestyle redesign interventions by occupational therapists. At the national level, attention toward genetics can be supported. AOTA’s continued involvement with NCHPEG and leadership and collaborations between the Commission on Practice and Commission on Education should be encouraged. Development of continuing education and entry-level education products and events will likely find an audience as genomic-based medicine advances and public media continue to make genetics a topic of interest and concern for everyone.

Acknowledgments

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